

Circle of Care Modeling:
Improving Continuity of Care for End of Life Patients.

by

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Hon BSc, University of Victoria, 1997
MD, University of Calgary, 2000

A Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of

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Supervisory Committee

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Abstract

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Objective: This study sought to answer the question *“What feasible changes can be made to care processes and clinical information systems to improve Continuity of Care for end of life patients?”*

Methods: This study adapted Genre Theory and Soft Systems Methodology into a new systems approach, the Circle of Care Modeling Approach. Thirty-four healthcare providers and health IT professionals were interviewed in two communities in British Columbia, Canada. The interviews sought to discover the nature of care provided for end of life patients and how clinical information systems supported care. Interviews were centered on two simulated end of life patients. The patient centric healthcare system, or Circle of Care, was described for each of these patients in each community. Rich Pictures and Conceptual Models were developed based on interview findings. These diagrams were used with participants to discuss gaps in continuity and to seek improvements during a series of structured discussion groups.

Results and Discussion: The Circle of Care for end of life patients was found to be large and complex in both communities. Potentially dozens of providers would have been involved in each patient’s care over their last year of life. No provider knew all members of the Circle of

Care. All communication activities that were described by participants could be described within the Circle of Care with ten Abstracted Genres. Patient information was housed in many disparate repositories (both paper and electronic) and access to these repositories was limited. The participants described several aspects of Continuity of Care. A new model to describe Continuity of Care was developed based on the findings and taking into account the systems orientation of this study. Six suggested improvements were generated with the study participants to better support Continuity of Care within the communities in this study. These are described in the dissertation. The suggested improvements were compared to existing functionality of clinical information systems.

This novel approach to exploring and visualizing the healthcare system from a patient-centric lens, the Circle of Care Modeling Approach, provided a new way of describing and reasoning about the complexities associated with Continuity of Care.

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May you rest in peace.

INTRODUCTION

Chapter 1 Study Synopsis, Objectives and Overview

This chapter summarizes the study for the reader, highlighting the research question, methods, contributions to knowledge, and recommendations for improving Continuity of Care for the communities in the study. The research objectives are described and an overview of the dissertation is provided.

Study Synopsis

Continuity of Care is how consistent and cohesive care provided to an individual patient is over time (Haggerty, et al., 2003). Continuity includes how the discrete care events interrelate, such that patient goals and needs are effectively communicated and managed amongst all members of the care team (see Circle of Care below). Continuity is important for patients with chronic illnesses, such as those with progressive conditions at end of life, and includes aspects of communication and coordination between providers involved with each patient and it is a component of quality of care. As healthcare has become increasingly team based and more patients with complex chronic illnesses are managed outside the hospital, the need for continuity increases. Communication between providers who are involved with the same patient becomes important to connect the discrete care events into a cohesive whole, ensuring continuity. Gaps in continuity have an impact on patient safety (R. Cook, M. Render, & D. Woods, 2000). Haggerty and Reid in their multidisciplinary literature review of

Continuity of Care defined three levels of Continuity of Care: Information Continuity, Management Continuity, and Relationship Continuity. Their model has been adopted nationally by the Canadian Health Services Research Foundation and was used as the foundational definition of Continuity of Care for this study. Clinical Information Systems (CISs), with their capability to support information sharing, communication, and clinical decision support, may well be one of the important tools to improving Continuity of Care. In this study, I sought to work with clinicians and those responsible for regional CISs to discover improvements for the Continuity of Care for End of life patients at all three levels. I took a systems-based approach to answer the question:

What feasible changes can be made to care processes and clinical information systems to improve Continuity of Care for end of life patients?

The study was constructed on foundations from Soft Systems Methodology (SSM) and Genre Theory to understand the communication activities related to Continuity of Care for end of life patients. The research was centered in two communities on Vancouver Island, British Columbia that were both part of the Vancouver Island Health Authority (VIHA). There were four key phases to my work: Finding Out (data collection), Conceptual Modeling (analysis), Structured Discussion Groups (confirmation), and Recommendation Development / Sharing.

Finding Out occurred primarily through thirty-four participant interviews, but also through reviewing literature and publically available documentation from VIHA. The interviews included health care providers in each community and Information Management / Information Technology (IM/IT) professionals who were responsible for the various regional clinical information systems. Two end of life Patient Personas¹ were created to be the focal point for all interviews and modeling activities. I developed these Patient Personas from Canadian Institute for Health Information (CIHI) statistical data on End of life patients in British Columbia. The Personas provided the framework for the participant

¹ A Patient Persona is a simulated patient case, with sufficient detail about their specific situation to allow participants to feel that they know the individual and can make realistic treatment decisions about care. Mrs. Cann and Mr. Hart were the two Patient Personas developed for this study.

interviews. I asked each participant to describe, from his or her perspective, the care these simulated patients would likely receive over several key transitions over the last year of their lives. By being patient-centric and using these personas consistently, I was able to compare perspectives from different providers within each community and between the two communities. Family Physicians were engaged in both communities for the first round of interviews. Additional participants were determined based on findings from the previous interviews (i.e. participants were asked to name other provider roles involved in each patient's care). This iterative recruitment continued until there was sufficient coverage of the Circle of Care to make informed recommendations. For this study the **Circle of Care was defined as the care system around an individual patient that provides care to that patient over a period of time**. It is the system within the healthcare system that provides care to a particular patient. The Circle of Care contains all the providers, repositories and the communication activities associated with providing care.

I then interviewed IT professionals at VIHA to review current state of the clinical information systems and explore possible feasible improvements to those systems, based on gaps described by providers. Conceptual Models visualized the patient's set of providers (as described by all participants), the communication patterns related to Continuity of Care, and the collection of repositories that contain data about the patient. Two Structured Discussion Groups were held with a subset of the participants served to confirm the findings and to review possible improvements to address gaps in Continuity of Care. Six suggestions for improvement were generated with the IM/IT professionals to address gaps described by the providers. These suggested improvements were when confirmed and refined with Structured Discussion Groups with representation from both the provider and IM/IT participants.

There are four key contributions from this study: a method and modeling approach that is both patient-centric and systems based, a set of ten Communication Patterns that are related to Continuity of Care, an Extended Continuity of Care Model, and specific recommendations for improvement of Continuity of Care for the region and the two communities that participated in the study. Each is described below.

First, I developed a method and modeling approach to explore Continuity of Care from a systems perspective, the *Circle of Care Modeling Approach*. When taking a patient-centered view on the care delivery system, it is the patient's Circle of Care that is one of the smallest systems that can be studied. The Circle of Care, as defined in this study, contains all providers who are involved in the single patient's care over time. The methods developed for this study were based on Soft Systems Methodology, (P. Checkland, 2000) and so were well suited to address issues in the complex adaptive systems that are part of healthcare (Begun, Zimmerman, & Dooley, 2003). The Circle of Care Modeling Approach effectively highlighted the challenges within a complex web of that is around a patient: providers, communications, and various paper and electronic information repositories. The three-level modeling approach includes a provider view, a communication view, and an information / repository view. It proved useful in exploring the complex system created around end of life patients. It allowed participants to appreciate the complexities that need to be considered to maintain Continuity of Care. Being patient centric was useful when exploring how information systems could be consolidated, streamlined, or designed to be interoperable. The Circle of Care Modeling Approach provided a meso-level of analysis. It is more granular than a regional or jurisdictional plan, showing the specific challenges between facilities and organizations to support care for patients. It was at a higher level than some of the common workflow analysis techniques (process mapping, etc) that look at single organizations, users, or processes. Thus, the patient centric model can provide a more rich description into the needs for cross-organizational communication and interoperability to support patient care than either pure process modeling or organizationally centric strategies.

Second, I developed a set of ten communications patterns to describe the types of communication discovered through the interviews. These Communication Patterns are, effectively, an "abstracted" Genre. Genres (from Genre Theory) are communication activities that are applied to recurrent situations within an organization or group. The set of Abstracted Genres capture the communication patterns between providers that were described in the study in a way that they could be reused when evaluating or designing clinical information systems to better support communication practices and Continuity of Care. They were abstracted from the specific examples of communication. The Abstracted Genres are: Communicate with Patient (Family), Request Historical Information, Provide

Current Information, Document in Shared Record(s), Review Shared Record, Request Generic Advice, Request Assessment / Treatment for Patient, Order, Transfer Care, and Coordinate as Care Team. These were used to describe communication in the communication models above and are described in more detail in the dissertation. The concept of Abstracted Genres was an extension to existing Genre Theories. By abstracting common elements from the individual organizations or groups to a common set, I have shown that these could be considered repeatable patterns of communication that can be used to describe activity in multiple care settings in a way that may have more broad application than traditional Genre descriptions. This was confirmed by successfully mapping the Abstract Genres to the Genres previously described in pediatric nephrology (Lara Varpio, Schryer, Lehoux, & Lingard, 2006).

Third, I extended the Haggerty and Reid model of Continuity of Care. The Extended Continuity of Care Model was developed from the systemic approach to analysis and the findings in this study. Five additional elements were made explicit in the Extended Continuity of Care Model. First, the patient and family that were central to the definition of Continuity of Care were made central to the model. Second, the Circle of Care defined the boundaries of the system in which Continuity of Care occurs. The Circle of Care included the care providers, the information repositories and information flow involved in that patient's care over time. Third, when providers in the Circle of Care were highlighted, an additional type of continuity became apparent: *inter-provider continuity*. These relationships and the trust between individual providers were important components to improving continuity for a shared patient. Fourth, the Abstracted Genres serve as the ways in which Continuity of Care is actualized through communication amongst the Circle of Care. Finally, there were environmental contexts that impact continuity that were outside the system. From these findings, I present the Extended Continuity of Care Model (Figure 1).

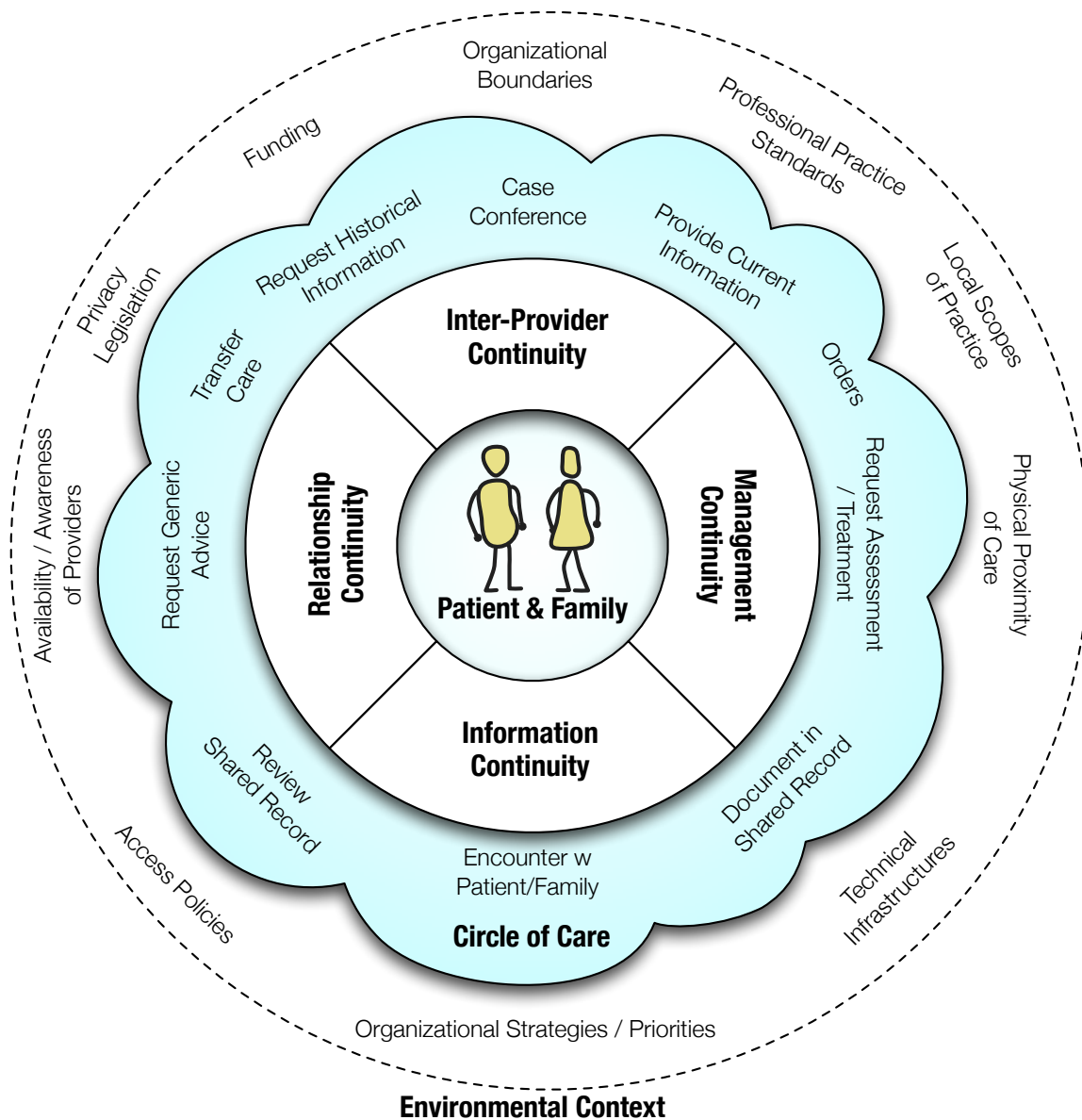


Figure 1: The Extended Continuity of Care model, making explicit the patient and family, the Circle of Care, inter-provider continuity, Abstracted Communication Genres, and the Environmental Context.

Finally, my objective was to seek a set of suggested improvements in Continuity of Care for end of life patients. End of life patients were selected for this study as they are typically complex patients with multiple chronic conditions who transition through several stages of care, and they can have a diverse Circle of Care. Thus, they are an exemplar for other people with other chronic conditions. I sought to discover feasible improvements for the region and

for the participating communities that addressed gaps that were raised by the participants in managing our two Patient Personas. A feasible improvement was defined as an activity that was thought to improve at least one level of continuity in both communities and be something that could be realistically achieved within one year. Six suggested improvements were made for the health region: improve provider access to appropriate Clinical Information Systems, develop an advance directives repository, enhanced electronic documentation of patient-provider relationships, develop automatic notifications to providers of key patient transitions, improve use of case conferences, and design a regional clinical communication tool to support cross team communication and coordination.

In summary, I sought improvements in Continuity of Care for patients as they transition through end of life. Although the stories and recommendations are based around the needs of two typical patients at the end of life, my findings and analysis are applicable beyond the transition to end of life. Indeed many of the issues can be generalized to situations where people transition between multiple providers and settings as they seek care. By taking a patient centric view, I found a new way of visualizing the health care system and in describing communication patterns between providers that support Continuity of Care. Through this work, I have made recommendations for improvement to care in the region for End of life patients but also for Continuity of Care in general, extending existing models of Continuity of Care to a more systems based model.

Research Question and Objectives

This study was designed to answer the overarching research question:

What feasible changes can be made to care processes and clinical information systems to improve Continuity of Care for End of life patients?

This question came about through a combination of reflection and engagement. I reflected on my interest as a family physician in both Continuity of Care and end of life care and explored the existing literature as ideas formed. I discussed concepts and challenges of Continuity of Care with providers and academics with experience in Continuity of Care and end of life care during the formative stages at the University of Victoria and the University of British Columbia to see if the ideas resonated. With an overall positive response, I continued to design the study, exploring approaches that could answer the above question.

In order to answer that question, there were four specific objectives for this study:

- 1. To develop and apply a method that combines Genre Theory with Soft Systems Methodology to generate suggested improvements in processes and design or use of clinical information systems to support Continuity of Care.*
- 2. To describe the Genres used by providers caring for patients who are at the end of their life, focusing on the Genres used to provide and coordinate the transitions of care.*
- 3. To compare the Genres and needs of Continuity of Care at the end of life with the current design for the Vancouver Island Health Authority's (VIHA) primary, regional clinical information system to see where specific improvements to content and functionality can be made.*
- 4. To seek improvements in Continuity of Care within two communities in British Columbia, making recommendations that would ensure the right providers are aware of key care decisions for community-based patients at the end of life.*

Dissertation Outline

The body of this dissertation contains six sections, each containing several chapters. Each section is briefly described here:

1. **Introduction** – Provides a synopsis of the study for the reader and describes the objectives for the study.
2. **Background** – Describes the necessary foundational components needed for this study. It provides the reader with the necessary context for this study and includes literature reviews on: Continuity of Care, end of life care, Genre Theory, and Soft Systems Methodology. This section also describes the context of the healthcare system where this study was conducted and includes a brief description of Clinical Information Systems functionality, as they relate to Continuity of Care.
3. **Methods** – Describes the details of the study objectives and the methods followed, based on Soft Systems Methodology. There are four phases of investigation: finding out, conceptual modeling, structured discussion groups, and generating suggested improvements. These phases are iterative and also include considerable reflection. The two Patient Personas Mr. Hart and Mrs. Cann are also described in this section.
4. **Results** – Describes the findings of the study as they relate to the study objectives. The current delivery of end of life care in the communities is described in the form of Rich Pictures that highlight gaps in Continuity of Care. Elements of Continuity of Care are reviewed. The specific Genres are analyzed. Conceptual Models of the Circle of Care are reviewed, highlighting differences between providers, patient personas and the communities. Finally, the suggested improvements, as developed with the participants, are described.
5. **Discussion** – The broader applications of the study's findings are described. Wider applications for the suggested improvements are considered. The Extended

Continuity of Care Model is developed and its implications are explored. The application of the Abstract Genres as Communication Patterns outside of this study are considered, both for clinical studies and for clinical information system design. The Circle of Care Modeling Approach, based on the methods of this study, is introduced. The section concludes by revisiting the study objectives.

6. **Conclusion** – Considers contributions to knowledge, study limitations and opportunities for future research.

The dissertation is also supported by a number of appendices that are included to provide further detail and example materials from the study.

BACKGROUND SECTION

Chapter 2 The Circle of Care and Continuity of Care

This chapter introduces the reader to the study's concept and definition of the Circle of Care as a system to be studied. It also reviews Continuity of Care as it relates to this study. A Continuity of Care model is described, as is the current state of tools used to measure Continuity of Care.

The Circle of Care

To properly orient the reader for this study, I have chosen to start with a description of the *Circle of Care*. The concept of a patient's Circle of Care was central to the design of this study and, therefore, a reasonable and important place to begin this section. For this study the **Circle of Care was defined as the care system around an individual patient that provides care to that patient over a period of time.** This definition was developed specifically for this study.

A system is a collection of components that are related to each other such that that they create a whole. A system has emergent properties that are distinct from any of the individual parts. These emergent properties can be studied through the use of a systems approach (P. Checkland & Scholes, 1990). The Circle of Care as a system, then, consists of aspects of

components of healthcare that are related to each other through a common patient and that patient's needs over time. The Circle of Care consists of four elements: the patient (and family where relevant), the providers that are involved in that patient's care, the interactions between members (patient, family and providers), and the information repositories that store information about that patient (Figure 2). One of the emergent properties from this system is the concept of Continuity of Care, described shortly.

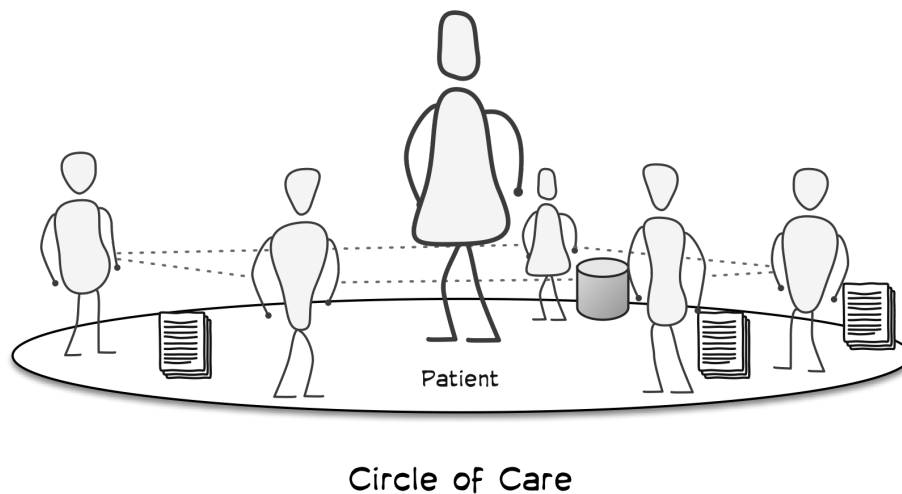


Figure 2: The Circle of Care is a system that is centered on a patient and contains the providers, information and activities related to that patient's care.

The Circle of Care contains providers involved in a patient's care. The number of providers that support a patient increases significantly for patients with multiple chronic illnesses (Bodenheimer, 2008). One US Medicare study found that patients with many chronic illnesses might see up to 16 physicians in a single year (Pham, Schrag, O'Malley, Wu, & Bach, 2007). Providers in the Circle of Care could include physicians, nurses, other formal providers, as well as informal providers (lay people providing care, such as family members or friends).

Communication activities are a focus within the Circle of Care. This includes communication between providers and between providers and the patient. Communication is thought to be

particularly important in transitions of care (such as admission to hospital), where gaps in communication and information can lead to adverse events (Kripalani, LeFevre, et al., 2007) (Behara, et al., 2005). Nearly half of discharges from hospital, as an example of a common transition, have been associated with an error in continuity (such as lack of follow up, or medication error) (Moore, Wisnivesky, Williams, & McGinn, 2003).

Information repositories are also included in the Circle of Care. All forms of persistent information related to patients that can be accessed or need to be accessed by more than one provider were included in scope. Patient information repositories have been seen as shifting from paper to electronic systems and from departmental records to regional systems (Haux, 2006). As this shift occurs, it is important to consider how this could impact the Circle of Care.

The Circle of Care contains both planned and unplanned care as well as formal and informal care. Planned care would be delivered by those providers involved intentionally in the management of expected issues, such as the patient's family physician and specialists managing a particular chronic disease. Unplanned care is delivered by groups that respond to acute, unpredicted changes in a patient's condition that are not predicted, such as Emergency Physicians. Formal care providers are those with training and who have a defined, paid role. Physicians, nurses, and care aids are all examples of formal providers. Informal providers were those that are involved, but do not have a defined role. Family, friends, even neighbours who check in on patients all could play important, informal roles within a patient's Circle of Care.

The definition of the Circle of Care does not include organizational boundaries. Health care organizations may well be involved within a patient's Circle of Care and they may impact health care delivery. However, they are intentionally not a defining feature of the system.

Others have used the concept of Circle of Care in their own research, with different meanings. Several groups studying end of life care and care for patients with chronic conditions use the term Circle of Care. McKinlay, in her qualitative study on patients receiving palliative care, used the concept of the Circle of Care to describe and organize the themes that emerged from her research (McKinlay, 2001). The Circle of Care was the

metaphor used to connect the 11 themes of her research such as “Keeping Control”, “Mortality Awareness” and others. The themes “form[ed] a pattern of lived existence which *is complete in itself*– the Circle of Care.” (McKinlay, 2001) (emphasis added). Although a different use of the term, the Circle of Care is used to describe a whole, or a system. Levine used Circle of Care to describe a model for palliative care services that is part of long-term care facilities. His model positioned patients and families into the circle for a “truly holistic approach” to palliative care (Levine, 2000). When studying home care support for rural older adults, Magilvy discovered that Circles of Care were a key theme that assisted patients to maintain their independence in the community (Magilvy, Congdon, & Martinez, 1994) (Congdon & Magilvy, 2001). Members of the circles were involved in supporting transitions of care (e.g. discharge planning), maintaining Continuity of Care, and also they were important for providers to network with each other in the community. Andersen used the concept of the Circle of Care to describe the process of personalized nursing care for women with HIV (Andersen, Smereck, et al., 2003) and for persons living with substance abuse issues and HIV (Andersen, Paliwoda, et al., 2003). Here, the concept of the Circle of Care has been used to describe the iterative nature of care and chronic disease over time, as opposed to the system of providers, communication and repositories.

Each of these studies used Circle of Care in its own way, yet there were some similarities. Circle of Care was important for patients with chronic illness, including those at end of life. The Circle of Care was used to describe ways of integrating care, including better continuity and engagement with patients and families. My study, while it defined the Circle of Care differently, also used this concept to address issues related to patients at end of life with chronic illness and to seek improvements in Continuity of Care.

The Circle of Care gave this study its focal length. This was not a macro-level system study, looking at care delivery for a region or province. Nor was it a study at a micro-level, exploring the interactions with a single provider or in a single clinic. The Circle of Care fits between those two levels. It has centered on a patient within a community, can include several providers and can span organizations. My study was, therefore, focused at a meso-level. I explored the communication and information sharing between a patient and their providers as well as between providers within a patient’s Circle of Care. This spanned across multiple settings and included exploration of the clinical information systems that supported

communication between members of the Circle of Care may improve Continuity of Care. It is within the Circle of Care that Continuity of Care emerges. It is within the Circle of Care that Continuity of Care is or is not maintained. Continuity of Care is described next.

Overview of Continuity of Care

Continuity of Care has been defined in many ways, (Wall, 1981) depending on the author and the clinical discipline being examined. Multiple definitions are challenging when comparing research findings. Instead of creating my own, tailored definition for this study, I chose to start with an existing, inclusive, definition that is applicable across multiple disciplines, as it is based on a multidisciplinary review. For this research, Continuity of Care is defined as how the care provided to an individual patient over time is experienced as a cohesive and consistent whole (Haggerty, et al., 2003). Continuity includes how the discrete care events interrelate, such that patient goals and needs are effectively communicated and managed amongst all members of the care team. There are two additional relevant aspects of this definition: first, continuity is focused on the individual person and is not about health planning activities to populations of patients. Second, the provision and coordination of care occurs over time, beyond a single encounter; there is a sense of both historical and future cohesiveness and a need for coordination of care. Both of these aspects to continuity were important for our study. This definition is also consistent with the definition, above, of the Circle of Care, which was important as I have assumed that Continuity of Care occurs within the Circle of Care.

The Haggerty and Reid Model of Continuity of Care

In their review, Haggerty and Reid proposed a three-tiered model to further describe the types of Continuity of Care (Figure 3). In their model, continuity begins with informational continuity, where information is accessible to providers involved in care. This is complemented by management continuity where the decisions of how to manage health

problems are shared and are consistent between providers. Finally, the third tier of continuity is relationship continuity² where a patient has an ongoing therapeutic relationship between one or more providers. These three tiers of continuity were consistent across the various disciplines in their review. Patients and providers are only implied in their model, they are not made explicit. Their review included literature from primary care, nursing, mental health, and specific disease management groups, such as cardiovascular diseases and cancer. This model of continuity of care has been adopted by the Canadian Health Services Foundation's definition of continuity of care (Reid, Haggerty, & McKendry, 2002), which made it particularly relevant to this Canadian study. The three types of continuity are described in more detail below.

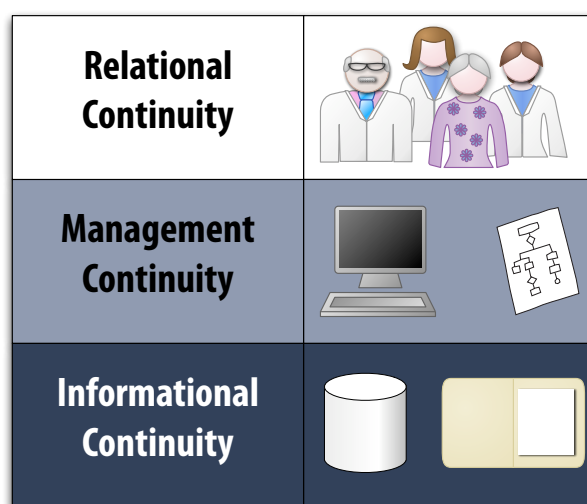


Figure 3: Three levels of Continuity, based on (Haggerty, et al., 2003).

Informational Continuity allows providers access to relevant patient data / information when making care decisions. This requires seamless access to information (e.g. laboratory results, a shared hospital chart) to providers in a manner that allows them to make informed decisions wherever those decisions are made throughout the care process (Gulliford, Naithani, & Morgan, 2006). Informational continuity requires that the information is both

² Haggerty and Reid use relational continuity. For this paper, I have chosen to use Relationship Continuity to clearly focus on the provider – patient relationship.

available and consistent. Gaps in information can occur, particularly during transitions in care (e.g. hospital discharges) and have adverse outcomes (Kripalani, LeFevre, et al., 2007).

Management Continuity occurs when the care delivered is consistent between providers involved with that patient. They work together achieve common care goals. Ensuring that this level of continuity is achieved prevents care providers from working to “cross purposes”. There are two clinical aspects to Management Continuity, first that standardized (preferably evidence-based) processes are consistently followed and second that the patient’s personal goals are taken into account. Tools such as clinical practice guidelines, standardized reminders and alerts can improve the former consistency. Shared care plans, that include patient specific goals, are an example of a mechanism to increase the latter form of Management Continuity. Case conferences, where providers meet to discuss management options and come to an agreed-to path, are another example of a tool to enhance Management Continuity. This level of continuity should also include ensuring sufficient patient engagement / contact to ensure that goals are being met. Providing consistent care for patients with chronic, complex care involving multiple providers is key to preventing complications for patients and reducing the burden on the overall system.

Relationship Continuity is focused on patient-provider relationship(s). Relationship Continuity includes developing connections between patients and providers that include a sense of trust and a sense of responsibility (Starfield, 1980). Clear roles of a single provider or small group of providers allow for this type of continuity to occur. This type of continuity can be achieved in both inpatient / acute and outpatient settings by ensuring that specific individuals are given explicit roles (e.g. family physician) and these roles are maintained over time. Relationship Continuity provides patients with a sense of predictability into the future, knowing that they will have specific people involved in their care, even if situations change.

Other Models of Continuity of Care

Continuity of Care is a fundamental principle to several disciplines, including: family medicine, nursing, and end of life care. Several groups have developed other models to describe Continuity of Care.

In family medicine, there have been several papers discussing Continuity of Care. Hennen, in a series of articles, discussed four dimensions of continuity in family medicine, these were: chronologic, geographic, interdisciplinary, and interpersonal (B. K. Hennen, 1975) (B. Hennen, 1981). Wall has proposed a definition of continuity of care that has five dimensions of continuity: chronologic, geographic, interdisciplinary, interpersonal and informational continuity (Wall, 1981).

Saultz, in two critical reviews on the subject (Saultz, 2003), (Saultz & Lochner, 2005), also explored features of Continuity of Care. Saultz also presents a three-tiered model, similar to Haggerty's model above. Management Continuity is replaced with longitudinal continuity. Longitudinal continuity is defined more for a patient as having a "medical home", a location or practice where much of the care is provided for the patient. Saultz also described several additional aspects of continuity. Geographic continuity occurs when continuity occurs regardless of location (e.g. office or hospital). Interdisciplinary continuity occurs when various members of a care team are engaged with a patient. Finally, family continuity extends the concept of continuity to a patient's family, where providers are familiar with familial context that can impact care. Familial continuity would include both genetic risk and social impacts of care, such as family stress.

Continuity is also fundamental to nursing practice. In their two-part review of the nursing literature on Continuity of Care, Sparbel and Anderson discovered a gap in the conceptual definition of Continuity of Care (Sparbel & Anderson, 2000b) (Sparbel & Anderson, 2000a) as it relates to nursing. They found that some of the key factors influencing Continuity of Care included: communication (i.e. between organizations or between providers within an organization), coordination / networking processes, and patient needs. System issues were also captured in their model of Continuity of Care, including organizational commitment to continuity, provider knowledge, and consistency of personnel (e.g. scheduling process).

Continuity of Care is a key component of end of life care as well; this is discussed in the next chapter on end of life care.

Clinical Benefits of Continuity

A systematic review found that increased Continuity of Care corresponded with improved quality of care for patients with chronic conditions (Cabana & Jee, 2004). Continuity was important for any condition that involved more than one provider and did not resolve within a single encounter. Reducing gaps in care provision was also found to be an important aspect to patient safety (R. I. Cook, M. Render, & D. D. Woods, 2000).

Improving Information Continuity can benefit overall quality of care. This was shown to be particularly true during transitions of care, such as discharges from hospital, where improving information transferred between providers could improve care (Kripalani, LeFevre, et al., 2007) and possibly decrease chances for readmission (Moore, et al., 2003).

The focus of clinical information systems is often to improve Information Continuity in order to improve quality of care delivery. *“The [clinical information system] is not a goal in itself, but a tool for supporting the continuity of care and consequently the quality, access and efficiency of health care delivery.”* (Iakovidis, 1998) Clinical information systems have played a role in improving Information Continuity, for example, with older adults with complex conditions where the need for continuity is greater (Weiner, et al., 2003) and for patients at the end of life (Trask, Nash, & Teno, 2004).

Management Continuity, particularly achieved through the coordination of teams with defined roles, can benefit patients with chronic disease in primary care. Care team composition and clear roles of team members are important to improving quality of care (Wagner, 2000). Improved Management Continuity for chronic diseases, such as end of life care with cancer or heart disease, is seen in many jurisdictions as a key enabler for sustainable, high quality systems and also the *“single greatest challenge facing organized medical practice”* {Wagner, 1998 #1064. Activities to promote consistent, evidence-based care for Chronic Disease have shown improvements in quality of care (Bodenheimer, Wagner, &

Grumbach, 2002). Improving chronic illness requires looking at healthcare from a systemic perspective to make improvements in the management of patients (Wagner, Austin, & Von Korff, 1996).

There is also evidence to support that there are improvements to the overall quality of care when Relationship Continuity is improved, particularly with patients with chronic conditions, such as asthma or diabetes (Cabana & Jee, 2004). While studies have explored Relationship Continuity, future research is still needed to better understand and measure this type of continuity (Saultz, 2003) (Wierdsma, Mulder, de Vries, & Sytema, 2009). Relationship Continuity has benefits to patient satisfaction, quality, and reduction in costs to the healthcare system (G Freeman & Hjortdahl, 1997).³ Relationship Continuity can reduce the rate of hospital admissions (Mainous 3rd, 1998). Mainous examined Medicaid claims data and found a correlation between repeat visits to a single physician and a *reduction* in hospital billings (corresponding to reduced admissions or time in hospital). This correlation was not found if patients saw multiple providers in the same group practices. However, others have described benefits to continuity provided through a care team rather than one single provider (G Freeman & Hjortdahl, 1997), provided that roles and communication are clear amongst team members. As team care becomes more prevalent, communication and role definitions will be more important to improving care while maintaining sustainable healthcare systems.

Quantifying Continuity of Care – Continuity Indices

Even though the specifics of continuity are somewhat elusive, several instruments have been developed to measure Continuity of Care. In a recent systematic review, Jee discovered forty-four papers that used or developed indices that measured Continuity of Care (Jee & Cabana, 2006). In her review, there were thirty-two different indices (described in the forty-four papers) that measured Continuity of Care. These quantitative indices were grouped into

³ Personal Continuity is the term used in the Freeman paper, which is equivalent to Relationship Continuity for this context.

5 categories: duration, visit density, visit dispersion, visit sequence, and patient's subjective response.

Duration Indices focused on measuring the length of the relationship with a primary provider (e.g. pediatrician, family physician). The longer the duration of that relationship, the greater the continuity score. Although easy to measure, the challenge with duration indices is that care may frequently, or even routinely, be sought elsewhere. This is not captured in this index. These indices were considered weak proxies for analyzing the relationship between patient and provider. Two studies used these indices.

Visit Density Indices were the most commonly used index group in Continuity of Care studies. Density indices typically focus on a single provider and took into account frequency of visits with that primary provider over time. Visit density indices can be easy to calculate from claims data, schedule records, or chart records. 17 studies used this type of index.

Dispersion Indices considered the percentage of visits that patients have with multiple providers over time. These indices do not take into account the nature of visits, simply quantities, indicating a decrease in continuity by an increase in dispersion of visits. Eight studies used these indices.

Sequence Indices reviewed the chronologic patterns of visits, providing higher scores when patients see the same provider repeatedly, rather than alternating visits between multiple providers. These indices, however, have limitations if the providers are providing complementary services and, perhaps visits are meant to coincide (e.g. a family physician sees the patient and then consults a nurse for wound care). Sequencing indices do not typically consider the types of visits in the analysis, rather simply the order of visits. Only one study applied this type of index.

Subjective Indices look at how patients interpret their level of continuity with care providers. Many of these rely on surveys to collect data. Four studies applied subjective indices.

In Jee's systematic review, there was only a single RCT (Wasson, et al., 1984). In this double blinded study with 776 men 55 years old and over, patients were randomly assigned to either

receive provider continuity or provider discontinuity over an 18 month period as their main source of primary care. The results included increased patient satisfaction as well as absolute reductions in emergency visits (20% vs. 39%) and the length of hospital stays (15.5 vs. 25.5 days) when patients received provider continuity.

While there is value in these indices, they have explored only a limited aspect of continuity: they describe continuity through visit patterns. A richer understanding of Continuity of Care was needed. Qualitative analysis may help unlock new aspects of Continuity of Care. However, many qualitative analyses of Continuity of Care have focused on the nature of patient's subjective impressions on the benefits of continuity (Saultz & Lochner, 2005). While this is important, these studies have not sought a way of describe the system in which continuity is maintained.

Thus, there was a gap in both the qualitative and quantitative literature in modeling continuity and communication patterns amongst a patient's care providers. More work was needed to understand how Continuity of Care is maintained between providers. There was a lack of studies that describe a patient's care providers and the work that they do to maintain Continuity of Care. It was in this gap that I positioned this study.

IM/IT Approach to Continuity

Discussions on continuity in the informatics literature have focused on Informational Continuity and related issues such as how improved electronic information access improves safety and quality (Bates & Gawande, 2003). Canada Health Infoway (see 0 on Clinical Information Systems), in their blueprint for the pan-Canadian Electronic Health Record Solution (EHRS) cite Continuity of Care as a key benefit for the pan-Canadian EHRS. Infoway described the EHR benefit to Continuity of Care as:

“Continuity of Care – the delivery of effective quality care requires that providers in many disciplines be able to access and understand information in the EHR that is relevant for their purposes.” (Infoway, 2006), p62.

The focus on informational continuity is perhaps not surprising, considering these are considered “information systems”. Still, there are ways that the other levels of Continuity of Care can be supported by clinical information systems. Table 1 provides some examples⁴ of tools that support the three levels of Continuity.

Table 1 Examples of clinical information technology that supports the three levels of Continuity of Care from British Columbia.

Type of Continuity	Types of CIS Tools	Examples in BC Healthcare System
Informational Continuity	Regional Information Systems	PharmaNet System – BC provincial repository of community (outpatient) medication dispensing claims.
Management Continuity	Evidence-based Care reminders (standardized clinical decision support systems) Shared Care Plans	Chronic Disease Management Toolkit – BC provincial system that is web-based and has electronic flowsheets to record patient information for several chronic diseases. Include defined goals, targets and patient goals and can be shared amongst care team members.
Relationship Continuity	Tools that support knowledge of care relationships and / or that promote strengthening of those relationships with patients through improved communication (e.g. secure electronic communication).	Some regional Hospital information systems capture some provider roles. For example, the VIHA Cerner system allows for documentation of each patient’s Family Physician as a lifetime provider-patient relationship. Telehealth tools can improve relationships by providing more frequent engagement of patients with providers over distance. VIHA has an active telehealth program.

⁴ These examples were chosen as they are relevant to the two communities in this study and provide the reader with some early context.

Summary on Circle of Care and Continuity of Care

The Circle of Care was chosen to define the system for this study, within which Continuity of Care is or is not maintained. The Circle of Care provided the boundaries of a useful system for this study, focusing on the meso-level of the health care system. It contains all providers, communication, and information related to an individual patient over time.

For this study, I chose to begin with the three level model of Continuity of Care from Haggerty and Reid (Figure 3) (Haggerty, et al., 2003). This definition of Continuity of Care was based on a multidisciplinary review and has been adopted by the Canadian Health Services (Reid, et al., 2002). Continuity of Care has been considered an important aspect of quality of care, particularly for patients with complex care needs and chronic conditions. Patients, such as those with chronic diseases at the end of life, have a need for improved Continuity of Care, as will be discussed in the next chapter.

Chapter 3 End of Life Care

This chapter defines and describes end of life care and introduces the British Columbia (BC) Context by presenting the BC End of Life Framework. Rationale is provided as to why Continuity of Care is important to quality care and to patients at the end of life.

End of life is an intense and important period of life for patients and their families. It involves, from the healthcare perspective, a shift from the “diagnose and cure” and life prolongation activities to a focus on symptom management and quality of life. For this study, **end of life care is defined as collection care activities provided to dying patients in order to improve quality of life for both patients and families.** This is based on the current BC health definition (BC-Health, 2006). The end of life period is difficult to define, but for this study we would consider the final year of life to be the typical scope of end of life. Over 90% of patients in BC die as a result of the progression of chronic conditions (e.g. cancer, heart disease) (BC-Health, 2006). The changes to care during this progression are important to understand. Over the course of the final year, there can be several transitions in care as the needs of patients change.

End of Life Care in BC

The BC End of Life Framework (BC-Health, 2006) describes the BC government’s commitment to “*establishing high quality end of life care and support as an integral part of our provincial health system*” (ibid, p5). A key principle for end of life care in BC is that care is collaborative, where patients, families and care providers across the spectrum work together to achieve high quality care. In short, continuity is a key principle in the BC End of Life Framework.

The framework has outlined services from multiple domains that are needed for patients in BC, including: home-based care, residential care, hospices and hospitals. End of life care in BC is provided in multiple locations including office practices, homes, residential care sites, hospices, and acute care facilities. Each setting today requires a different complement of providers and offers a different set of services (although some providers and services overlap). Continuity during transitions between these settings is required to maintain high quality care.

Coordination of end of life services is seen as a critical *system* characteristic. The preferred approach to end of life care in BC is through an interdisciplinary team.

“At the level of an individual case, effective co-ordination is best achieved by ensuring that all members of a care team are identified, share common information about the patient’s and family’s needs and have clear roles, as well as a means of recording and communicating important information.” (BC-Health, 2006) (p10)

A recent review of health care utilization in BC for patients at end of life revealed several key statistical findings about end of life care in BC (based on 2003-2004 retrospective data) (CIHI, 2008). Family physicians coordinated the majority of services for patients at end of life. Decedents⁵ tended to use an increasing and complex bundle of health services in the last 3-6 months of life. Decedents with pre-existing chronic, co-morbid conditions tended to use this bundle of health services earlier than the last 3-6 months of life. The analysis divided end of life care into 13 groups based on their health care utilization. Coordination of care was thought to be important and found to be primarily through family physicians, and Home and Community Care case managers and nurses.

Findings from this report were used to develop the Patient Personas used in this study so that these cases would be representative of patients in BC at the end of life (see Methods).

⁵ That is, patients who have died.

Quality and Continuity at End of Life

End of life, while an integral and inescapable aspect of life, is distinctly different than other times in one's life. Healthcare delivery shifts from a curative approach to a quality of life and symptom management approach. Thus, some of the typical medical quality indicators may not be relevant or are impossible to measure at end of life (Morrison, Siu, Leipzig, Cassel, & Meier, 2000). Despite an agreement that quality of end of life care should improve, there is variation in what constitutes quality. Work has been ongoing to define the elements of quality for people at the end of life. This section explores the similarities between some of the end of life quality frameworks.

The American Geriatrics Association set out ten principles for high quality end of life care (Lynn, 1997). The Institute of Medicine published on improving end of life care (Cassel, Field, & Life, 1997) as it was felt that the *"time is right for action at all levels to improve care at the end of life"* (ibid, p1). In the late 1990s and early 2000s, there were several additional end of life quality frameworks proposed from Singer (Singer, Martin, & Kelner, 1999), Stewart (Stewart, Teno, Patrick, & Lynn, 1999), and Steinhauser (Steinhauser, et al., 2000). These frameworks are summarized in Table 2. Each framework includes Continuity of Care as part of their definition of quality. The elements where continuity was captured are highlighted (some bundle Continuity of Care under larger terms; they were expressed in their detailed descriptions in the individual papers).

Table 2: Summary of end of life quality frameworks from American Geriatrics Association (Lynn, 1997), Institute of Medicine (IOM) (Cassel, et al., 1997), Singer (Singer, et al., 1999), Stewart (Stewart, et al., 1999), and Steinhauser (Steinhauser, et al., 2000). Highlighted items reflect where Continuity of Care is explicitly captured as a measure of Quality.

American Geriatrics Association	Institute of Medicine	Singer	Stewart	Steinhauser
Global Quality of Life	Overall Quality of Life	Pain and Symptom Control	Quality and Length of Life	Pain & Symptom Management
Physical / Emotional Symptom Control	Physical Well-being & functioning	Avoiding Prolonged Dying	Personal / Social Environment	Gain Sense of Completion of Life
Functional Support	Psychosocial Well-being and functioning	Achieving Sense of Control	Structure of Care	Ability to Plan/Prepare for End of Life.
Advance Care Planning	Spiritual Well-being	Relieving Burden	Process of Care	Strong Relationships with Providers
Avoid Aggressive Care Near Death	Patient Perceptions of Care	Strengthening Patient-Provider Relationships	Satisfaction with Health care	
Pt & Family Satisfaction	Family well-being and perceptions			
Reduced Family Burden				
Survival Time				
Provider Continuity & Skill				
Bereavement				

Continuity is a core element of quality care provided at end of life across each of these major quality frameworks. Not surprisingly, several groups have explored Continuity of Care for patients at the end of life. Several of these individual studies have been highlighted here, and will be described next.

In a qualitative study exploring Continuity of Care for end of life care in Belgium, Michiels discovered the ways in which patients and families perceived the role of their family physician. The family physician was seen to play a pivotal role in Continuity of Care at end of life. Specifically, he or she was seen as the provider that supports Relationship Continuity and Information Continuity (Michiels, et al., 2007). Michiels' definition for Information Continuity, based on the qualitative data derived from the interviews, included aspects of

Management Continuity. Thus the family physician was found to be integral to ensuring much of the continuity for his or her patients.

Patrick et. al (Patrick, Curtis, Engelberg, Nielsen, & McCown, 2003) in their survey-based study of the families of decedents explored factors that improved patients' and families' perceptions on what makes a good end of life experience. Dying at home, sufficient symptom control, and effective communication were important aspects of a good dying experience. It was noted that Continuity of Care at end of life was difficult to achieve, especially for patients in the community, where providers are not physically collocated. Yet, this was seen as important to patients and families. Having providers available 24 hours a day was a specific improvement to continuity in the community, where patients often die in the "off hours" (i.e. outside of typical weekday working hours). This is not always available outside of institutionalized care. Transitions of care were a major point in care where discontinuity occurred, particularly in the transitions between outpatient and inpatient care.

In recent years, continuity of providers (i.e. Relationship Continuity) has decreased during this transition. For example, in a study of 21,183 Medicare beneficiaries in the US, provider continuity in the last inpatient visit decreased from over 60% in 1992 to 51.5% in 2002 (Sharma, Freeman, Zhang, & Goodwin, 2009). This impacted outcomes. For example, it was found that those patients who received one or more visits from their usual (outpatient) provider while in their last stay in hospital had a 3.8% absolute risk reduction in ICU admissions (22.5% no continuity vs. 18.7% with continuity). Patients at end of life can feel abandoned if their ongoing therapeutic relationships are not maintained or they do not receive proper closure of those relationships with their providers {Back, 2009 #1145}.

Coordination of end of life care is needed in order to ensure that the care team is able to consistently support the patient. This requires effective communication and action in a timely manner to changing patient conditions. Hospital based palliative care teams have been shown to improve care. However, there is a need to determine better approaches and to describe and compare models (Zimmermann, Riechelmann, Krzyzanowska, Rodin, & Tannock, 2008), (Higginson, et al., 2002). A review of best practices for Canadian end of life care (D. M. Wilson, 2004), recommended four components for an integrated end of life care program. A single coordinator of care was one of those four components, in order to best

ensure continuity. End of life patients want to have trust and confidence in their care providers, have clear plans for pain control and care transitions, and to ensure that information is available as they transition to hospital (Heyland, et al., 2006). Patients see their family physicians as having a pivotal role in end of life care, maintaining continuity and individualizing their care (Michiels, et al., 2007). The challenges facing many programs is that family physicians do not have the time to act as the coordinator and dedicated nurses with end of life skills are not legislated to act (e.g. prescribe medications). What often results is a mesh of coordinators, which was considered less optimal.

The BC provincial framework included “Collaborative” as a guiding principle, which includes the cross-organizational need to support effective use of resources but also at the individual patient level to ensure that care is appropriately provided. The framework also explicitly addresses the need for informational continuity as part of an effective system (BC-Health, 2006).

Other Important Aspects of End of Life Care

Continuity of Care is important to end of life care as described above. There are other aspects of end of life care that are important, including: end of life discussions on prognosis and transitions in the stages of care⁶.

End of Life Discussion

Discussing prognosis is a difficult activity that requires significant communication skill, it is valuable to discuss with patients as they make major transitions in their illness (Edwards, 2005). Parker’s recent systematic review on end of life discussions highlighted trust in the provider was considered a key aspect by patients when discussing prognosis (S. Parker, et al., 2007). Trust is an indicator of Relationship Continuity. A key aspect to a successful end of life discussion (e.g. discussion about prognosis) is the relationship between a patient and

⁶ These were different than physical transitions in where care was provided (inpatient vs. outpatient, for example).

their provider (Clayton, Butow, & Tattersall, 2005). That is, relationship continuity improves this challenging conversation.

Although this discussion was not directly explored in this study, improved Relationship Continuity specifically supports the end of life discussion.

Transitions

As patients move through their lives, there are changes. This is particularly true in end of life care where patients move through key phases in their disease and illness. One model for these phases is illustrated below (Thulesius, Hakansson, & Petersson, 2003).

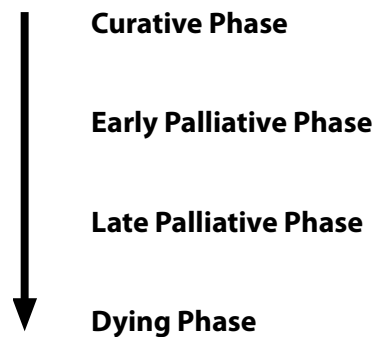


Figure 4: Transitions at end of life for cancer patients, based on (Thulesius, et al., 2003).

It is important that patients are properly engaged and aware of prognosis and options as they move through the end of their life (Edwards, 2005). As patients transition from one phase to another, it is important for the patient and the members of the care team to be aware of those changes (i.e. Management Continuity) and have similar information (Information Continuity); clear discussions with patients benefit from Relationship Continuity (as above).

These transitions in the phases of end of life are different than physical transitions in care (e.g. inpatient to outpatient), but they may coincide. For example, as a patient moves to the dying phase, they may move to a hospice or hospital. My study was also interested in the physical transitions, as those are where Continuity of Care may be lost as care teams could

change. Therefore, the study examined the care for patients as they moved through the various phases of end of life.

End of Life Care or Palliative Care?

Before concluding this chapter, a brief comparison between end of life care and palliative care is warranted. End of life is typically defined quantitatively for a period of time prior to death, in our case, one year. This type of definition is useful for retrospective analyses. Some argue that palliative care is a more precise, functional, skills-based definition that is more in keeping with other forms of specialization in care.

“The field of palliative medicine encompasses seven major skills:

- 1. Communication,*
- 2. Decision making,*
- 3. Management of complications,*
- 4. Symptom control,*
- 5. Psychosocial care,*
- 6. Care of the dying,*
- 7. Coordination of care.” (Davis, Walsh, LeGrand, & Lagman, 2002)*

This study explored end of life care as opposed to palliative care. End of life care provided a useful a structure for my study. As end of life is defined by a quantity of time (one year for this study) it allowed me to develop clinical cases that have a clear trajectory over a longer period of time and a greater range of transitions. The activities were not limited to palliative care activities. It also provided the ability to focus more on the transitions of care between providers. With a focus more on communication and less on medical management, it was felt that end of life care fit the subject area more closely for this study.

End of Life Care Summary

Patients at end of life are often patients with complex chronic conditions. Indeed, the majority of deaths in BC (over 90%) have been the result of complications from chronic conditions, such as cancer and heart failure. As patients approach their end of life, they have increasing care needs and require increasing resources. They often have multiple care providers involved both in outpatient activities and inpatient activities (e.g. primary care, home care, ER visits, hospital inpatient stays, and hospice). Improving quality of end of life care is difficult; there have been questions around whether or not some of the current end of life indicators can actually be acted upon (Morrison, et al., 2000). Without the ability to make improvements, quality indicators will not have the positive impact they are intended to have. Continuity of Care is a major indicator in many of the quality frameworks for end of life care and worth exploring ways to seek improvements.

With these challenges in mind, this study adopted a theoretical and methodological framework designed to support an understanding of practice and to create a set of feasible suggestions for improvement to difficult and complex problem situations. The theoretical and methodological foundations (Genre Theory and Soft Systems Methodology) are described in the next two chapters.

Chapter 4 Genre Theory

This chapter outlines the concepts of Genre Theory, its extensions, and its application in healthcare.

Genre Theory Overview

Genre Theory was developed in the 1990s to provide a foundation that better described the observed, repeated communications that occur within organizations or groups over time (JA Yates & Orlikowski, 1992). These repeated communicative acts were termed Genres. Genres derive their standardized content and their form through the social rules within the organization and their repeated use within a group. Genres are defined as:

“Typified communicative actions characterized by similar substance and form and taken in response to recurrent situations” (J. Yates & Orlikowski, 1997).

There are three aspects to this definition of Genres that are worth exploring here: first, they are “communicative actions”, activities related to the transfer of information, ideas, and feelings between people. Next, Genres have “similar substance and form;” they are recognizable in their content and delivery mechanism. Finally, they are developed “in response to recurrent situations.” The specific Genres are built-up to fill needs in repeated situations within an organization and thus have a socio-historical legacy to their use within organizations.⁷ Members of organizations expect certain Genres in certain situations, based on past experiences. Genres, then, are the combination of the **form**, the **purpose** (intent) and the **recurrent situation** (the environment, including participants involved). (Figure 5)

⁷ The term organization, here, is used somewhat loosely for collections of people working together. These may be within a formal organization or groups of individuals either outside an organization or between organizations.

Genres are not limited to paper communication. They may take many forms, including: written (e.g. briefing note, history and physical note in a hospital paper chart), electronic (e.g. email, progress note in an Electronic Medical Record (EMR), blog post), voice (e.g. phone request for prescription renewal, voice mail), face-to-face discussion (e.g. meeting, patient case presentation) or others.

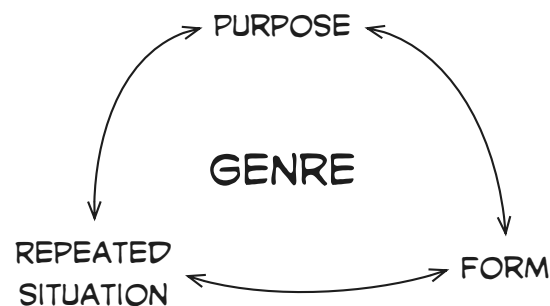


Figure 5 A Genre is a communicative action that is repeated in a specific context for a particular purpose, and has identifiable content and form.

Genres can be formal or informal and the flexibility of the content and structure varies. Formal Genres can be considered those that have a prescribed structure and content, such as prescriptions. A written prescription is a formal Genre that requires specific information in a precise manner that is used to communicate information for medication dispensing between physician and pharmacist. Without clear and specific drug information including name, dose, frequency and duration, and prescriber identification a prescription cannot be accepted. Handover of care from one nurse to another at shift change is another example of a Genre in healthcare, although it is less formal and the content of the handover depends on the complexity and acuity of the patient. Genres can be officially sanctioned or explicitly described within the organization. Local team members can also informally, or implicitly, support preferred communication patterns that become Genres over time (JA Yates, Orlikowski, & Okamura, 1999). Genres become part of the organizational culture.

Genres evolve as they are repeatedly applied and adapted by individuals over time within their organization, see Figure 6. This is a key aspect of Genres and points to the

foundational underpinning of Genre Theory: Structuration Theory (described below). Genres have grown from their historical application within an organization or group. They evolve over time as they are reapplied within an organization and as situations, forms, and purpose change.

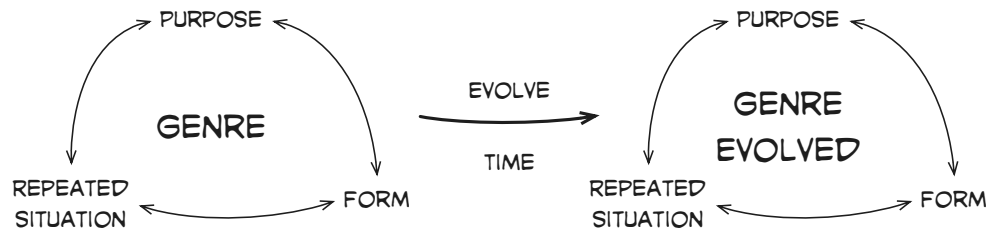


Figure 6: Genres evolve over time as they are used. Implementing an Electronic Medical Record, for example, will change the form of a Genre, but its purpose and the situation may remain essentially the same.

Genre theory is based in organizational research, but the term organization is used loosely. Genre Theory applies equally to communication within informal groups. It can also be applied across groups that share similar heritage. Studies of written Genre have looked at the differences and similarities between academic and workplace Genres, such as banking (Russell, 1997). These are not organizations, but related groups that, through their societal role and education history, have similarities in communication. Healthcare, like banking, has a common cultural and training heritage that spans organizations. Thus, Genres in use in healthcare may have application across care settings and organizations.

Theoretical Foundations of Genre Theory

Genre Theory was developed from Structuration Theory. The more broad Structuration Theory was adapted specifically to communicative actions and formed the basis for Genre Theory (J. Yates & Orlikowski, 1997).

Structuration Theory (Giddens, 1986) seeks to explain how point in time phenomena that are observed in social sciences research are created and evolve within groups being studied.

It was developed as a response to the dichotomy between objectivists and subjectivists. Structuration sought to break the dichotomy by taking the stance that social reality is developed within organizations and groups over time. This reality is developed through the adaptation of prior experiences and behaviours to current situations rather than the de novo creation of novel activities. Thus social phenomena are neither entirely objective, adhering to universal laws as might be seen in physics, nor are they completely subjective, point in time observations that are non-replicable. Between these, Structuration Theory states that there are local “rules” within organizations that develop over time as the organization develops. These local rules, which include aspects such as organizational structure, behaviour, and power relationships, guide the behaviours and patterns that are seen. These patterns repeat and evolve over time based on what is successful within a particular organization. These structures continue to exist as they are reaffirmed by the choices made to use them by people within organizations. Those that are no longer reused (with the assumption that they no longer have value) degrade over time.

Genre Theory inherits the Structuration perspective that structures are developed and adapted over time within organizations and tailors Structuration to communication activities. Thus, individual attempts at communication within organizations or social groups become routinized into Genres when they are successfully reused over time. Genres that are observed, while not universally generalizable, have a degree of predictive power within an organization and sometimes between groups that share some of the same cultural / social “evolutionary materials”. Healthcare contains some shared evolutionary pressures, for example, increasing evidence for care practices, standardized care planning, payment and insurance models, and accreditation of both training programs and of care facilities may well encourage similarities in practice.

Genre Theory Extensions

Over the past sixteen years, Genre Theory has been expanded to seek greater understanding about how different individual Genres work together as different kinds of Genre collections (Spinuzzi, 2004). There have been several different attempts to organize Genres collections, including: Genre Sets (Devitt, 1991), Genre Systems (J. A. Yates & Orlikowski, 2002), Genre

Repertoires (W. J. Orlikowski & Yates, 1994), Genre Taxonomies (Yoshioka, Herman, Yates, & Orlikowski, 2001), and Genre Ecologies (Spinuzzi & Zachry, 2000). Each approach collects Genres in different ways. The details of each are described below. Shifting focus from individual Genres to collections allows researchers to think of various communication processes, business activities and systems instead of single communication forms (Berkenkotter, 2001). Focusing on Genre collections as systems is relevant to this study. Continuity is achieved through communication, and thus through a variety of Genres. It is, therefore, useful to review the different ways Genres have been collected.

Genre Sets were developed to describe the collections of Genres available or used by people who have a particular role. They are perhaps best described in Devitt's work on tax accounting Genres (Devitt, 1991). In this work, Devitt described the "intertextuality" of documents, describing how Genres build sequentially on previous Genres (referential intertextuality) and how they interact as a whole (functional intertextuality). The focus was on formal documentation that was used to build up a corpus of documentation over time and less on the informal communication patterns. In the case of tax accountants, the information held in the Genres was so core that it "constitute[d] its products and its resources, its expertise and its evidence, its needs and its values." (Devitt, 1991) (p.354) The Genre Set describes the complete collection of Genres available to a particular role. However, a Genre Set may not consider other actors in communication (Bazerman, 1994).

Genre Systems were developed to describe the collection of Genres used through the path of a particular communication or process. Genre Systems are focused on how multiple actors select / use Genres *in sequence* to reach a specific goal. With patents as the domain of study, Bazerman explored how Genres sequence together to reach the goal of receiving a patent (Bazerman, 1994). Yates and Orlikowski have used Genre Systems to explore collaborative work within teams using Team Room⁸ (J. A. Yates & Orlikowski, 2002). Unlike a Genre Set, a Genre System is focused more on a particular process or goal and describes only a sub-set of all Genres available to an actor. Genre Systems, however,

⁸ Team Room, developed by Lotus Development Corporation, was software for electronic team collaboration across time and distance.

explore the Genres used by multiple actors in that focused, series of sequential communication actions.

Genre Repertoires are the collection of common Genres used within a group or community. Studies of Genre Repertoires have looked at the composition of Genres within a community, the use of those Genres (e.g. by which actors, frequency, and in what contexts), and how the Genres may have evolved over time as they are selected and performed (W. J. Orlikowski & Yates, 1994). Repertoires have also been thought to be helpful in understanding how a community begins to start using a new communication medium (JA Yates, Orlikowski, & Okamura, 1995). Repertoires are less interested in describing the sequence of Genres for a specific purpose.

Genre Taxonomies have been developed to act as knowledge repositories for communicative structures within organizations (Yoshioka, et al., 2001). The taxonomy provides mechanisms to place individual Genres in a related hierarchy. Features such as specialization (e.g. from generic “consultation letter” to “surgical consultation letter”) allow for Genres to be organized within a taxonomy for an organization. Taxonomies also consider information flow. They describe the individual Genres using 5W1H framework of questions.⁹ The taxonomy has been described as being useful for organizations to learn about their own communication patterns and to improve on those patterns through the evolution of the knowledge repository of Genres.

Genre Ecologies were developed, building on work in Genre Systems and theories such as Distributed Cognition.¹⁰ Genres in Genre Ecologies “act just as much as they are acted upon” (Spinuzzi, 2004). Genre Ecology takes a systems approach to documentation and

⁹ 5W1H questions are: Why? Who? What? Where? When? And How?

¹⁰ In Distributed Cognition, systems include multiple actors, both human and non-human, that share the cognitive processing to reach an understanding (Hutchins, 1995a). External representations of information actually process data. This processing changes the way the subsequent actor(s) handle information. For example, charting coordinates on a map allows human navigators to allow the map to process information like direction and speed. Distributed Cognition, as applied to understanding how CISs mediate clinical decision making is an important concept in exploring how electronic records can change quality of care delivery (Price, 2008).

Genres. For Genre Ecologies, the system is an open-system where activities are necessarily decentralized and variable in a flexible interaction between actors (both human and not) (Spinuzzi & Zachry, 2000). Ecological niches were an important concept in the development of Genre Ecologies. These allowed for flexible use and adaptation of Genres in decentralized niches. Ecologies can also be impacted by events outside of a declared system, such as mandated new forms or reporting requirements from outside agencies, such as funders or insurance companies.

Some work has been completed in visualizing and modeling Genre Ecologies (Spinuzzi, 2002). Visual models have been developed through the inductive codification of the mediating relationships between Genres (e.g. Genre – mediates – Genre). Examples of these mediatory relationships from Spinuzzi's work include "Ripples information to", "Summarized by", and "teaches about". Modeling of Genres in this manner has been helpful in understanding the variety of information and the relations of documents to each other within an ecology.

Of the currently described Genre collections, Genre Ecologies best fit with our Circle of Care construct as it considers both the mediation effects of Genres plus the localized, contextual re-use of Genres. The visualization aspect of Genre Ecologies is also aligned with our systemic approach to this research, as Soft Systems Methodology relies on several diagram types to represent findings and drive out improvements.

Genre Theory and Communication in Healthcare Organizations

Genre Theory is well suited to the exploration of communication patterns in healthcare organizations for several reasons, described here. (Examples from the literature of applying Genre Theory to healthcare communication are summarized next).

First, healthcare consists of primarily knowledge-based disciplines and activities. As care becomes increasingly team based and distributed, there is much more information to communicate amongst team members and between teams. The communication patterns are

often formal or semi-formal when it comes to patient care, with many paper-based forms and standardized processes developed for common activities. The patient record, for example, has standardized in most hospitals over time to contain consistent sections with consistent documents in those sections. Informal communication processes between providers complement these formal aspects of the patient's record.

Second, professional bodies and others are making recommendations as to the types of communication forms that are to be used, and the types of information to be captured and shared (or not shared). Professional Colleges have standards on documentation practices for the patient record, for example.¹¹ Accreditation of hospitals looks at documentation practices and communication processes as part of their reviews. Individual providers make adaptations to those recommendations to suit their local needs and practices.

Third, there are several “cultures” within healthcare. Physicians, nurses and other providers have had extensive, standardized training. This common training develops cultural norms within each profession. The various colleges and associations span care organizations and uphold these norms. Communication and documentation processes are included in these norms. The training includes standardizations in case presentation, recommendations for processes, the specific terms used to describe conditions (e.g. diagnoses), and how to document activities, such as taking a history and physical on admission and using SOAP¹² notes for documenting a clinical encounter. Thus, a nurse in one hospital is able to quickly adapt from one organization to another, as there are many similar Genres in use. They may differ somewhat in form and content, but many are clearly recognizable across organizations. Recurrent situations as triggered by patient condition (e.g. need for surgery) and clinical practice standards require a certain level of consistency.

¹¹ See <https://www.cpsbc.ca/files/u6/Medical-Records-in-Private-Physicians-Offices-0609.pdf> for an example from the BC College of Physicians and Surgeons resource manual.

¹² SOAP stands for “Subjective, Objective, Assessment and Plan” and has been taught and used for decades as a way of organizing a progress note to ensure adequate and clear organization to describe what the patient described (S), what was seen (O), the provider's interpretation (A) and the actions that will occur to address the issues (P).

Finally, Clinical Information Systems (CISs) often support documentation with some level of standardization (e.g. common sets of forms or templates) as well as provide communication tools. Healthcare environments are becoming increasingly dependent on these electronic records. Further, implementations of these CISs have a high failure rate, in part because they do not adequately address needs of providers, such as their communication needs (B. Kaplan, 2001). Genres have been helpful in understanding the various methods of communication both inside and outside of clinical information systems (L. Varpio, 2006).

Thus, there is considerable potential for studies in Genres to aid understanding communication patterns in healthcare. The findings of Genre studies should have some amount of applicability between health care organizations due to the cross-organizational nature of professional practice, clinical conditions, and care standards. Genres, such as “operative report”, “handover”, “wound care progress note”, “consultation letters”, and “clinical case presentation” will have some similarities that cross organizations.

Genre Theory Research in Healthcare

Genre Theory has been applied to several areas of healthcare research. Some are highlighted here that are relevant to my study.

The Genre of the Clinical Case Presentation has been explored to gain knowledge on how medical students learn both clinical and cultural aspects of medicine (Lingard, Garwood, Schryer, & Spafford, 2003). A Clinical Case Presentation is a way to present findings on a patient and is used both to provide care and to educate. It often includes a short “stem” of information about a patient, either real or representative, from which discussions on diagnostic and treatment decisions can be made. In this study, Lingard, et. al were able to use the concept of Genre to explore how medical students and attending physicians each handle medical uncertainty and share medical knowledge with the framework of a Clinical Case Presentation. This Genre provided a consistent set of structures to allow for both communication of clinical information and for teaching of junior clinicians. Schryer (Schryer & Spoel, 2005) has shown how rhetorical Genres in general and the Case Presentation specifically, provide structures in discourse that help develop and maintain professional

identity of physicians and other providers. Interestingly, the BC End of Life Framework (BC-Health, 2006) makes extensive use of “vignettes” to describe the patient groupings. These are very similar to the Clinical Case Presentation Genre. My study leveraged this cultural base and common Genre by developing two Clinical Case Presentations that structured my interviews.

Genre Theory was used while evaluating the social impacts and organizational issues of Computerized Physician Order Entry (CPOE) through a detailed case study. CPOE is, at one level, simply a change in *form* of the Genre of orders (Davidson, 2000). However, this study found that the implementation of CPOE changed the way physicians and nurses interact during the ordering process, leading to decreased use of other informal Genres. This resulted in less discussion and less feedback. The ordering process became more isolated; the physician was more likely alone with the computer than near the nurse on the ward (change in context). Data in CPOE became more structured than the written orders, making some aspects clearer, but losing some of the more descriptive orders (change in content). The implication from this study, beyond CPOE, is that changes in Genres are not necessarily isolated.

The impact of the DSM-IV on psychology and psychiatry has been explored through Genre Theory (Berkenkotter, 2001). Berkenkotter used Genre Theory to explain the balance achieved between the organizational communicative structures (formal Genres) and how individuals adapted of those structures to particular needs. Berkenkotter also explored Genre Systems, describing the DSM-IV as a “meta-Genre” that informs many other Genres through its framework of diagnoses and conditions. This is a useful concept to consider when discussing use of terminologies.

Popham (Popham, 2005) explored the Genres of medical forms and also the electronic genres of social work and mental health (Popham, 2008). She discussed the importance of understanding the amount of “professional commitment” there is to the purpose of each Genre. For example, if a form is a billing form, the attention to quality of the clinical information will be different (typically poorer quality) than that of a consultative report where the author has a greater stake in providing useful and accurate information.

Varpio applied Genre Ecology theory to understand documentation practices in a pediatric practice (L. Varpio, 2006), (Lara Varpio, et al., 2006). She explored the Genre Ecology of both formal and informal Genres during an implementation of an electronic record. In her work on a pediatric nephrology ward, she developed two Genre Ecologies, one for physicians and one for nurses. She also observed how Genres interact and how changes or improvisations in one Genre may have propagating effects to other Genres in the ecology. She has also used Genre when exploring documentation and communication practices in optometry clinics (L. Varpio, Spafford, Schryer, & Lingard, 2007).

Genres: Summary

Genres are constructs used to describe repeated communicative activities used within organizations or groups. They have a recognizable structure based on their physical form, their purpose and the recurrent situations in which they are used (J. Yates & Orlikowski, 1997). Genres are not necessarily defined by a technology or organizational structure but by their repeated use in practice (W. Orlikowski, 2000). Genres may reflect organizational structures and may be influenced by policies and other “meta-Genres” that describe aspects of communication. Research from several groups has extended Genre Theory into various types of Genre collections, such as Genre Ecologies. The application of Genre Theory in healthcare has been relevant and helpful in understanding complex communication patterns.

Genre Theory, as a theoretical foundation to understand communication, has been important to my research in two ways. First, Continuity of Care is maintained through various forms of communication. Thus, focusing on Genres that were used in ensuring Continuity at transition points and between providers across locations would highlight continuity challenges. Second, Genre collections (of various kinds) can help understand the larger interactions from a systemic perspective. By developing a Genre collection related end of life care, I can seek to understand how Continuity of Care is maintained. Genre Theory provided a theoretical foundation and Genre Theory complemented my choice of methodology, Soft Systems Methodology, described in the next chapter.

Chapter 5 Soft Systems Methodology

This chapter provides an overview of the Soft Systems Methodology, its historical roots, its appropriateness to Wicked Problems, and the evolution of the methodology since its inception. The chapter concludes by highlighting a few examples of SSM in healthcare.

Systems Methodology: The Historical “Hard” Roots

Systems approaches have been developed in many disciplines, from physics to psychology to politics (von Bertalanffy, 1969). General Systems Theory was developed to provide “*a level of theoretical model-building which lies somewhere between the highly generalized constructions of pure mathematics and the specific theories of the specialized disciplines*” (Boulding, 1956). Systems theory has goals such as “*aiming at exact theory in the nonphysical fields of science*” and “*developing unifying principles running ‘vertically’ through the universe of the individual sciences, this theory brings us nearer to the goal of the unity of science*” (von Bertalanffy, 1969) (p38). In short, systems theory seeks to describe the whole instead of the parts. This movement from reductionist and isolated studies to considering integrated systems was a significant step forward. With successful development of systems approaches in the harder sciences, there was interest in developing similar approaches for organizational systems.

The organizational systems theory of the 1960s and 1970s¹³ relied heavily on mathematical models (Mingers, 2000). These models were used to find explicit optimizations of overall processes. Systems were described and based on the assumption that there could be a

¹³ Considered as “Hard Systems Theory” as a contrast to the developing Soft Systems Theory / Methodology

desired or ideal state. Mathematical models were developed for many systems in physical and biological sciences and these had had considerable impact in their fields (Polderman & Willems, 1998). It was assumed that similar benefits could be derived at all levels, including social and organizational science. In part, this assumption bore fruit.

Hard Systems methodology, then, relied on describing a system, understanding the interrelationships within the system and then modeling and testing hypotheses in order to select and then implement the optimal solution. This stepwise approach to understanding a problem and then seeking a systemic solution, as illustrated in Figure 7, has an elegant appeal.

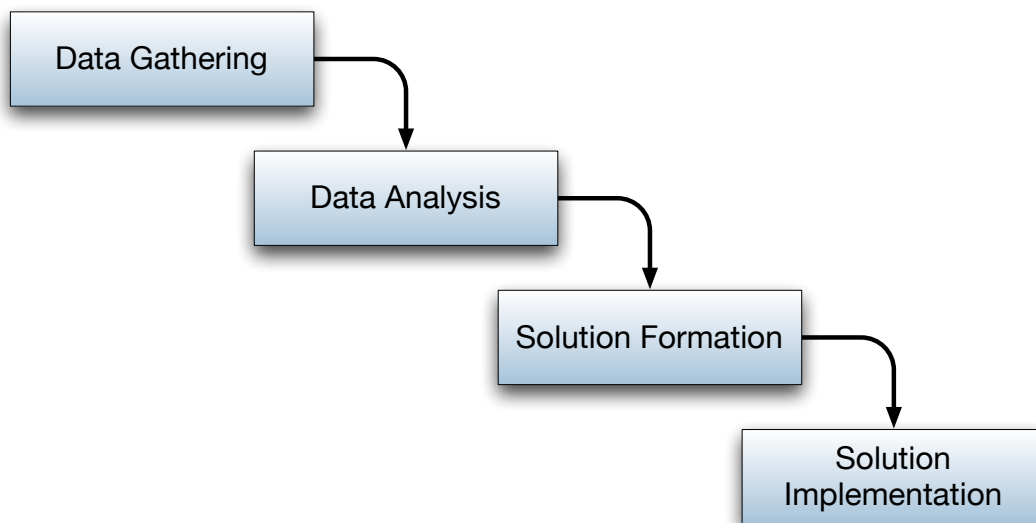


Figure 7: Linear Problem Solving Method, based on (Periyakoil, 2007).

However, in the business and organizational sciences, it was noted by some that systemic approaches with mathematical optimizations to processes were often not sufficient to address all issues that management saw as core issues. Further, the recommended solutions, based on optimized mathematical models, were often not being adopted successfully in the real world. It was these types of issues that led Peter Checkland to develop Soft Systems Methodology. When he was a manager (with a PhD in Chemistry) at ICI Fibres, he struggled

with many of these issues and found the then current management literature lacking in addressing many of the issues he was tackling in the real world. His challenges and the lack of support from the traditional systems thinking were important drivers when he then accepted a professorship at Lancaster University and he began to develop an approach that addressed some of the softer aspects of organizational problems (Flood, 2000). At Lancaster University, Checkland developed Soft Systems Methodology (SSM) as a response to “hard” systems theory. It was meant to become an approach to deal specifically with the “soft” or “wicked” social / organizational problems where one could not assume that there was a “right solution”. Before describing the various aspects of the methodology, a description of Wicked Problems would be appropriate to understand the types of challenges that SSM set out to address.

Wicked Problems

Wicked Problems was a term coined by Horst Rittel in 1967 to describe:

“Social system problems which are ill-formulated, where the information is confusing, where there are many clients and decision makers with conflicting values, and where the ramifications in the whole system are thoroughly confusing.” (Churchman, 1967)

These are in contrast to “tame problems”, where the problem and its solution can be clearly articulated. Tame problems lend themselves to more traditional approaches to problem solving as illustrated in Figure 7. Tame problems have a finite and definable set of options with clearly described outputs and outcomes and a solution can be pre-defined. Wicked Problems do not. Rittel has described several key characteristics of Wicked Problems, which make them “wicked” or challenging. These are summarized in Table 3.

Table 3: Characteristics of Wicked Problems, based on (Rittel & Webber, 1973), with comparable characteristics of tame problems.

Wicked Problems	Tame Problems
No definitive formulation of the problem	Problem can be clearly formulated and contain all information to reach a solution.
No clear description that defines the end or solution	Solution can be clearly defined so that people know when they are finished.
Solutions are shaded “good” or “bad” and reside on a spectrum of quality without clear end points.	Solution options are either true or false (correct or incorrect)
There is no test/proof for a solution to a wicked problem.	Solutions to tame problems can be tested / confirmed “on the spot”.
Each attempted solution to a Wicked Problem impacts outcomes irreversibly.	Solutions to tame problems can be safely tested, repeatedly until “right”
Wicked Problems do not have a finite set of potential solutions that can be (practically) defined.	Tame problems had a defined / definable set of options for solution.
Wicked problems cannot be grouped into classes, they are effectively unique	Tame problems can be categorized into classes of problems with well-specified characteristics and solution approaches.
Wicked Problems are just symptoms of other, higher-level Wicked Problems.	Tame problems are well encapsulated.
The same Wicked Problem can be described in numerous ways, depending on perspective.	Tame problems have a fairly consistent description from multiple perspectives.
The hypothesizer of solutions to Wicked Problems cannot afford to be wrong.	The hypothesizer of solutions to tame problems offers solutions that are meant to be refuted as part of testing those hypotheses.

An example of a Wicked Problem would be poverty: it is difficult to define; impossible to define when it is “solved”; and it can be tackled at many levels. Wicked Problems are complex, challenging issues that limit our ability to describe them in finite detail, let alone describe accurately, their solutions. These problems can be described in many ways, as can the possible resolutions. Wicked Problems defy hypothesis testing as the impact of testing a hypothesis changes the problem itself. Wicked Problems are often the types of problems designers face in many domains (Buchanan, 1992). They require a different set of tools to address these problem situations.

Wicked problems have many of the characteristics that complexity theory has been designed to address. Complexity science addresses problems in large, dynamic systems where the system cannot be completely known (Cilliers, 2002). Complexity science has supported

organizational science in several ways, including the development of new models to describe complex systems and problems (Lissack, 1999). Complexity science has dealt with adaptive systems, where agents act with a certain level of autonomy within the system. They typically act on internal, but fuzzy, rules (Plsek & Greenhalgh, 2001). Thus the systems are not entirely predictable and respond to change in non-linear ways (Barnes, Matka, & Sullivan, 2003).

In healthcare, where systems are large, complex sociotechnical ecosystems, the effects of change can occur at many levels (B Kaplan, Brennan, Dowling, Friedman, & Peel, 2001). Impacts of technology can be very human, and we are realizing now, the extent of reach that clinical information systems have with a broad range of unintended consequences, both macro and micro in nature (Ash, Mls, & Coiera, 2004) (Campbell, Sittig, Ash, Guappone, & Dykstra, 2006). These are wicked problems.

Continuity of Care has all the hallmarks of a complex or wicked problem. Rittel's characteristics of Wicked Problems have been mapped of the challenge of Continuity of Care in Table 4.

New models of development, design, testing and monitoring of clinical information systems are needed to seek improvements instead of solutions with possible negative outcomes. In the systems research, Peter Checkland began to develop what is now known as SSM to address these types of complex, real world problems. SSM was developed to seek feasible improvements instead of solutions to these social / organizational situations. SSM has a long tradition of problem focused, improvement oriented interpretive research (P. Checkland, 2000). Over the past 30 years, SSM been used successfully in many complex situations (Mingers, 2000), including healthcare applications, such as aiding in the creation of information systems for the National Health Service (NHS) in England (P. Checkland & Holwell, 1993). Over that time, SSM has undergone considerable evolution as a methodology. The major SSM approaches are described next.

Table 4: Characteristics of Continuity of Care as it relates to the characteristics of Wicked Problems, based on (Rittel & Webber, 1973).

Wicked Problems	Continuity of Care
No definitive formulation of the problem	Continuity of Care is a recognized problem, but is defined differently, depending on the perspective (e.g. each profession may define Continuity of Care differently).
No clear description that defines the end or solution	Improving Continuity of Care is a process for each patient without a clear, defined, testable, objective endpoint. There are no blood tests for Continuity.
Solutions are shaded “good” or “bad” and reside on a spectrum of quality without clear end points.	Clearly, solutions can improve continuity and make continuity worse. Possible solutions are shaded.
There is no test/proof for a solution to a wicked problem.	There is no objective, agreed to test for “Complete Continuity Achieved”
Each attempted solution to a Wicked Problem impacts outcomes irreversibly.	Changes to improve Continuity of Care will impact future options, such as through the changing of communication pathways, changing resource allocation, skill development, etc.
Wicked Problems do not have a finite set of potential solutions that can be (practically) defined.	Continuity of Care has extremely broad range of solutions that are effectively unbounded.
Wicked problems are “essentially unique”	The Continuity of Care problem not only is unique to a jurisdiction, but also can be unique to the individual patient level (e.g. factors such as family support, independence, etc will impact Continuity of Care).
Wicked Problems are just symptoms of other, higher-level problems.	Continuity of Care issues can be described at many levels from the individual patient, individual provider, local community, to regional, jurisdictional and (inter)national levels. Continuity of Care issues are symptoms of overall quality of care issues.
The same Wicked Problem can be described in numerous ways, depending on perspective.	Continuity of Care varies depending on who is describing it (as seen in the literature).
The hypothesizer of solutions to Wicked Problems cannot afford to be wrong.	Negative impacts to Continuity of Care will not be tolerated as it represents Healthcare Quality and Patient Safety. An unintended consequence could have life altering impacts to patients.

The Original SSM Seven Step Model

The initial SSM, described in 1972 (P. B. Checkland, 1972), was a clear, prescriptive, seven step methodology. It required practitioners to move through the seven steps, engaging participants in each stage to: discover issues, model the problems, seek improvements, and reflect on learnings. This engineering-like model that was characteristic of early SSM is outlined in Figure 8 and described below.

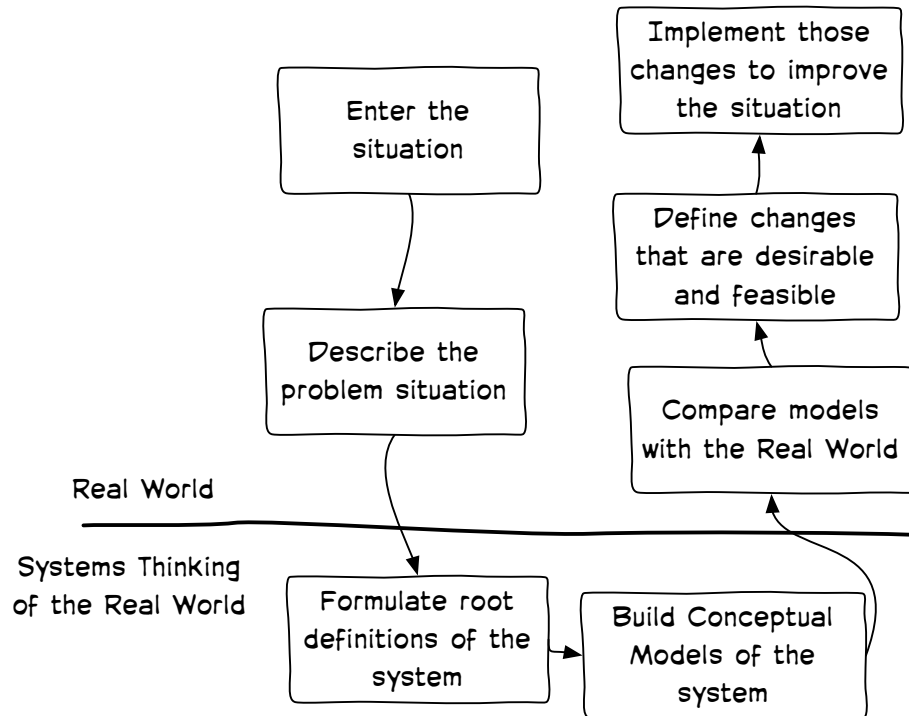


Figure 8: The original 7-step model for SSM. Based on (P. Checkland & Scholes, 1990)

First, the practitioner needs to **Enter the Situation**, immersing sufficiently to be able to begin to **Describe the Problem Situation**. The intent of these first two steps is to provide the practitioner with sufficient knowledge to begin modeling the real world situation. **Formulating Root Definitions** and **Building Conceptual Models** occur once some understanding of the situation occurs. These definitions and models are meant to reflect the relevant activities in the system model. The fifth stage, **Compare Models with Real World**, questions the knowledge gathered. In this stage, further need for assessment and comparison is determined. The sixth stage, **Define Changes that are Desirable and Feasible**, captures the agreed to changes that both are expected to improve the problem situation and that are agreed to as feasible to implement. The final stage, **Implement Changes to Improve the Situation**, takes the ideas into action. This, of course, changes the problem situation and the process can continue.

Although this seven-stage model has arrows hinting at chronological direction from a beginning to end, it is meant to be iterative. The arrows show *dependencies* rather than

definitive steps. For example, you must be able to, at some level, describe the problem situation before you can formulate some approximations of root definitions.¹⁴ Refinement of the understanding is meant to occur through out the process, although it is not explicit in the diagram.

Peter Checkland, in his formulations of SSM makes a strong case for separating our thinking about the real world and the real world itself (P. Checkland, 1988). There is value in abstraction. More importantly there is value in understanding that our models are only models. They are made up descriptions that approximate aspects of problems; they are not the problems. Keeping the modeling aspect explicit allows the practitioner to focus on relevant aspects of purposeful activity instead of trying to exhaustively model complete systems in complete detail, which would an impossible task. Models are meant to help us focus our thinking to improve situations, not to be fully accurate representations, especially in seeking improvements to complex situations and Wicked Problems.

Evolved SSM

Through reflection on SSM itself over the past more than thirty years, the SSM methods have evolved. They have moved beyond their prescriptive roots in general systems theory to a more fluid, flexible approach that better reflects how SSM has been used in practice. The more general description of SSM is captured in Figure 9. This current practice of SSM, described here, is based on the descriptions in (P. Checkland, 2000) and (P. Checkland & Poulter, 2006). It includes five activities involved in investigating a problematic situation. Figure 10 outlines the current SSM approach (this figure is itself an SSM conceptual model). The activities are numbered because of the dependencies from one to the next. The order of tasks is not prescribed by the numbering, as the current SSM is quite iterative and dynamic. The five activities are described next.

¹⁴ A Root Definition is the description of a purposeful activity system. They are used to focus the understanding of particular SSM models and often can take the form “Do X by Y in order to achieve Z.” For example, “Work with patient by taking a history and performing a physical exam in order to address the patient’s concerns.”

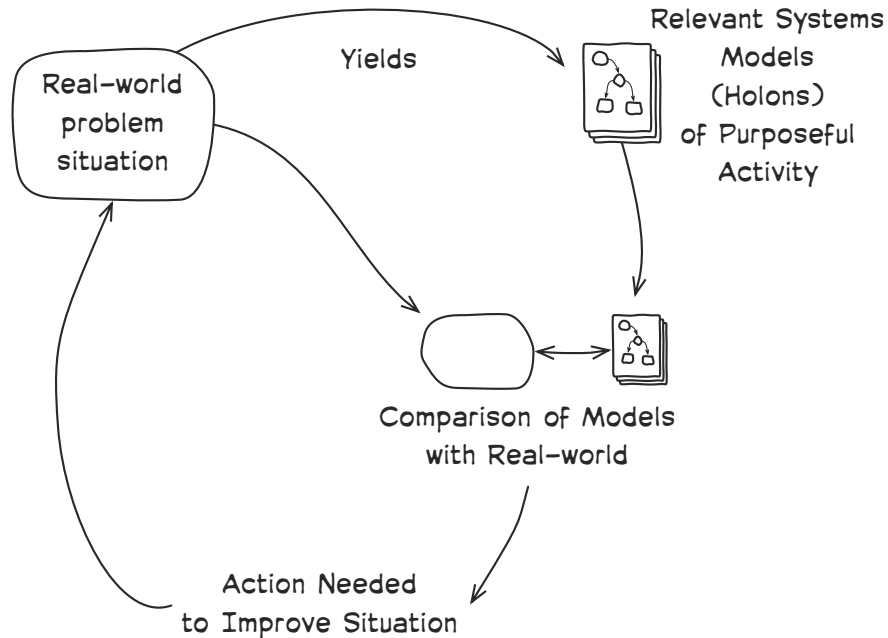


Figure 9: Soft System Methodology's current basic form as a Rich Picture. Based on (P. Checkland & Scholes, 1990), page 7.

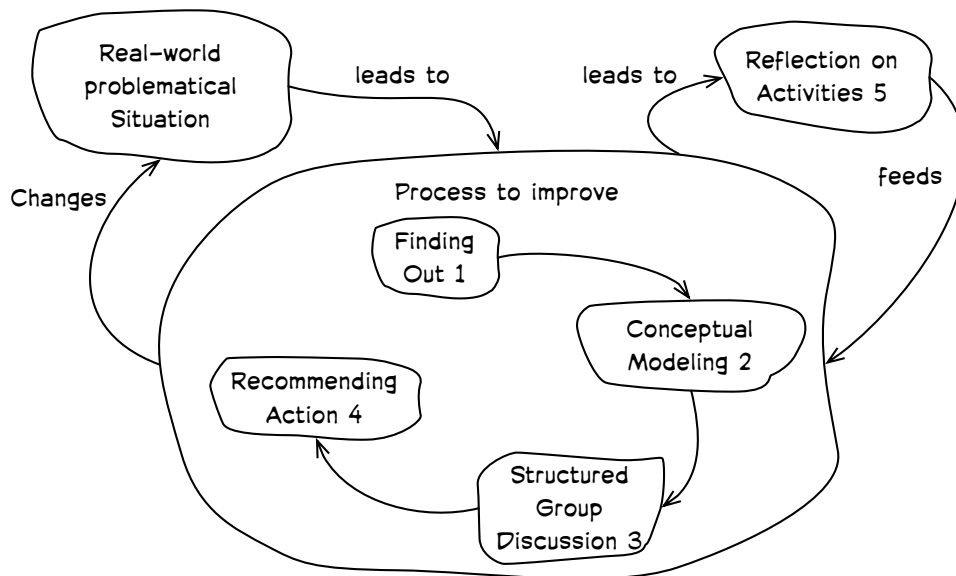


Figure 10: An SSM conceptual model illustrating the five phases of current SSM practice: finding out, conceptual modeling, Group Discussion, Recommending/taking action for improvement, and reflection. Based on (P. Checkland & Poulter, 2006). The numbers indicate dependencies, rather than explicit sequencing.

Finding Out

The first activity is **finding out**, or learning, about the situation. Finding out can be accomplished in many ways. However, there are of four concepts that are core to the analysis: the development of “rich pictures” and three levels of analysis, dubbed Analyses 1, 2 and 3:

1. *Rich Pictures* – Rich pictures was a term used initially to describe the need to deeply understand a situation so that the practitioner can have a rich mental image of the problem situation. Over time, the pictures changed from mental to physical pictures that represent actual practices, as the practitioner understands them.
2. *Analysis 1: The intervention* -- This explores the needs of the *client* (who asked for the investigation), the activities of the SSM *practitioner* (who performs the activities), and the *issue owners* (who are impacted by the outcomes). The explicit consideration of the views of these three roles drives much of the rest of the work.
3. *Analysis 2: The social environment* -- This examines the people involved, their roles, values and norms. This analysis is often captured in a reflection journal, where the practitioner documents impressions after each encounter and activity.
4. *Analysis 3: The political environment* -- This explores the power distribution across the system. Political power is key to achieving change. Like analysis 2, these findings are typically captured in a reflective journal specifically used for this analysis.

Conceptual Modeling

The second SSM activity is to develop **conceptual models** to aid in the exploration of the problem situation. Each model is developed to describe a specific, purposeful activity based on a single, declared perspective or “worldview”. Purposeful activities are a core concept to SSM. A single purposeful activity model is not meant to represent real life or even proposed future state. They are meant to capture an idealized state from a single, clearly stated perspective. These worldviews are developed from understanding the roles uncovered in the

finding out. The models of purposeful activity from a single perspective can be clear in a manner that the real world activities cannot be. They make explicit the intentions that may be buried in current activities.

Structured Discussion Group

The third activity is the **structured group discussion** or debate. Discussion of findings is a key aspect of SSM for it is here that solutions are discovered. The models, designed with their distinct worldviews, are chosen to spark debate. Unlike unstructured discussion on difficult topics, which can range widely and not be productive, experience with SSM has shown using the models to structure the discussion improves the process, maintaining focus on the observed findings. Questions or scenarios can be developed around the models to structure the debate and focus on appreciating the collection of different worldviews.

Recommending Action

The fourth activity in SSM is to **make feasible recommendations for improvement** and/or to take agreed actions to improve the situation. The goal of SSM is to arrive at agreed and feasible solutions for improving the problem situation. These solutions, likely, are not the result of consensus being developed (although this can happen), but rather it is more likely that there is accommodation by members in the group who now better understand the various worldviews. The types of changes that are often considered are: structural changes (e.g. Change in organizational structure), process changes (e.g. Workflow changes), or attitudinal changes (often hardest to define / produce).

Reflection and Iteration

The fifth activity is **reflection**. By ensuring that reflection is embedded into SSM, it allows the practitioner and the practice to improve throughout the process. As no situation is ever in a perfect state, reflection establishes the evaluation of the process (i.e. efficacy, efficiency, and effectiveness). Reflection during the process allows the study to improve over time, thus the study should have an iterative nature, so reflections can be acted upon.

These five activities, described here in linear fashion, occur as needed while approaching the problem and should cycle continuously in a reflective practice. The end point in an SSM study is felt to be arbitrary, as improvement is not meant to stop.

Fundamental Principles of SSM

As Soft Systems Methodology evolved to a more organic and more encompassing approach, people questioned what defined SSM? With the seven-stage model, it was clear and easy to see where people used SSM. With the more current evolution, how could one know if SSM was being used? To answer this question, Checkland developed five “Constitutive Rules” (Table 5) and a collection of definitions (Table 6) that, together, help to better define SSM, allowing it to exist as a Methodology, but with the benefit of flexibility.

Table 5: Constitutive Rules of SSM, based on (P. Checkland & Scholes, 1990) p286-287.

SSM is a structured way of thinking about problem situations with the aim of improving the situation that can be part of day-to-day managerial work or as part of a specific study.
SSM's structure is derived from a systems approach. Any account that claims to be based in SSM must be expressible using the SSM epistemology (see Table 6).
Any account that claims to have used SSM should follow these guidelines: <ul style="list-style-type: none"> • An explicit assumption is made to describe part of the real world as a system to be engineered. • The SSM user is explicit in the transitions between real world and the reflective, systemic thinking about the real world. • Models are created that typically capture purposeful activities and contain: emergent properties, layered structure, and mechanisms for communication and for control. • Models are used to trigger discussion and debate to define feasible improvements.
Each application of SSM should be consciously adapted to its particular situation.
Reflection on the methodology in practice can reveal new lessons to refine and extend SSM.

Table 6: SSM epistemological definitions, based on (P. Checkland & Scholes, 1990) p288-289.

Term	Description
Real World	The experience of everyday life, as it unfolds.
Systems Thinking World	The place where conscious reflection on the Real World occurs.
Problem Situation	A situation that is felt could be improved in the Real World.
Analysis One	Intervention Level Analysis – considering the needs of the client or issue owner in the context of the Problem Situation.
Analysis Two	Social Level Analysis – considering the roles, norms and values within the Problem Situation
Analysis Three	Political Level Analysis – considers power distribution in the Problem Situation.
Rich Pictures	Diagrams highlighting a Problem Situation’s people, things, processes, relationships and challenges.
Root Definition	The verbal description of a purposeful activity system. Formally described as “Do X by Y in order to achieve Z.”
CATWOE	The acronym that captures the six key elements that should be considered when creating Root Definitions. They are: Customer – who benefits from the Transformation Actor – who will do the Transformation Transformation – the activity of changing system inputs into system outputs. Weltanschauung or World View – the specific perspective / context for the purposeful activity being described. Owners – the person / group that can stop the transformation Environmental Constraints that are outside the control of the system but need to be considered.
5 E’s (or 3 E’s in bold)	The control / judging criteria for a given system: Efficacy, Efficiency, and Effectiveness Also: Ethicality and Elegance
Conceptual Model	The activity model for a system that includes both an activity portion and a control portion (to monitor against the 5/3 E’s)
Comparison	Central to SSM is the comparison between the Real World and the Conceptual Models in order to trigger debate on the relevance of the models and on the possible improvements.
Changes	Changes in SSM to the system at that point in time in the analysis that are considered an improvement to the system (i.e. the change is desirable) and would be culturally possible to achieve (i.e. the change is feasible)
Actions	The Real World change taken to improve the problem situation. This is in contrast to the systemic Change.

Examples of SSM in Healthcare

Checkland and others have applied SSM to healthcare with some success since its inception. Checkland explored several aspects of the National Health Service (NHS) in Britain while attempting to support and understand the information systems needs from a business /

clinical perspective (P. Checkland & Holwell, 1993). This study leveraged the use of SSM conceptual models that were developed through the study, such as “Inform GP of outcome” and “Carry out medial examination”, to determine information needs and make recommendations on information system functionality. Rose and Hayes (Rose & Haynes, 1999) also used SSM to explore changes in the NHS. Specifically, they developed an evaluation plan based on SSM that was used to monitor significant organizational change efforts in the NHS. The use of SSM ensured that IT efforts were not evaluated solely as IT projects, that is, their evaluation also included social and political contexts. Further, the SSM based process encouraged formative evaluation, reflection and improvement. This was to better align the evaluation program to support activities of the NHS change, rather than being only a summative evaluation where blame was assigned.

Another case study showed how SSM could support reasoning with simulation development, when exploring improvements in the Watford General Hospital’s outpatient ‘Care of the Elderly Clinic’ (Lehaney & Paul, 1994, 1996). This study looked at the system around this clinic, including activities within the clinic as well as external X-ray, ECG, and laboratory testing services. SSM proved, in this study, to be a useful methodology to support reasoning with the simulations on what improvements could be considered. SSM has been used to explore system improvements that could result in improvements in quality of care (Macias-Chapula, 1995). Here, information access was seen as an essential component for analysis, but there was also a need to better describe and include the patient-provider relationships into traditional analysis. Both of these elements are part of Continuity of Care.

It has been argued that SSM is one of the tools that can be used to decrease the failures rates of clinical information systems (Heeks, 2006). SSM has been extended and adapted into a method, SISTeM, specifically designed to take a soft systems approach to the early exploration of information systems (Atkinson, 1997). Atkinson has applied SISTeM to develop the vision for the electronic patient record system with the Electronic Patient Record Programme Management Board of the NHS Executive's Information Management. This approach proved to be a useful complement to traditional requirements engineering.

Carson argued that taking a systems approach is necessary to understand the management of

chronic diseases, such as diabetes or end stage kidney disease (Carson, Cramp, Morgan, & Roudsari, 1998). Specifically, having a systems view was a necessary aspect to successfully designing clinical decision support tools and telemedicine care for chronic disease programs. In their study, they found SSM was an effective methodological choice for their work.

SSM Summary

SSM has proven itself as a flexible evaluation and improvement tool for wicked problems. SSM has been used in several aspects of healthcare, from addressing problematic situations at an organizational level to determining the early requirements for clinical information systems. SSM can be used as a tool to support research and evaluation in several different ways, including as a *problem-structuring tool* (to help develop research questions) as a *good-fit research tool* (to conduct research) and as a *coordination tool* (to help define and support the process of the research itself) (Rose, 1997). I felt that it was a good methodological approach to exploring the challenging and ill-defined nature of Continuity of Care. SSM was used in my study both as a research tool and as a coordination tool.¹⁵

¹⁵ The reader will see throughout this dissertation SSM used to describe findings in the research (SSM as research tool) and the research processes (SSM as coordination tool).

Chapter 6 British Columbia Healthcare Context

This chapter provides the reader with the necessary context of the BC healthcare system. Specifically, the Vancouver Island Health Authority (VIHA) and its overall strategic vision as well as a focus on VIHA's Information Management / Information Technology (IM/IT) approach. The Provincial Health Services Authority (PHSA) is introduced, as it is responsible for cancer care in BC. The BC Physician IT Office (PITO) is briefly described.

The Two Study Communities: Duncan and Victoria

This study was situated in two communities on Vancouver Island, British Columbia, Canada: Duncan and Victoria.

- **Duncan** is the smaller of the two communities. The population of Greater Duncan was approximately 41,000 people (BC_Government, 2006a). 17% of the population was over 65 years old (slightly higher than the BC average of 14%). It was located 60 km north of Victoria (BC_Government, 2006c). It had its own community hospital, Cowichan District Hospital with a full Emergency Room, inpatient services, inpatient and outpatient laboratory and diagnostic imaging and an ICU (VIHA, 2009a). Duncan refers patients both to Nanaimo (50 km north) and to Victoria.
- **Victoria** is the province's capital. Its population was slightly over 330,000 (BC_Government, 2006b). 16% of the Victoria population was over 65 years. Victoria has several hospitals, including two tertiary care centres, Victoria General Hospital and Royal Jubilee Hospital (VIHA, 2009b).



Figure 11: A map of Canada and Vancouver Island, highlighting the location of the two communities that were part of this study, Duncan and Victoria, BC.

Both communities are within the Vancouver Island Health Authority (VIHA).

VIHA Overview

VIHA is one of five regional Health Authorities in British Columbia and is the major provider of health services on Vancouver Island. It provides health care services to over 750,000 people within the region (mostly Vancouver Island, with a portion of the BC mainland see Figure 12). VIHA employs approximately 17,000 health care providers and staff and manages all acute care facilities in the region (VIHA, 2008).

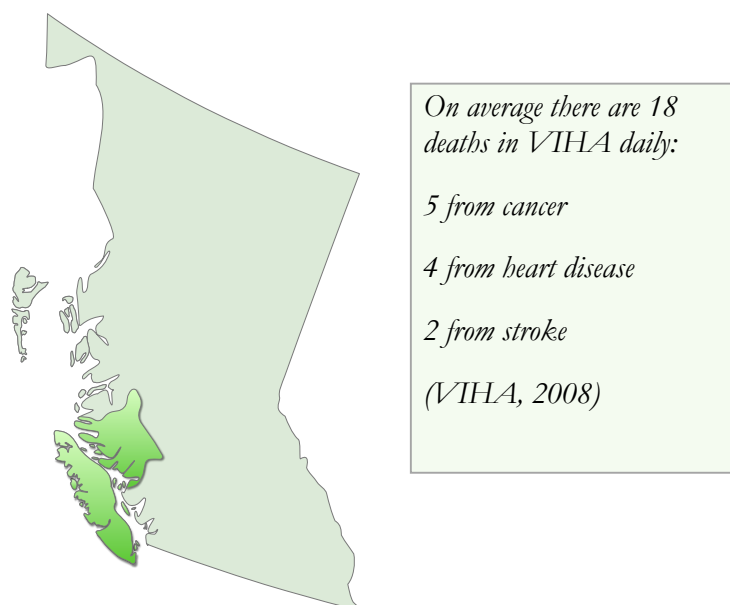


Figure 12: Approximate Geographic Coverage of Vancouver Island Health Authority.

As a regional health authority in BC, VIHA does not provide all care services in the region, but it does provide a number of health services to people in the region, including: population health, mental health and addictions, some primary care, much of the long-term care, nearly all acute care, rehabilitation services, and Home and Community Care. VIHA provides these services directly and in partnership with local resources. Most physicians are independent providers and bill directly to the provincial government in a fee for service model. Primary care is provided mainly through private family physician offices, but VIHA also has several owned and operated clinics across the region and additional partnerships with other organizations to facilitate primary care delivery to special populations (i.e. underserved populations).

Cancer services in the region are primarily provided through the Provincial Health Services Authority (PHSA), although this is done in collaboration with VIHA and private physicians. PHSA is described below.

VIHA Vision, Goals and Priorities

VIHA's overall strategic plan was updated and released in September of 2008. In it, VIHA has described its high level vision. The vision was supported by three goals. These goals, in turn, were supported by nine more detailed strategic priorities (VIHA, 2008). In this section, VIHA's strategy was summarized in the context of three aspects of our study: Continuity of Care, end of life care, and Clinical Information Systems.¹⁶

VIHA Vision:

*“Healthy People, Healthy Island Communities, Seamless Service.” (C, E, IT)
(VIHA, 2008)*

In order to achieve the vision, quoted above, VIHA described their future state health system as including *“Patient and client records that are available electronically to authorized health service providers and to the individual anywhere, anytime so people don't have to repeat health histories or tests for each service provider they see”* (ibid, p12), addressing the needs of Continuity of Care through Information Systems. They also describe a healthcare system with *“more options for end of life care”* (ibid, p12).

VIHA Goals:

1. Improved Health and Wellness of Residents.

This included a focus on the general VIHA residents and advocated for health promotion / disease prevention for the general population.

¹⁶ NOTE: Each item that is described from VIHA's Vision, Goals and Priorities is followed by a letter that indicates that either (C) continuity, coordination, communication are indicated or (E) the patient population likely includes end of life care or (IT) Information Technology is explicitly described as part of the scope or solutions.

2. **Quality, Patient Safety and Client-Centered Care and Services. (C, IT)**

Care delivery is focused on the patients within VIHA, so improvements and activities are driven by patient needs, not necessarily system oriented changes.

3. **A Sustainable, Affordable, Publicly Funded Health System. (IT)**

This goal included realizing efficient and effective ways of delivering public care and ensuring that resources match the changing needs of the population.

The three goals only explicitly covered two of the three aspects of this study. End of life care are not explicitly mentioned in VIHA's goals. However, from these three high level organizational goals, VIHA has articulated its nine strategic priorities, which did include end of life care.

Strategic Priorities:

1. Improved Health of High Needs Populations¹⁷
2. Comprehensive Primary Care (C, E)
3. Enhanced Quality and Safety Performance (IT)
4. A Sustainable Network of Hospitals (C, E, IT)
5. A Centre of Excellence in Senior's Care (C, E)
6. Integrated Mental Health and Addictions Services (C, IT)
7. Improved Access and Patient Flow (C)
8. A Healthy Workplace and Engaged Workforce (IT)
9. Fiscal Sustainability and Innovative Business Models

Continuity of Care, end of life care, and improved clinical information systems were highlighted in various forms at each level of VIHA's vision, goals, and strategic priorities, with only one exception.¹⁸ The three aspects of this study appeared to be well aligned to VIHA's over all strategic direction. This suggests that this study, which seeks to improve Continuity of Care for end of life patients and the clinical information system would be of

¹⁷ End of life care were not specifically named in the list of high needs populations, but frail elderly were.

¹⁸ End of life care was not expressly captured in the description of any of the Goals.

interest to VIHA and could provide VIHA with additional information that may help it to achieve its vision.

VIHA Information Management / Information Technology (IM/IT)

VIHA's overall strategy was supported by several infrastructure strategies. These were more granular and specific than VIHA's overall strategy. VIHA's Information Management / Information Technology (IM/IT) plan was one of the infrastructure plans.

The Information Management/ Information Technology group was under the co-leadership of the Chief Information Officer and the Chief Medical Information Officer. At the time of this study, IM/IT in VIHA was responsible for clinical information systems, the Health Authority's technology infrastructure (e.g. network, server management, desktop deployment, phone system, etc), regional business systems, and Medical Records.

The VIHA IM/IT Infrastructure Plan was last released in 2007 (VIHA, 2007). In this plan, several strategic directions were described that relate to Continuity of Care, including:

- *“Provide access to a complete, integrated set of core clinical content across the continuum”*
- *“Provide seamless, secure access wherever clinical information is required”*

The focus was on establishing the information infrastructure and providing general availability of “core clinical information” (described below) to providers across the region using a single, integrated system.

In 2008 VIHA IM/IT completed a significant regionalization of their primary acute care CIS, Cerner Millennium, to all but one hospital in the region (Powers, 2009). Cerner Millennium was deployed in these sites as a “single instance”, where each patient has a single acute electronic record in Cerner that was shared across the region. At the time of this study, VIHA's Cerner Millennium system contained the following patient information:

- **Patient registration information** (demographics, address, etc. captured during an encounter at a VIHA facility).

- **Encounter information** for the majority of VIHA inpatient and some outpatient activities.
- **Provider – patient relationship information** (such as family physician, admitting physician for each encounter, and clinical nurse).
- **Laboratory results and Medical Imaging performed at a VIHA location** (this includes information from both inpatient and outpatient VIHA facilities, but not private facilities)
- **VIHA transcribed documents** for admissions, discharges, some consultations and procedures.
- **Order History for inpatient medications** (NOTE: this is captured in the facility pharmacies, not through CPOE or ePrescription)

Over time, additional functionality will be added including more extensive clinical documentation and computerized physician order entry (CPOE).

At the time of this study, some of the region's hospitals ran a parallel chart: the local paper chart (for provider notes, orders and other information) and an electronic record. All information in the electronic record (Cerner) was printed and placed in the paper record. This is the case in Victoria. Other locations ran a "hybrid chart", with part of the record on paper and part only available online in Cerner (i.e. the Cerner content was not printed). This was the case in Duncan.

The Cerner system was accessible to providers at all acute centres and was available remotely to privileged physicians outside of these facilities through the Internet (e.g. from the family physician office).

The focus for IM/IT was on improved access to clinical information (laboratory results, medical imaging reports, and transcribed documents), and the regionalization of Cerner Millennium as a single instance across the region. The strategy has not focused on the needs of small specialty groups. There were no IM/IT focused projects described that addressed the specific needs of end of life care.

Also of note, IM/IT was on the verge of implementing a regional CIS for Residential and Home and Community Care during this study. This was not a Cerner application, but a separate application. At the time of this study, however, Home and Community Care relied on paper charts. Residential Care used a combination of paper, Cerner, and some local Clinical Information Systems that did not interoperate with Cerner to share clinical data.

BC Provincial Health Services Authority

In BC at the time of this study there were five geographic health authorities and a sixth, non-geographic “Provincial Health Services Authority” (PHSA). PHSA provided certain specialty services across the entire province. Specifically related to this study, cancer care was coordinated through the PHSA; it supported multiple Cancer Centres across the province. These facilities existed within the geographic boundaries of the other health authorities, but acted distinctly. On Vancouver Island, the main Cancer Centre was in Victoria, the Vancouver Island Cancer Centre. It was the only facility that could provide radiation therapy and it provided a full range of medical oncology (chemotherapy), symptom management and other ambulatory services to support patients with cancer (such as dietitian services and counseling). The Cancer Centre is ambulatory, it relied on VIHA for inpatient services, medical imaging, and surgical services. There were several small centres throughout the island where chemotherapy can be administered. These are, to varying degrees, hybrid VIHA-PHSA clinics. Duncan had a small chemotherapy ambulatory unit where local VIHA staff support cancer patients in consultation with the Vancouver Island Cancer Centre.

At the time of this study, PHSA had its own clinical information systems. Oncology had the Cancer Agency Information System (CAIS). CAIS was a locally developed information system, built and maintained at PHSA. It included features to support: patient scheduling, management of results, management of transcriptions, and some provider communication. CAIS did not support electronic documentation or CPOE. Access to CAIS required PHSA privileges or an employee relationship with PHSA. The only direct link between the VIHA information systems and CAIS was the sharing of medical imaging from VIHA to CAIS.

Physicians in BC

At the time of this study, most physicians in BC were not paid by a health authority for clinical services. Most ran their practices as independent businesses. Physicians could have admitting privileges to one or more hospitals, depending on the services they offered. Most physicians billed the provincial government in a fee for service model that was negotiated between the provincial government and the BC Medical Association, even for hospital services (BC_Government, 2007). The agreement between physicians and the government described the fees that can be billed for specific services, such as office visits, procedures, and hospital admissions.

CIS Context in Canada and BC

In Canada over the past several years, there has been considerable activity to define and implement Clinical Information Systems at local, provincial, and pan-Canadian levels. Each of these programs may impact the options that VIHA was able to consider as part of this study.

Canada Health Infoway's EHR

Canada Health Infoway (Infoway) was established as a non-government, not for profit organization to accelerate the adoption of Electronic Health Records (EHRs) in Canada. Among their activities, they have developed interoperability standards and an architectural blueprint for a pan-Canadian EHR (Infoway, 2006). They have also been heavily involved as strategic investors, providing partial funding to provincial initiatives that adopt, at a provincial level, the EHR standards. BC was developing a provincial EHR, supported by Infoway and aligned to their blueprint.

The Infoway EHR (and thus the BC EHR) was designed as a provincial level repository that contains patient specific information from multiple local systems. The access to the information is controlled through a common information access layer (Figure 13). The EHR was designed as a cross-organizational repository of information, meant to collect data from

multiple point of service systems,¹⁹ both public and private. The EHR would be able to provide an aggregate view of a patient's record independent of location. Only a portion of the EHR had been implemented at the time of this study. This portion was not available to providers in the communities being studied.

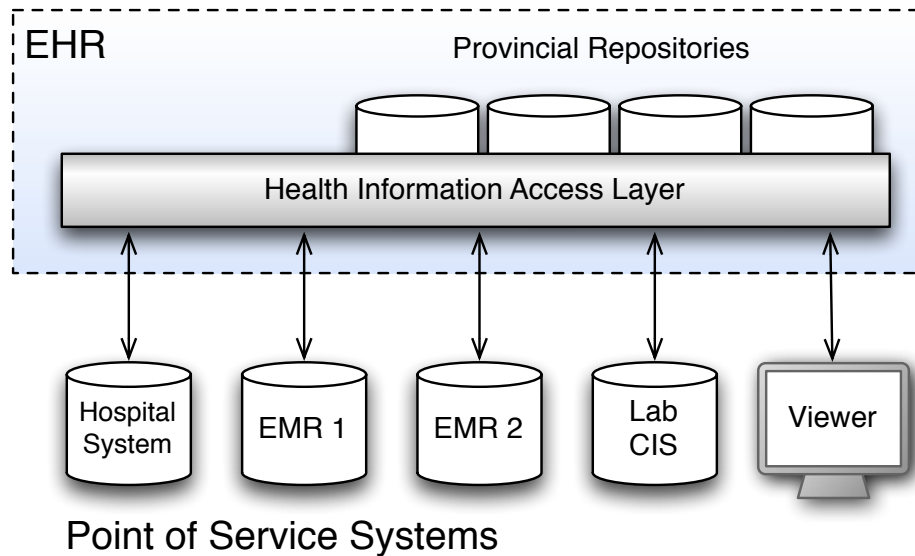


Figure 13: High-level overview of the pan-Canadian EHR design. Note that multiple point of service systems are in use in a given region. Access is controlled through an access layer, to the shared repositories in a jurisdiction, such as BC. Based on (Infoway, 2006).

VIHA, as a regional Health Authority, will be expected to interoperate with the BC EHR (highlighted in the above diagram with Cerner as a point of service system).

¹⁹ This is the term used by Infoway to describe the CISs in use as transactional systems within various organizations, such as hospitals, laboratories, and private offices.

BC Physician IT Office (PITO)

The BC Physician IT Office (PITO) was established as part of the 2006 Physician Master Agreement (BC_Government, 2007) to implement Electronic Medical Records in 50% of physician private offices by 2012. A joint BC Ministry of Health Services and BC Medical Association program, it was established to accelerate the adoption of office-based electronic records in BC through a combination of provincial standardization, funding, and implementation support. PITO was created with a \$108M budget, to be used over six years to reach its targets by 2012. Through a public RFP process, PITO selected and certified five private EMR vendor products for BC (PITO, 2009). Physicians who implemented one of these five products were eligible for up to 70% funding of the implementation and ongoing licensing costs.

Physicians were able to apply for funding through two streams: standalone EMR and Community of Practice. The standalone EMR option allows a single office (of one or more physicians) to implement an EMR for their practice. The Community of Practice option allows for larger groups of physicians (multiple offices within a community) to group together and implement a single vendor product through their community. Both options required hosting of the data in a secure, PITO approved, vendor-hosted data centre. At the time of this study, several physicians in Victoria had been approved for funding and considering EMRs. The physicians in Duncan were approved as a single community of practice²⁰.

PITO was not an Infoway funded project and, at the time of this writing, the products were not required to adhere to the same interoperability data standards.

At the time of this study over 1000 eligible physicians in BC had been approved for funding and are in the process of selecting and adopting EMRs. PITO is an initiative that is available to private physicians. PITO's program did not include regional Health Authority outpatient clinics, such as VIHA.

²⁰ The physicians were in the process of selecting their PITO vendor during the course of the interviews.

Chapter 7 Clinical Information Systems

This chapter provides the reader with an overview of Clinical Information System (CIS) functionality. Specific attention is paid to functionality that can support the three levels of continuity. Finally, this chapter relates key types of CISs and functionality to terms specific to the Canadian and BC environment.

A Clinical Information System (CIS) has been defined as a computer system containing both the electronic health record repository of patient data and the information management tools needed to support care delivery (P Tang & McDonald, 2006). There is a wide range of CISs such as departmental systems (e.g. laboratory information systems); office based electronic medical records, hospital records, and personal health records (Hayrinen, Saranto, & Nykanen, 2008). CISs have the ability to change practice in many ways, based on their functionality and how they are used. For this study, the following terms have been used to describe types of CISs:

- **Provincial Electronic Health Record (EHR)** – based on the Canadian Health Infoway Standards, a provincial EHR contains a defined set of data from multiple sources
- **Regional CIS** – Some regions, such as Health Authorities, have adopted regional CIS strategies to provide integration of data and support workflow across regional facilities. VIHA has taken this approach.

- **Hospital Information System (HIS)** – the CIS for a single hospital.²¹
- **Electronic Medical Record (EMR)**– the office based CIS that supports the workflows and documentation needs of office based practices.

There are additional CIS categories that are less relevant to this research, such as the specialized departmental CISs.

Clinical Information Systems and Continuity

Clinical Information Systems (CISs) have been touted as being able to improve continuity of care by improving access to patient information (Hellesø & Lorensen, 2005), (Donna Strating, 2006). Regional (i.e. Health Authority) and jurisdictional (e.g. Provincial, national) EHRs have been seen as platforms that will reduce costs and improve quality by improving Continuity of Care (Infoway, 2006) (pg 61). There have been several standards developed to improve continuity; such as the Continuity of Care Record, which contains a summary of patient data (Ferranti, Musser, Kawamoto, & Hammond, 2006). Most of the discussion of CISs and Continuity of Care has focused on increased accessibility to patient data (e.g. laboratory results) across care settings.

Functional Standards for Clinical Information Systems

There are many sets of standards that define the functionality of CISs (Drury & Senior, 2006). These standards have been developed for different reasons, including safety, accreditation, interoperability, and for qualification for funding. The Certification Commission for Healthcare Information Technology (CCHIT) in the US is one such organization developing standards and approving CISs. At the time of this study, Canada Health Infoway had developed their interoperability standards for Canadian EHRs and the

²¹ In the case of VIHA, they had taken a Regional CIS approach instead of multiple, standalone HISs in their acute care centres. There were still some local HISs used in Long Term Care facilities in VIHA.

other CISs that interoperate with the EHR; in BC, PITO had developed their standards to qualify vendors for their EMR program. These various standards have varying levels of detail, structure and language. Most have developed hundreds of functions enumerated (e.g. HL7 138, CCHIT 315). At a high level, there are five functional components of a CIS that can be considered: (Dick, Detmer, & Steen, 1997), (P Tang & McDonald, 2006)

- **Integrated view of patient data** - Providing an integration of patient data has been considered “*clearly...the primary purpose of a [CIS].*” (P Tang & McDonald, 2006) (p 452) A CIS is able to pull together data from multiple sources into a patient centric view or views. This can provide a level of Information Continuity that disparate paper records cannot, as they lack the ability to rapidly reorganize content into specific views.
- **Clinical Decision Support** - Clinical Decision Support provides a level of interaction between the user and the patient record to suggest activities that should be consider (reminders) or to trigger when an activity that is about to be performed should not be (alert). It has been shown to improve aspects of quality, including medication dosing, preventive care (Hunt, Haynes, Hanna, & Smith, 1998). Studies on Clinical Decision Support have focused mainly on behavioural change, showing improvements on practitioner performance. Patient outcomes have been less well explored (Garg, et al., 2005).
- **Computerized Provider Order Entry (CPOE)** - Functionality that supports clinician order entry (e.g. physician prescribing through the CIS) allows workflows to be streamlined (routing of orders) as well as provide the clinical decision support at the point of decision making. Order entry has helped standardize practice by providing recommended options (e.g. recommended dosing options, low cost alternatives, evidence-based groupings of multiple orders for specific protocols) (Kuperman, et al., 2007).
- **Access to Knowledge Resources** - Providers typically have many clinical questions throughout practice, the majority of which often have gone unanswered (Ely, et al., 1999). Providing access to knowledge resources has helped providers answer the many questions they have (Westbrook, Gosling, & Coiera, 2004). Thus, it is useful to

- clinicians to have ready access to reference material that can be filtered based on the needs of the current patient that is being managed.
- **Integrated communication and reporting support** - Integrated communication and reporting support describes two discrete sets of functionality. Communication support includes interactions between providers and between patients and providers. Clinical communication is often synchronous, which has caused interruptions and has increased the chance for errors in care. New communication tools could be introduced within CISs that change and possibly improve communication (J. Parker & Coiera, 2000). Reporting tools allow the generation of population level aggregation of data from multiple patients for activities such as quality improvement, research, or public health monitoring.

For this study, understanding the details of these requirements was not necessary, however an understanding of what CISs could do to support Continuity of Care is important. The following section highlights the CCHIT functionality standards as they relate to Continuity of Care.

CCHIT Functionality Standards and Continuity of Care

CCHIT is a non-profit, US based organization that has “the sole public mission of accelerating the adoption of robust, interoperable health information technology by creating a credible, efficient certification process” (CCHIT, 2009). They have been active in the functional standardization of CISs for a number of years and have published specifications for both inpatient CISs (i.e. hospital information systems) as well as ambulatory CISs (i.e. Electronic Medical Records). Many systems have been certified against the CCHIT standards. They provide one of the more detailed lists of functional specifications (Drury & Senior, 2006).

Although the functional requirements have not specified continuity, many of the published requirements relate to improved Continuity of Care. Captured below are two mappings between the three levels of Continuity of Care and the summarized set of hospital

information system requirements (Table 7) and the ambulatory EMR requirements (Table 8). Example requirements from both sets of functional standards are highlighted in Table 9.

Table 7: Outline of sections in the CCHIT Functional Requirements for Hospital Information Systems and how they relate to the three levels of Continuity of Care (I=Informational Continuity, M = Management Continuity, R = Relationship Continuity), based on (CCHIT, 2007b).

2007 Functional Requirements Sections for Inpatient CISs	CONTINUITY
Patient Demographics and Administrative Data	I
Provider Information	R
Patient list Management	--
Problem Lists	I
Allergy Information	I
Medication List	I
Results Access and View	I
General Ordering Requirements	-
Order Sets	M
Ordering: Medication Orders	-
Medication Reconciliation	M
Decision Support for Medication Reconciliation and Immunization Orders	M
General Clinical Decision Support	M
Medication, Immunizations and Blood Products Administration	-
Decision Support for Medication, Immunization, and Blood Product Administration	M
Clinical Task Management	M
Capture Patient-Originated Data	I
Health Record Management	-

Table 8: Outline of sections in the CCHIT Functional Requirements for Ambulatory EMRs and how they relate to the three levels of Continuity of Care (I=Informational Continuity, M = Management Continuity, R = Relationship Continuity), based on (CCHIT, 2007a)

2007 Functional Requirements Sections for Ambulatory CISs	CONTINUITY
Identify and Maintain a Patient Record	I
Manage Problem List	I
Manage Medication List	I
Manage Allergies and Adverse Reaction List	I
Manage Patient History	I
Summarize Health Record	I
Manage Clinical Documentation and Notes	I
Capture External Documentation	I
Generate and Record Patient specific Instructions	M
Order Medications	-
Order Diagnostic Tests	-
Manage Order Sets	M
Manage Results	-
Manage Consents and Authorizations	M
Manage Patient Advance Directives	M
Capture Variances from standard care plans, guidelines, protocols	M
Support for drug interaction checking	M
Support for medication or immunization administration or supply	-
Support for non-medication ordering (referrals, care management)	M
Present Alerts for disease management and preventive services and wellness.	M
Notifications and reminders for disease management, preventive services and wellness	M
Clinical Task Assignment and Routing	M
Inter-provider communication	M
Pharmacy Communication	M
Provider Demographics	R?
Scheduling	-
Report Generation	-
Health Record Output	-
Encounter Management	-
Rules-driven financial and administrative coding assistance	-
Eligibility verification and determination of Coverage	-
Manage Practitioner/Patient Relationships	R
Clinical Decision support system guidelines updates	-
Entity Authorization	-
Enforcement of Confidentiality	-
Data Retention, availability, and destruction	-
Audit Trail	-
Extraction of Health Record Information	-
Concurrent Use	-

Table 9: Examples of CCHIT Requirements that support Continuity of Care: ambulatory requirements from (CCHIT, 2007a) and inpatient requirements from (CCHIT, 2007b). The number in the right column corresponds to the specific requirement ID.

Information Continuity	
The system shall provide the ability to document a problem / diagnosis associated with a patient.	Inpatient 4.01
The system shall provide the ability to display patient specific medication list based on medication orders.	Inpatient 6.01
The system shall provide the ability to capture and store external documents.	Ambulatory 76
The system shall provide the ability to capture, store, display, and manage patient history.	Ambulatory 47
Management Continuity	
The system shall provide the ability to define a set of related orders to be ordered as a group.	Inpatient 9.01
The system shall provide the ability to establish rules for identifying patients with potential gaps in standards based care.	Inpatient 13.03
The system shall provide the ability to notify the relevant providers (ordering, copy to) that new results have been received.	Ambulatory 139
The system shall provide the ability to capture scanned paper consent documents	Ambulatory 147
Relationship Continuity	
The system shall provide the ability to identify all clinicians who have been associated with care for a specific patient.	Inpatient 2.02
The system shall provide the ability to assign clinicians to appropriate teams, where teams are defined as groups of clinicians who share responsibility for covering the same group of patients.	Inpatient 2.03
The system shall provide the ability to specify the principal caregivers responsible for the care of a patient within the hospital	Inpatient 3.05
The system shall provide the ability to specify the role of each provider associated with a patient, such as encounter provider, primary care provider, attending, resident, or consultant.	Ambulatory 241
The system shall provide the ability to specify the primary or principal provider responsible for the care of a patient within a care setting.	Ambulatory 242

Clinical Information Systems Summary

Clinical Information Systems have the ability to change practice. They have been held as a tool to improve quality of care, including improving Information Continuity. Groups, such as CCHIT, have sets of functional requirements for CISs. Embedded in these requirements have been functions that could improve Continuity of Care at all three levels of continuity.

Summary of the Background Section

End of life is a complex time of life for patients, their care givers, and their healthcare providers. Care for a patient during their last year of life typically occurs across several care settings with multiple providers as care needs change. Ensuring continuity has been considered key to improving quality for end of life care and has also been described as one of the reasons to pursue adoption of Clinical Information Systems. However, improving continuity is complex, without a clear “right” answer. There are many aspects to Continuity of Care, including understanding what it is, pacing it in the realm of a Wicked Problem.

In this background section I have provided reviews and descriptions of several elements of this study. These were captured in the Rich Picture below (Figure 14). This picture illustrates the relationship between the component chapters that act as a foundation for this study. First, end of life patients are the focus of the study. The Circle of Care defines the system of care around these patients. Continuity of Care becomes an emergent property of the Circle of Care as a system. Within the Circle of Care, communication can be described using Genre Theory. Genre Theory provides a theoretical foundation to explore the nature of communicative actions that are key to maintaining continuity. The Circle of Care does not exist in isolation, but rather is situated within multiple contexts, in this case within the context of BC. The chapter on Clinical Information Systems offers background into the capabilities of existing electronic records and how they might support Continuity of Care. Finally, Soft Systems Methodology was used to seek improvements in care and to answer the question:

What feasible changes can be made to care processes and clinical information systems to improve Continuity of Care for End of life patients?

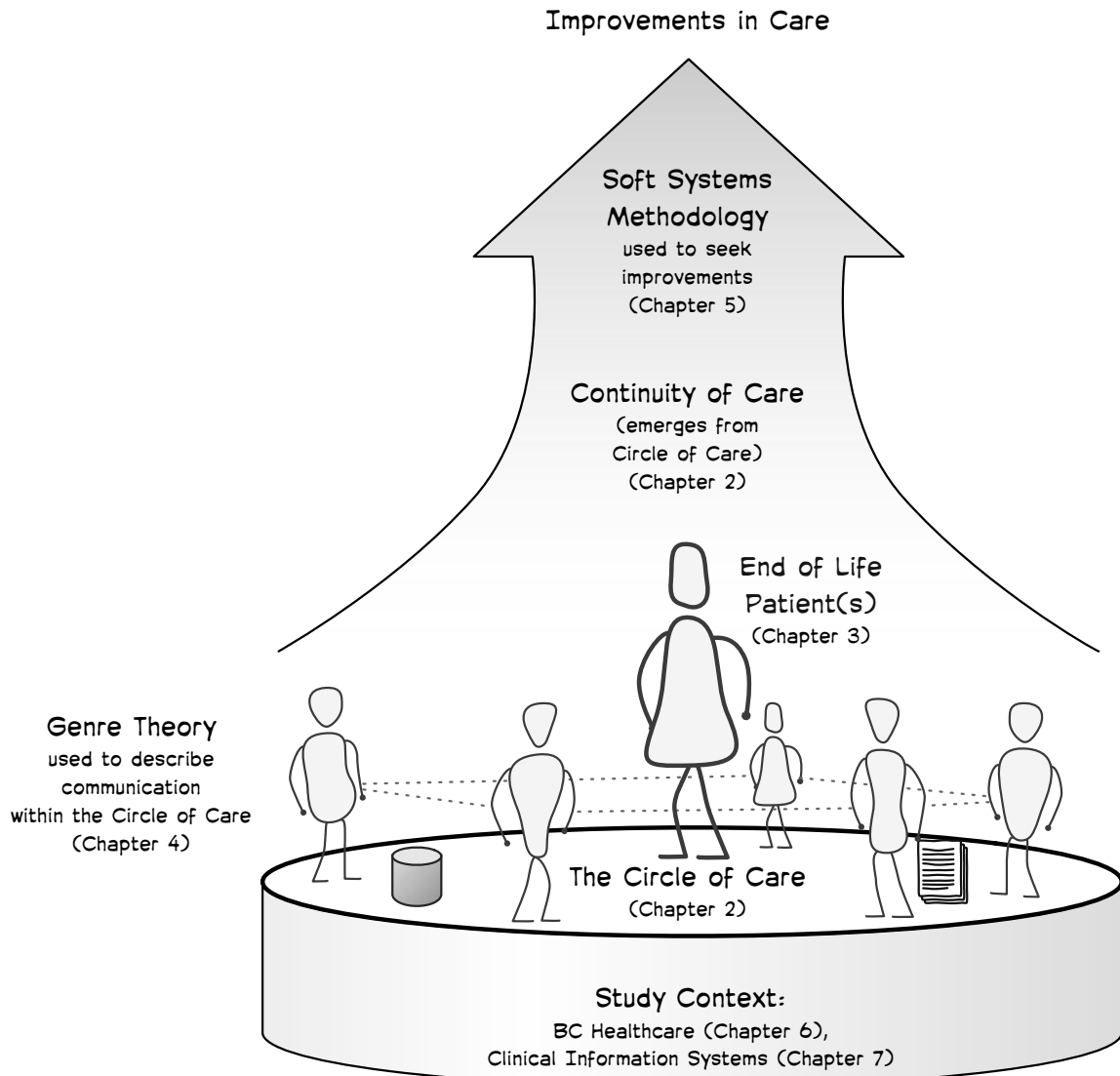


Figure 14: An SSM Rich Picture describing the relationship between each of the chapters of this section and how they are meant to support this study to find improvements in care, specifically Continuity of Care for end of life patients.

METHODS SECTION

Chapter 8 Research Question and Objectives

This chapter describes the four objectives for this study in more detail, now that the reader has reviewed the necessary background.

As described in the introduction, this study was designed to answer the overarching research question:

What feasible changes can be made to care processes and clinical information systems to improve Continuity of Care for End of life patients?

There were four specific objectives for this study that support the overarching question:

- 1. To develop and apply a method that combines Genre Theory with Soft Systems Methodology to generate suggested improvements in care processes and design or use of clinical information systems to support Continuity of Care.*
- 2. To describe the Genres used by providers caring for patients who are at the end of their life, focusing on the Genres used to provide and coordinate the transitions of care.*
- 3. To compare the Genres and needs of Continuity of Care at the end of life with the current design for the Vancouver Island Health Authority's (VIHA) primary, regional clinical information system to see where specific improvements to content and functionality can feasibly be made.*

4. *To seek improvements in Continuity of Care within two communities in British Columbia, making recommendations that would ensure the right providers are aware of key care decisions for community-based patients at the end of life.*

These objectives are described in more detail below before describing the specifics of the study methods.

Objective 1: Method Development

Early in the exploration of the research question, I sought suitable theoretical frameworks and methodologies that would provide the necessary foundations to help answer the overarching research question.

This objective will be considered met if:

- A method was developed and accepted by both the PhD supervisory committee and the appropriate ethics boards that was based on sound theoretical foundations.
- The study findings led to a set of supported recommendations for improvement in Continuity of Care for end of life patients in the region.

The use of Genre Theory provided the theoretical foundation for the study (J. Yates & Orlikowski, 1997). It also focused the research on the communicative aspects related to Continuity of Care for end of life patients. Genre Theory provided a framework for describing and relating recurrent communicative actions, their content, and their form. These features were felt to be useful to understanding the communication patterns required to understand Continuity of Care.

Soft Systems Methodology (SSM) was considered a good fit to address this study's question as it was designed to seek feasible improvements to "Wicked Problems" (see Chapter 5). It provides an effective engagement process to explore problems within communities and seek out improvements that are agreed to and owned by the study participants. The specific methods for this study also needed to be feasible for a single researcher and for the communities. The scalability and iterative nature of SSM allowed the study to match the capacity of both the researcher and the communities. The specific method developed for this study is provided in Chapter 9.

Objective 2: Genre Collection to support Transitions of Care

Creating a Genre Collection for Continuity of Care is an important component of the analysis work of this study; it could also be useful to others who are exploring Continuity of Care. This Genre Collection was meant to contain, in an accessible form, the discovered Genres used by providers as part of coordinating care for end of life patients. The collection would contain Genres related to communicating between providers across settings and during transitions of care (e.g. being admitted to hospital, being transferred to a long-term care facility). The focus was not on internal Genres that do not support Continuity of Care.

This objective will be considered met if:

- It is determined how the Genre Collection will be developed and organized (e.g. will it be a Genre System, Genre Ecology, or another type of Genre Collection).
- The various Genres are captured and described for each provider role.
- The Genre Collection is available for other researchers to build on.

The Genre Collection will be an artifact that can be shared and used for future end of life care and Continuity of Care research.

Objective 3: Comparison of Genres with Existing EHR Functionality

The intent, at the time of this study, of the Vancouver Island Health Authority (VIHA) is to move to complete electronic documentation for their health record (VIHA, 2007). A gap analysis in the area of clinical communication provides areas to focus upon. It would also more generally be useful to the Health Authority and others as they increase functionality in their EHRs and consider the purpose of particular forms of documentation and communication when changing the form of those communications from traditional (e.g. paper, voice) to electronic forms. The study's focus on Continuity of Care may also provide a useful view into how to use / adapt EHR functionality to improve Continuity of Care.

This objective will be considered met if:

- The Genre Collection created from this study is mapped with the existing regional CIS / EHR functionality.

Objective 4: Recommendations to Improve Continuity of Care

The final objective of this study is to generate a set of recommendations to improve Continuity of Care for End of life patients. Specifically, these recommendations would be focused on VIHA and the two communities. However, Continuity of Care is a problem that is not unique to these communities or to this patient population. It is hoped that the study findings, if not the specific recommendations, can be helpful more widely.

This objective will be considered met if:

- A list of recommendations is generated through the study
- Participants agree that the recommendations are feasible and that they support the recommendations as potential improvements in Continuity of Care in the two communities.
- VIHA, community, and clinical leadership in the two communities consider the recommendations.

In summary, the success of this study will be defined by: its methodological contributions, its findings as they relate both to current Genres used for Continuity of Care and how they map to EHR functionality, and by the ability to support the development of a set of feasible recommendations for both communities to improve Continuity of Care for end of life patients. If these four objectives are met, then it is felt that this study will have answered the question:

What feasible changes can be made to care processes and clinical information systems to improve Continuity of Care for end of life patients?

Chapter 9 Study Methods

This chapter describes the methods used in this study to meet the research question and objectives. A detailed description is captured here of the five research phases, the recruitment process, and methods used to collect and analyze the data.

In order to reach the objectives, I developed a method based on Soft Systems Methodology (SSM). SSM was used both to support development of the process and to analyze the content, as described by (P. Checkland & Winter, 2006). SSM supported collecting my findings and developing the models that highlighted aspects of Continuity of Care with a patient's Circle of Care. Genre Theory was leveraged as the theoretical framework to describe communications amongst members in patients' Circles of Care. I have summarized the methods in their own SSM Rich Picture (Figure 15). The study was divided into the five iterative stages of SSM: *Finding Out* about the domain, *Conceptual Modeling* of three views of the Circle of Care, *Structured Discussion/Debate* with participants in order to develop feasible *Suggested Improvements*. *Reflection* (by the researcher) was important throughout the study. The study was considered complete when the researchers and the community members had co-developed and agreed on a set of feasible suggested improvements and the other study objectives were sufficiently met.

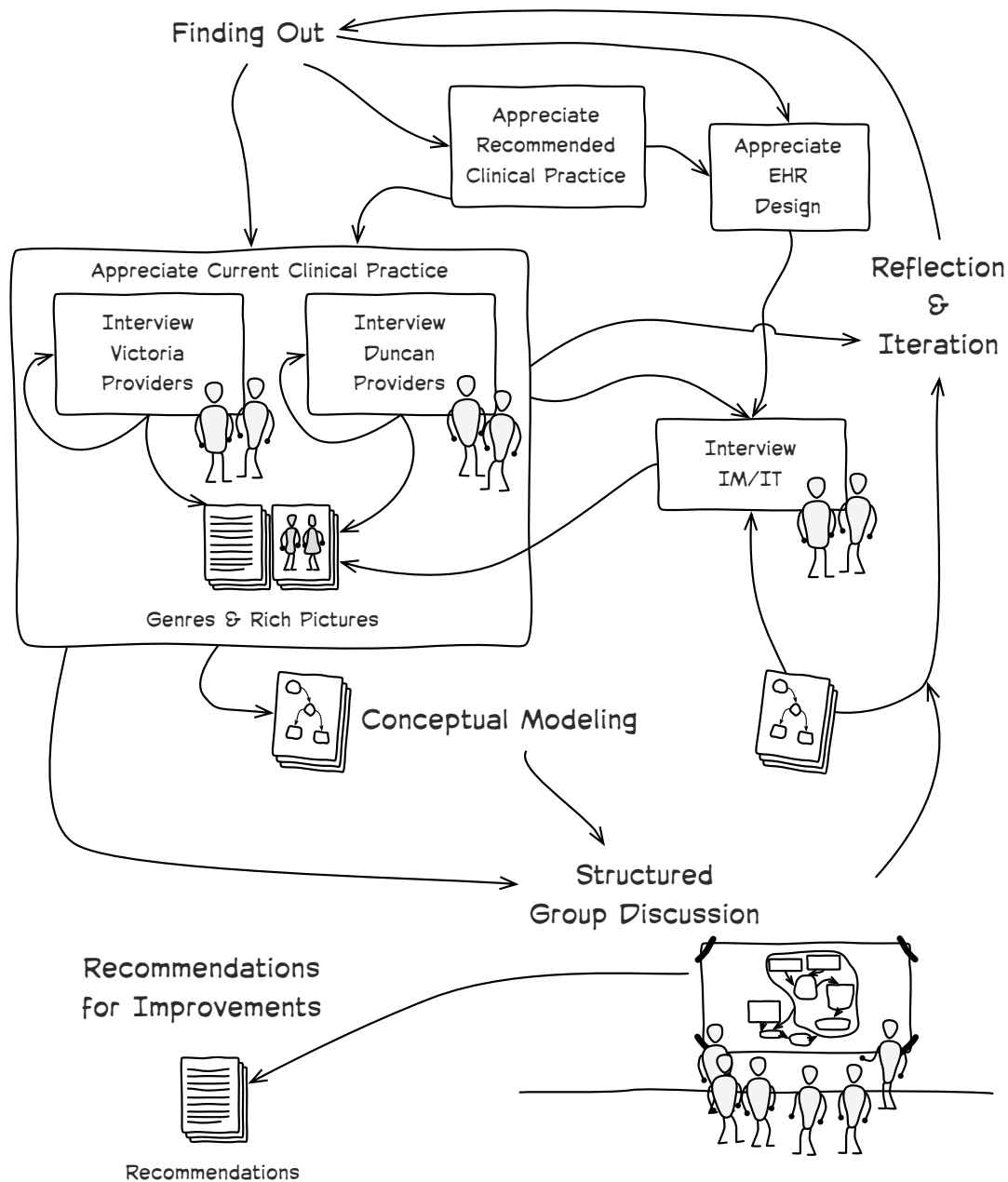


Figure 15: A Rich picture outlining the methods for this study. See text for more detailed description of activities in the five stages in SSM.

Two Patient Personas were developed from current BC statistics on end of life patients and used as the fulcrum of the study. These two Patient Personas were called Mrs. Cann and Mr. Hart. They were fictional patients, with sufficient detail in their stories to be realistic to

participants. They captured many of the characteristics of end of life care in BC. The interviews, described later, focused on exploring care for these two personas through the last year of their life, from the perspectives of the individuals recruited into the study. Each Patient Persona was presented using the format of the Clinical Case Presentation Genre.

The study received approval from the researcher's PhD supervisory committee and the joint UVic / VIHA behavioural ethics review board in March 2009, prior to starting to starting participant interviews (See Appendix G).

Stage 1: Finding Out

First stage in this research was to “find out” about the domain. This included three activities:

1. Appreciate end of life care
2. Appreciate the regional CIS infrastructure
3. Participant interviews. There were three sets of participant interviews:
 - a. Duncan Providers
 - b. Victoria Providers
 - c. IM/IT participants who have a working knowledge of the regional CISs.

Appreciate End of Life Care

A review of recommended practices in end of life care was undertaken as part of the initial work in this research and captured in the background section (see Chapter 3). This helped the development of the Patient Personas used in the interviews, which guided the discussions with providers during the interviews and the structured group discussions. It also provided a consistent vocabulary and understanding of recommended practices in palliative care.

Appreciate the Regional CIS Infrastructure

The regional CIS infrastructure in VIHA was based around the Cerner Millennium system and is configured and maintained by VIHA. There were several additional systems in use in the region and considerable paper in use. Documents Reviewed:

- VIHA Strategic Plan (VIHA, 2008)
- VIHA IM/IT Strategy 2007/2008 (VIHA, 2007) and 2009/2010 (VIHA, 2009c).
- Infoway's EHR Blueprint (Infoway, 2006).

The findings were captured in the background section (see Chapter 6). Further, the interviews with the IM/IT participants provided considerable information about the implementations of clinical information systems in Vancouver Island.

Appreciate Current Clinical Practice (in Duncan and Victoria)

The majority of the Finding Out phase was spent engaging with the care providers in each community. This was necessary to understand current practice. Individual interviews with providers occurred and existing clinical document templates²² were collected, such as care plans, flowsheets, and referral templates. The documentation templates served to aid in the triangulation of findings from the provider interviews. Provider participant interviews were the primary method to gather information about the current practice in end of life care in Duncan and Victoria communities.

I selected these two communities for several reasons. Victoria had an active and large hospice program that is well structured and funded. The Victoria Hospice also had an existing research office with ongoing relationships with the school of Health Information Science. Duncan was a smaller town with an end of life program that was more typical of smaller communities in BC. The communities were both geographically accessible to me and yet the care provided was fairly distinct. Both communities were approached prior to

²² Any sample documentation was collected in this study were blank templates and did not contain any identifiable patient data.

the study and expressed interest in participating in this research. Finally, both communities are within VIHA and they access the same regional hospital system and share the same regional policies. I felt that the specific recommendations from findings in these communities would be more likely applicable to the rest of the region.

Provider Participant Recruitment

The recruitment process for this study relied on the research participants to guide me in my search for the members in the Circles of Care for my two Patient Personas. There were two aspects to participant recruitment: first, the determination of the roles or types of providers involved in a patient’s care; second, the recruitment of individuals to interview who have those roles. Role determination for members of the Circle of Care will be discussed first.

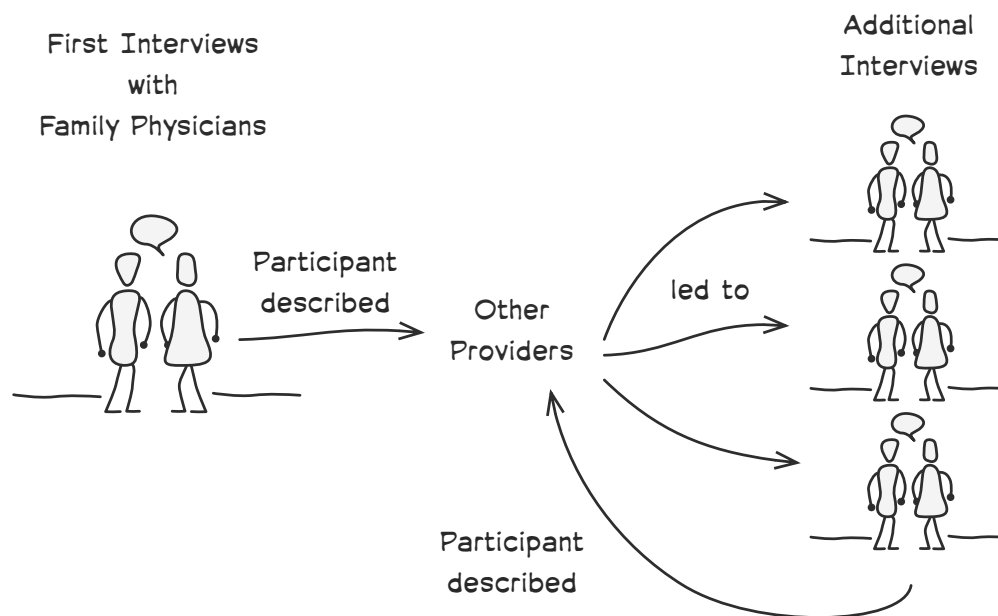


Figure 16: Rich Picture describing the iterative process of interviewing and recruiting participants. Roles named by participants helped to define subsequent participants.

I determined the clinical roles relevant to this study iteratively in a “bottom up” approach throughout the interview process. This was done in each community and for each Patient Persona. During the interviews, each participant was asked to describe other care

providers²³ that would be involved in the care of each patient persona. The roles named by participants and their descriptions directed my recruitment of subsequent participants. The role selection process is captured in Figure 16.

The first providers that were recruited for the study were family physicians. Family physicians were selected as the initial role as they delivered the majority of primary care in BC. They also delivered a significant amount of the longitudinal care coordination. They were a primary referrer to Hospices and to other specialists and programs in BC. Family physicians described other provider roles in the Circle of Care. As provider roles were discovered that had a significant impact on continuity of end of life care, individual providers with those roles were recruited to become participants in the study.

All participants were recruited through a standard process that was performed through third parties. The third parties were: the Research Director for the Victoria Hospice, a VIHA director or their delegate of a particular portfolio (e.g. Primary Care, Home and Community Care), VIHA's CIO (for IM/IT participants). Recruitment occurred in two ways. First, the recruiters sent a standard recruitment letter (see Appendix D) by mail or email to possible participants (either of their selection or blanketly to whole departments). I was also invited to briefly present the study at rounds or regional meetings as educational sessions to further recruit participants. The invitation letter was then circulated to attendees as part of the minutes. In the letter, potential participants were advised to contact me email or phone. That way I could answer any questions and arrange interviews. I was not aware of who received the offer to participate. The recruiters were not informed of who responded.

Participants were required to meet the following inclusion / exclusion criteria:

Inclusion Criteria:

1. Be in an active practice in the Greater Victoria or Duncan communities as a family doctor or in a role described by a previous interviewee.

²³ Roles were requested, not individual names.

2. Have been involved in the care of at least two patients over the past 12 months who have been at end of life.

Exclusion Criteria:

1. Not currently involved in practice or not practicing in either the Greater Victoria or Duncan communities (practicing in these communities would also include receiving referrals for patients who reside in these communities).
2. Do not engage in end of life care.

Provider Participant Compensation

Participants were compensated for their time. VIHA staff members were able to bill at their standard hourly rates (compensated by the research project) and physicians were compensated at BC sessional rates, as defined by the BC Medical Association. Funding was provided through the Canadian Institute for Health Research e-Health Chair research fund. IM/IT participants were provided with release time to participate in the interviews and discussion groups.

The interview process was designed to start with three family physician interviews in each community (six total). Recruitment of participants was then to continue iteratively during the interview phase until saturation of the roles of the circle of care occurred (i.e. no more roles mentioned) or a total of 35-40 interviews had been completed. This number was chosen as it reflected what was expected to provide reasonable coverage of roles across the 2 communities. It also represented a limit based on practical feasibility in this study. The specifics of the participant interviews are described below.

Interview Victoria Providers / Interview Duncan Providers

An in depth understanding of current practice was developed through the series of semi-structured interviews with providers in each community. The details of these semi-structured interviews were described in Appendix B. Wherever possible, participants were interviewed

at their place of work. The interview scenarios were reviewed with the Victoria Hospice Research Director.

These interviews served five purposes:

1. They helped define the Circle of Care (as above);
2. They allowed the researcher to develop a deeper understanding about the providers in the Circle of Care, appreciating social and political relationships within the Circle of Care (analyses 2, and 3 as per SSM methodology);
3. They described where patient information was stored;
4. They described the common communication that occurred (or did not occur) between providers (and to gathered samples if they exist);
5. They captured the challenges providers faced related to Continuity of Care.

As briefly described earlier, the interviews were structured around two Patient Personas (Appendix A), presented as Case Presentations. The Patient Personas were simulated patient stories, designed to be prototypical end of life patients, developed specifically for this research. The Patient Personas were developed to guide participants through visualizing the Circle of Care and the communication patterns between providers. This provided a consistency between interviews and between communities. The personas were created to capture the breadth of end of life care and are based on findings from a recent review of end of life care in BC (CIHI, 2008). One patient persona, Mrs. Cann, was a prototypical cancer patient at the end of life. The second patient persona, Mr. Hart, was a cardiac patient with heart failure at the end of life.

Mrs. Cann's story was visited with each participant at four key points in her last year of life. These points reflected changes in her condition, some potentially requiring urgent transitions in care of some kind. The four points in her life were:

1. Mrs. Cann has known metastatic cancer and is undergoing treatment. She is living at home alone and is beginning to have mild difficulty coping at home.
2. Mrs. Cann has a Pain Crisis: a rapid decline due to worsening pain, requiring immediate management.

3. Mrs. Cann has experienced a significant decline in her function due to the progression of her cancer. She is now staying at her eldest daughter's home. She is all but confined to bed.
4. Mrs. Cann is in her final days / weeks, requesting she be moved in to a facility as she is no longer wanting to burden her family.

Mr. Hart was also visited at four key points in his last year of life in the interviews:

1. Mr. Hart has Stage III Congestive Heart Failure, Diabetes, and lung disease. He is coping somewhat poorly in the community, fairly isolated with a questionable alcohol history.
2. Mr. Hart has a stroke, managed in the Emergency and admitted to hospital.
3. Mr. Hart is transferred to Long Term Care facility as rehabilitation not successful enough to safely discharge home.
4. Mr. Hart has his final heart attack while in the long-term care facility in the middle of the night and is transferred to the Emergency.

The two patient personas were described in detail in Appendix A.

While participants described the various providers that would be involved in each patient's care, I asked them to explain how they communicated with those providers, exploring the purpose and forms those communications take, that is, I attempted to elicit the Genres in use. Specific questions were also directed at use of the regional CISs to gain an understanding of how the CISs were used in practice.

After the interviews, I compared findings between participants of the same roles as well as triangulated findings between participants of different roles. This confirmatory step to ensure consistency on the findings about communications.

Between interviews I also took time to reflect on the social (analysis 2) and political (analysis 3) environments in my research journal. These notes were used when considering what suggested improvements could be feasible.

All interviews were recorded. A simple digital audio recorder was used as well as a Livescribe Pulse pen. This pen captured audio and synced it to the notes in my research

binder. This proved to be very helpful in the reflection and analysis, where I could quickly jump through my interview notes and replay audio from any point in the interviews.

The findings from the interviews were triangulated between participants and also compared to paper forms. This data was used in the Genre analysis and in the development of the rich pictures and conceptual models.

Developing Rich Pictures for the Patient Personas

As the interviews progressed, a detailed understanding of care delivery unfolded for each patient in each community. The resources, the providers, and the locations all were described as each participant told me how they would see care provision occurring for Mrs. Cann and Mr. Hart. As the interviews progressed, these findings were captured in four Rich Pictures, one for each Patient Persona in each community. The Rich Pictures were developed iteratively during the interviews and the specific details of the stories were selected in the Rich Pictures to highlight challenges to continuity that were raised by the participants.

Interviewing VIHA IM/IT Staff

IM/IT staff were engaged in this study to review the findings and help to make recommendations for feasible suggested improvements in the regional CISs to aid Continuity of Care. VIHA IM/IT staff also provided a richer view into the existing IM/IT infrastructure and the development plan. These were important in exploring what could feasibly be accomplished. The gaps highlighted in the provider interviews, along with some of the provider's ideas for IT improvements to these problems were discussed with IM/IT participants.

IM/IT participants were recruited through VIHA's Chief Information Officer's office and through information sessions.

While part of the finding out phase of the research, the interviews with IM/IT occurred after many of the provider interviews and after the initial conceptual modeling had begun. The IM/IT interviewees were able to review the draft Rich Pictures and Conceptual Models.

Thus, they could give feedback on how current practice and the Genres are supported (or not) by the CISs in the region and make suggestions for ways in which the existing infrastructure could or could not improve gaps discovered in the provider interviews.

See Appendix C for example questions for the IM/IT interviews.

Stage 2: Conceptual Modeling

In SSM, conceptual models are used to describe a system and its sub-systems from specific and defined worldviews. Conceptual Models complement Rich Pictures and serve as a form of triangulation (as per SSM). Conceptual models were designed to look at each aspect of continuity from the Haggerty and Reid model of Continuity of Care. Therefore three views of the Circle of Care were modeled for each Patient Persona's Circle of Care: a provider view (relationship), a communication view (management), and a repository view (information). Each of these views was *patient-centric* and highlighted aspects of Continuity of Care within the patient's Circle of Care. A further set of models was developed to describe the individual communication Genres.

These models, along with the Rich Pictures, served as guides during the IM/IT interviews and discussion groups. They were refined based on feedback in those discussions. The Genre models were developed using standard SSM conceptual modeling notation, as described in the background chapter on SSM. The three views of the Circle of Care are described here. See Appendix H for background on visual thinking and the Unified Modeling Language version 2 (UML 2).

Circle of Care – The Provider View

The members of Circle of Care were modeled for each patient persona in each community. The models consisted of all the providers described by the participants in the study. Development of the models followed a two-step process.

First, individual models were created for the different "world views" on the Circle of Care. Through the course of the interviews, some providers were found to be more involved in supporting Continuity of Care for the patients, such as family physicians. Other providers had more localized roles, providing specific services or communicating only within local teams. Those providers that were involved in greater communication and coordination were called "Continuity Providers"²⁴ in this study. Continuity Providers were more active in coordinating care across the various Care Teams.²⁵ The Continuity Providers became the focus of interviews and modeling activities. Individual models described the members in the Circle of Care as described by participants of the same role (e.g. family physician, Home and Community Care nurse) in a community. A set of these models was then available for comparison and review.

The individual models were then combined into a single diagram to develop the final model (Figure 17). Redundancies were removed and providers were clustered based on organizational and provider affiliation where appropriate. Providers without a strong linkage to any particular Continuity Provider were drawn with linkages directly to the patient. This illustrated the complete membership of providers in the Circle of Care, as described by participants. These models were built for each patient persona in each community.

²⁴Continuity Provider: A care provider who provides direct patient care, has the ability to adjust management plans, and who is actively involved in communicating with other members of a patient's care team that are outside of their current Care Team. A Continuity Provider is, therefore has potential to be involved in all three levels of Continuity of Care.

²⁵ Care Team: A team of providers within a patient's Circle of Care who a common organizational structure such that they are either co-located or function in a virtually integrated manner and have a shared chart. Examples would include: the hospital based providers involved in a patient's care while in hospital.

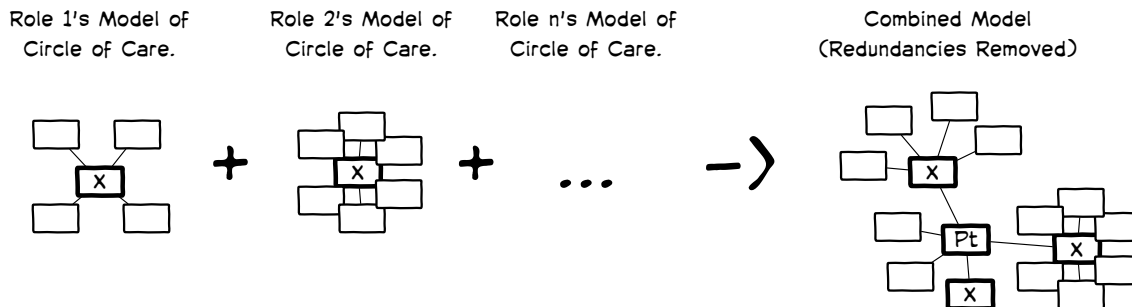


Figure 17: Process for developing the model that describes the Members in the Circle of Care. Continuity Providers marked with an X.

Circle of Care – The Communication View

Communication Views were developed to describe the communication patterns within the Circle of Care related to Continuity of Care. Specifically, the modeling focused on communication related to transitions of care between Care Teams. First, the Continuity Providers were extracted from the provider view models. From the interviews, the Genres discovered were used to describe the communication between individual providers (Figure 18). The diagrams were modeled using the UML 2.0 Communication Diagram notation.

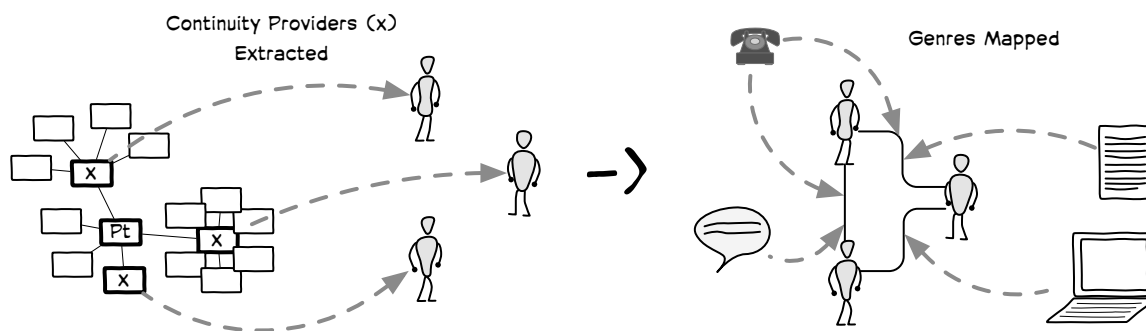


Figure 18: Development of the Communication View of the Circle of Care. Notation based on UML 2.0 Communication Diagram.

Although these diagrams were based on the UML 2.0 Communication Diagram standard, the icons were changed to highlight the individual providers graphically; this made the diagrams more consistent with the Rich Pictures. To simplify the diagram, lines were not drawn from each provider to Mrs. Cann and her family as all providers communicated with the patient.

Circle of Care – The Information/Repository View

The final Conceptual Model that was developed describes the information repositories that held patient information. These Conceptual Models based on the UML Deployment Diagram. Unlike other Deployment Diagrams, these were *patient specific* illustrations, like all the conceptual models developed in this phase. The conceptual models were developed based on findings from the provider interviews, where providers were asked about their use of information systems as well as where they described the use of paper records that were used in their practice and for each patient's care. Highly transitory documentation (e.g. faxes, daily rounds sheets that are shredded) was excluded from the modeling. These transitory documents either were found to be a part of the communication process captured in the communication view or the information that they contained was stored in one or more of the persistent repositories.

The intent of this view was to look at where patient information related to Continuity of Care is stored and potentially could be retrieved. It was meant to provide a visual representation of the integration or dis-integration of each patient's information within the Circle of Care. Information distribution, both electronic and paper, was highlighted on the diagram with simple arrows. Solid arrows represented automated, electronic distribution. Dashed arrows represented paper or manual information flows.

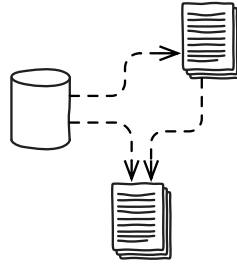


Figure 19: Repository Map is a simple view of the in use data stores that maintain patient information. Arrows are used to show how patient information is distributed between repositories.

Finally, a separate view of the repository map was developed that contained all the discovered repositories. On this model, a high level description of the typical content was included, represented using a very simple UML Class notation. The types of content were derived from the IOM white paper on Electronic Health Record Systems (Table 10) (P Tang & McDonald, 2006).

Table 10: Types of patient information that can be found in clinical information repositories.

Types of Content
Medical Summary Data
Narrative Notes
Laboratory Results
Radiology Results
Medications
Order Entry / Management
Care / Treatment Plans
Advance Directives
Communication Tools

Each of these models was used in the IM/IT interviews and revised based on the findings from those interviews. They were then used in the Structured Discussion Groups to highlight findings and challenges and trigger discussion on suggested improvements.

Stage 3: Structured Group Discussions

A series of two, 2-hour meetings were to be held with representative members of the study participants to discuss the findings and debate potential improvements in Continuity of Care. These sessions were also meant to serve as a form of member checking of the information received during the one on one interviews.

The rich pictures and conceptual models were used to structure the debate as per SSM. The group was walked through the two clinical presentations and the conceptual models, highlighting challenges and gaps. The groups were asked to discuss the proposed suggested improvements that had been developed through the initial analysis of the provider interviews and further developed through the IM/IT interviews. Also, the groups were challenged to ensure that the improvements are practical and supported as feasible by all providers and IM/IT participants represented.

As a conclusion to this phase, feedback from participants was incorporated into the artifacts, including the Rich Pictures, Conceptual Models and Suggestions for Improvement.

Stage 4: Suggestions for Improvement

The final phase of this study was to develop and document the proposed suggestions for improvement.²⁶ The improvements were selected based on the following criteria:

1. They addressed gaps raised by provider participants related to Continuity of Care, particularly inter-team challenges.
2. They were thought by participants to improve those gaps.
3. They had regional (or greater) application.
4. The participants, both providers and IM/IT, agreed and considered them feasible.²⁷

²⁶ NOTE: This study did not include the implementation of these recommendations.

²⁷ Feasible was defined as activities that could be incorporated into the currently planned activities and completed within one year. Larger changes, requiring significant resources and development, would not be feasible recommendations. If a request such as this that was

The iterative nature of this study meant that suggestions were being developed while the interviews were being conducted and refined through to the conclusion of the analysis of Discussion Groups. Key stages where the suggested improvements were developed were with IM/IT staff during their interviews and during the Discussion Groups with providers and IM/IT.

Local improvements that impacted a single community or a department were captured separately. Local improvements were to be shared back with the community or department where they originated after the conclusion of the study. This was an important part of giving back to the participant communities, to keep them engaged in improvements and future research.

After the conclusion of the study, the Suggested Improvements will be shared with regional leadership and the participating communities through various presentation opportunities. Finally, publication and presentation opportunities will be sought to share findings and methods with the informatics academic community.

Stage 5: Reflection and Continuity of Care

By way of concluding this section, it is important to note that reflection was a necessary component of this study. Reflection was embedded throughout the study. Reflection included documenting in a journal, capturing social and political factors discovered in the interviews as well as my own findings on the challenges and potential improvements. It guided me, as the researcher, in my selection of the roles to interview, in my understanding of the various communication patterns, in seeking clarification within interviews, in understanding the social and political challenges, in refining the models, and understanding aspect in the communities that impact Continuity of Care. Reflection was integral to the completion of this work.

deemed systemically desirable but infeasible, then accommodation would have to occur. For example, the recommendation would be scaled down to developing a *proposal* for strategic consideration or to design or pilot the improvement within the year.

RESULTS SECTION

Chapter 10 Results Overview

This chapter orients the reader to the results section of the dissertation. It describes the overall analysis process through a Rich Picture and Soft Systems model. This chapter also includes a summary of the study participants, findings in the two communities, and an example of the qualitative analysis processing of the raw interview data that led to the findings described in this section.

Organization of the Results Section

The results section was organized so that the reader could follow through the process of analysis. The flow of chapters in this section was designed for the reader to follow the lines of the key dependencies between the stages of analysis. The SSM conceptual model in Figure 20 describes the overall process for analysis.²⁸ The chapters that describe the specific findings are highlighted in this model to support the reader in navigating findings from this study. Throughout this section, the reader will notice that the results are often included with a level of interpretation. This is intentional and follows the style of presentation of other qualitative research, such as that found in (Ash, et al., 2004). Broader interpretation of findings outside the boundaries of this study are reserved for the discussion section.

²⁸ The actual analysis was quite iterative, with Rich Pictures and Conceptual Models being drawn and redrawn throughout the 34 interviews.

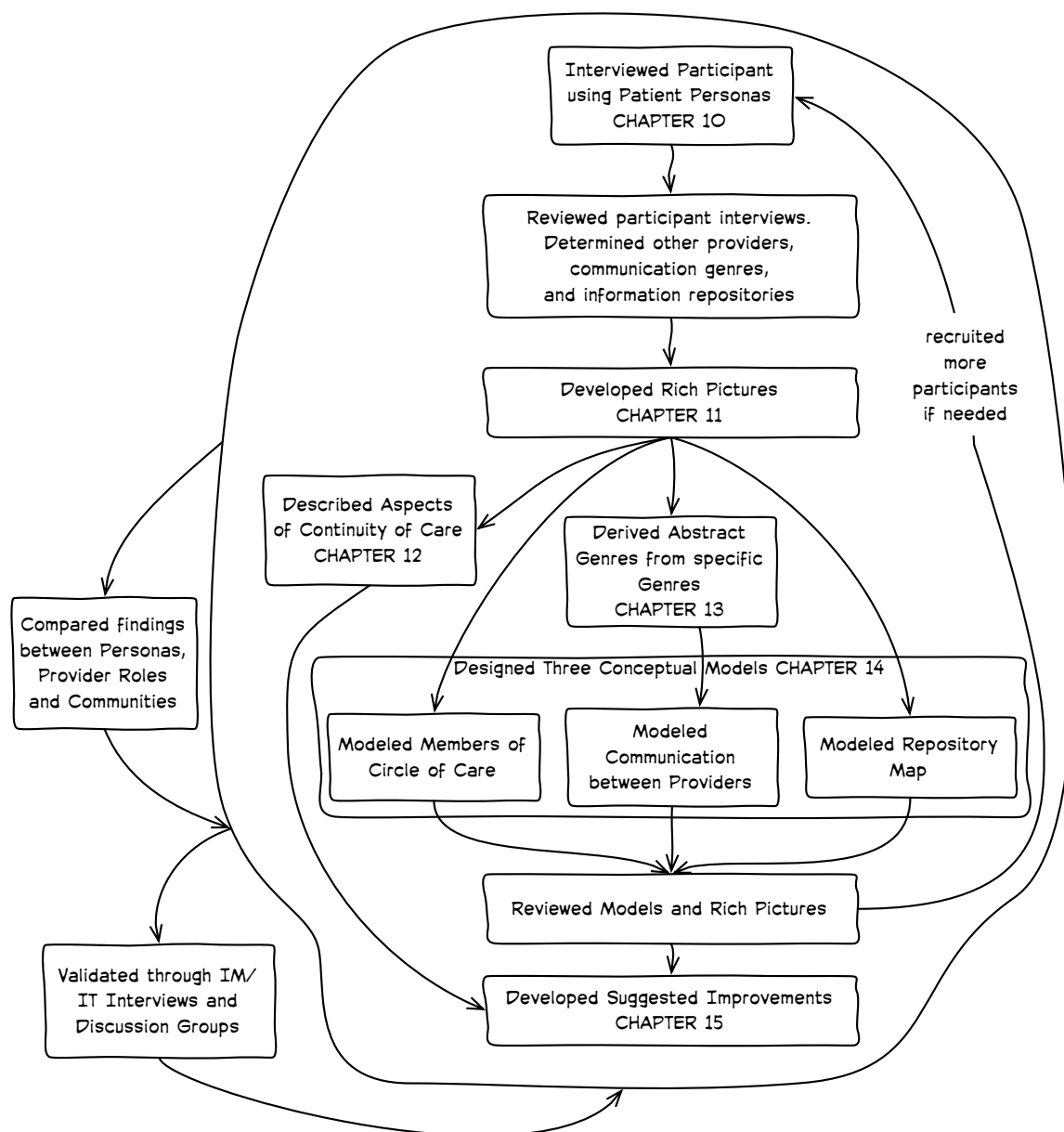


Figure 20: Conceptual Model of the analysis process, this diagram also reflects the organization of the results section (chapter numbers are indicated in the figure).

Participants were recruited and interviewed following the protocol established in the methods and approved by the ethics review board. The participants are described later in this chapter.

Rich Pictures for each patient were developed and refined throughout the provider interviews and then used in the IM/IT interviews and Discussion Groups (Chapter 11). These were designed to capture details of the patient stories told by the participants. They illustrated a scenario for each patient in community that highlighted common gaps raised by multiple participants. The aspects of Continuity of Care were reviewed (Chapter 12), including findings from the interviews with participants that were not captured in the Haggerty and Reid model.

Prior to modeling the system, the Genres needed to be collected. However, in the analysis (Chapter 13), it was felt that there were too many specific Genres. The number of individual Genres was impeding analysis. The specific Genres were grouped into a smaller set of Abstract Genres, based on their common purposeful activities.

Conceptual models were developed from the interview data to describe three views of each patient's care system (Chapter 14). The intent of the modeling at the onset of this study was to develop a model that supported reasoning on the three aspects of continuity from the Haggerty and Reid model (Relationship Continuity, Management Continuity, and Information Continuity). The specific form of these models was not predefined at the outset of the study. These were used, along with the Rich Pictures, in the development of Suggested Improvements with the IM/IT participants and in the final Discussion Groups (Chapter 15).

Throughout the study, findings were compared between the two Patient Personas, the different participants, and between the two communities. Findings were triangulated between providers of the same role and of different roles. The findings were further confirmed in two ways: first by sharing the draft Rich Pictures and Conceptual Models with the IM/IT participants (many of whom were clinicians as well), and through the Structured Discussion Groups. IM/IT participants helped shape the initial thinking of these suggested improvements. Participants in the discussion groups further confirmed and refined these suggestions through their discussions around each patient, the gaps in continuity, and about what changes might be feasible and helpful.

Study Participants

Thirty-four participants were engaged in the study. Each participant was interviewed once, using the interview protocols described in Appendices B and C. Interviews lasted from 45 minutes to over two hours, depending on the participant.

Recruitment of participants proved to be more challenging than anticipated and considerable time was spent waiting for responses and promoting the research study to the various clinical groups in both communities. While the iterative recruitment was necessary for this study, it did take time. Those that did participate tended to be very keen in their practices to support Continuity of Care and felt it was important part of their roles. As the first participant in the study said:

“I am the Continuity of Care... I coordinate everything.” (V01)

Of the thirty-four interviews that were completed, Twenty-eight were providers and six IM/IT staff. Several participants had multiple roles (e.g. part time palliative care nurse, part time Home and Community Care nurse). Those participants who had multiple roles were asked to comment from their multiple perspectives, where appropriate. Several participants also had administrative positions within VIHA, or positions of leadership within their community and at times reflected on their perspectives on the types of changes that could or could not be supported.

Six IM/IT staff were interviewed, five were from VIHA and one from the BC Cancer Agency. Four of those IM/IT staff were also clinicians (physician, nurse, pharmacist). Combining the IM/IT providers and the providers with multiple positions thirty-nine different clinical positions were reviewed. The summary of the participants is captured in Table 11.

Participants had an average of 23 years of clinical experience, 14.7 years of which were in their respective communities. In short, these were skilled professionals, who knew their communities, sometimes from multiple roles.

Table 11: Summary of research participants, roles and collective experience.

Study Interview Summary Data	
Total Number of Interviews	34
Number of Providers Interviewed	32
Number of Clinical Roles	39
Number of Clinical Roles in Victoria	22
Number of Clinical Roles in Duncan	17
Physician Participants	13
Nurse Participants	16
Pharmacist Participants	3
Male Participants	11
Female Participants	23
Average Years Experience in Practice	23.0
Average Years Experience in Community	14.7
Number of IM/IT Interviews	6

Half of the providers interviewed were nurses. Physicians (family physicians, ER physicians, oncologists and other specialists) and pharmacists made up the other half of the participants. The majority of participants were female (over two thirds) and all nurse participants were female. Half of the provider participants were from Duncan, despite Duncan being a considerably smaller town. All of the IM/IT participants were from Victoria, which is not surprising as the majority of the IM/IT infrastructure, particularly the leadership and CIS design teams, are based out of Victoria.

Participants were from several organizations and departments, including:

- Private Practice
 - Family physicians
 - Specialists
- PHSA / BC Cancer Agency
 - Vancouver Island Cancer Centre (Victoria)
 - Cowichan Cancer Centre (Duncan)
 - BC Cancer Agency's Clinical Informatics Department
- VIHA

- Home and community care – provides services in both communities
- Long Term Care
- Emergency Medicine
- Medical Services
- Pharmacy Services
- Information Management / Information Technology (IM/IT)
- Victoria Hospice (VIHA affiliation)
 - Outpatient palliative care, including the Palliative Response Team (PRT)
 - Inpatient palliative care

The order of the interviews did not proceed precisely as planned. Initially all family physician interviews were to be completed prior to embarking on recruiting the next round of provider participants. However, there was difficulty in recruiting and arranging all six family physician interviews. In order to proceed in a timely fashion, some other providers were interviewed before all family physician interviews were completed. This deviated from the planned methods. However, the delayed family physician interviews (one in each community) provided me with the ability to revisit the family physician's perspective without having to reschedule additional interviews. This reordering did not result in missing any additional provider roles in the final family physician interviews. The final family physician interviews were more confirmatory.

There were gaps in recruiting clinicians into this study. Several roles were not interviewed, due to lack of responses from providers with these roles. These included: ER physicians in Duncan, Quick Response Team nurses in Victoria (although they are part of Home and Community Care), cardiologists in Victoria, and community based pharmacists in both communities. While these perspectives were missing from the study, their loss was somewhat compensated for through the discussion other provider roles.

Community Findings

In general, the communities were more similar than different. Many of the same services were available in both communities. Both communities had private physicians (family physicians and specialists), local hospitals with 24-hour Emergency Departments, Home and Community Care services, private community pharmacies and hospital pharmacies, and long term care facilities.

Table 12: Summary of community findings for Duncan and Victoria.

	Greater Duncan	Greater Victoria
Population	41,000	300,000+
Hospitals	1 community hospital, primarily family physician run.	2 tertiary care hospitals with active hospitalist services. Victoria Hospice
Cancer Care	Small Ambulatory clinic providing ambulatory chemotherapy	Vancouver Island Cancer Centre with extensive services including Chemotherapy, Radiation Therapy, and a large care team.
Primary Care	Active community of family physicians providing full service practice.	Large number of physicians, mostly office based practices. Few providing hospital services.
Home and Community Care	Geographically Organized Home and Community Care, providing all services. Available ~12 hours / day.	Geographically Organized Home and Community Care, with specialized services. Home care available 24 hours a day if required.
Outpatient Palliative Care	Provided by Home and Community Care	Provided by both Home and Community Care and Victoria Hospice's Palliative Response Team.

Victoria, was a larger centre (Greater Victoria is over 300,000 people), had more providers and tended to deliver more focused and sub-specialized care (of multiple kinds). This was most noticed in the Mr. Hart scenarios as Mrs. Cann was referred to the Vancouver Island Cancer Centre in Victoria. There were two larger tertiary hospitals in Victoria (Victoria General Hospital and Royal Jubilee Hospital), which also acted as regional referral centres. There were relatively few family physicians that admitted to the hospitals in Victoria.

Instead, there was a large hospitalist service²⁹ that covered many of the patients in both facilities. The Victoria Hospice was located at Royal Jubilee Hospital with a 17-bed inpatient service and large outpatient service (over 350 patients).

The hospital in Duncan was a smaller community hospital. The Duncan hospital had an ER with dedicated staff (family physicians were restricted from covering the Emergency just prior to the start of this study). Nearly all patients were admitted under their family physicians in Duncan. Specialists generally acted as consultants, although they occasionally admitted patients at the hospital under themselves as well, particularly in the Intensive Care Unit.

Victoria and Duncan both had Home and Community Care services. The teams were organized geographically in both communities. That is, teams were responsible for patients who live within a specific geographical boundary. The Home and Community Care included case management, nursing, physiotherapy, occupational therapy, social work and community support workers. The community support worker services in Victoria were contracted out to a private company, whereas in Duncan they were managed directly by VIHA. In Duncan, Home and Community Care nurses provided all manner of support, including end of life care. In Victoria, the Victoria Hospice also had a Palliative Response Team that was available 24 hours a day to manage pain crises and other acute palliative issues for patients in the community. They worked with Home and Community Care when needed. Victoria also had a Quick Response Team that was part of Home and Community Care that was linked specifically to the Emergency Department. The Quick Response Team helped facilitate more rapid discharges from Emergency. Home and Community Care in Duncan was more homogeneous. It was also only available until 8 at night. After hours, family physician call groups covered care in the community.

The Vancouver Island Cancer Centre, one of the BC Cancer Agency's regional facilities, was located in Victoria. It was the only facility on Vancouver Island that could provide radiation

²⁹ Hospitalists at VIHA were family physicians that only do hospital medicine. They worked as a large team. Through rotating shifts they covered a large portion of the hospital's medical inpatients 24 hours a day.

therapy and had a large and active ambulatory program that provided care to the majority of cancer patients on Vancouver Island. Duncan could provide some chemotherapy and ran a small ambulatory cancer clinic out of the hospital. It was connected to the BC Cancer Agency and the Vancouver Island Cancer Centre, as are the other satellite centres across Vancouver Island.

Providers in both communities were confident that our Patient Personas would be typical patients seen in their community and in their practices or services. They saw end of life patients like Mrs. Cann and Mr. Hart and agreed that there were challenges related to Continuity of Care.

Example of the Qualitative Analysis of Interviews

The majority of data collected for this study was through the participant interviews. The data from the interviews was analysed to derive the rich pictures, conceptual models and to support the development of feasible suggestions for improvement. To provide some context on how the qualitative data was analysed, a detailed example is given here. This example highlights the initial review from an early interview with a family physician participant in Duncan.

The interviews were structured to elicit information related to Continuity of Care and to find gaps in continuity. There were four stages in each provider participant interview that are described here (the stages did overlap in the conversation, depending on the participant).

First, I attempted to draw out the different providers involved in the care of each Patient Persona (Figure 21). Here the provider participant has named several other roles, such as the home care nurse, several oncologists (in Victoria and Duncan), family members, and two volunteer organizations: the Duncan Cancer Society and the Duncan Hospice Society. Additional providers came out as the interview and scenarios unfolded.

Researcher: [Described Mrs. Cann's first scenario – see appendices for script]
 “In this scenario, who would you see would be involved in [Mrs. Cann's] care?”

D01:

“...The **home care nursing** program plays a huge role and they have a great experience in addressing and just taking the ball and running with that. It's one of their real fortes I would say here in our community and *letting me know what the needs are for a hospital bed or for other things* through the palliative care resources program. Filling out the forms for palliative benefits. There is one that goes to the province to make sure they can get funds for home modifications, for you know keeping tabs on the symptom management and the pain perspective. I would be doing some, either the *patients come in to see* me or – my sort of practice with *house calls* is I encourage patients to come out when they can. For cancer patients at home I do everything I can to make *home visits to assess them and manage their pain, their bowels, their side effects* and other specifics – if there are wounds and things like that...”

“So the **oncologist** is still in the loop here and we're going to be looking at palliative treatment for that metastatic disease involving the **medical and radiation oncologist**. A good resource we have in Duncan is an extension of the Cancer Clinic is in our hospital we have **one of our internists, who does hematology and oncology sub-specialty**. He is a local resource if there are some chemo issues, side effects, monitoring. She might even get her chemo here.”

“And then *trips down to the radiation oncology* [in Victoria]. So that might involve volunteer drivers from the **Cancer Society**, but **she has a few daughters** who would probably be the ones.”

“We do have a hospice group that functions without a hospice bed unit, but they are volunteers and some resources through that **Hospice Society**. That's a very active group in the community...”

Figure 21: Transcript from an early portion of a participant interview with a family physician in Duncan. In this section, the participant is describing who would be providing care to Mrs. Cann while she is ambulatory and living at home in Duncan. Providers are highlighted in bold. Communication activities are italicized.

Second, I attempted to elicit the communication between providers. Communication activities were captured from the interviews. Where necessary, communication patterns between the participant and the other providers were clarified (see example in Figure 22). This provided a richer understanding of who was communicated with and what the communications were like. In Figure 22 the participant was clear about information he would send to the oncologist, for example:

“I would send down the information in a letter format: some background, personal profile, any lab data of relevance.” (D01)

Figure 22 also highlights the exclusion of direct common communications between providers. The participant, although he knows of the chemotherapy nurses at the hospital

and is aware of their important work, he does not communicate with them about chemotherapy. They communicate with the Duncan oncologist. The family physician communicated with the oncologist through phone and letters.

Researcher:

“[Summarizes list of providers back to participants]. Those are the providers you see at the moment in this patient’s care. How do you communicate with, say, the medical oncologist?”

D01:

“So if there is some focal soft area in the bony skeleton, if we done a bone scan or other scan, CT, etc. If there was some palliative radiation focused on any of those boney [metastases]. It would be a *phone call* [to the oncologist] and I would *send down the information in a letter format: some background, personal profile, any lab data of relevance.*”

Researcher: “I guess you would get the traditional *consult letter* back”

D01: “Yes”

Researcher:

“How does that Victoria piece link in with the Duncan oncology?”

D01:

“Sometimes it’s completely removed. It depends a little bit on the patient preference. If they are happy to follow up [in Duncan] after an initial consult and recommendation down in Victoria, then Victoria medical oncologist sort of is not so much involved and it is mostly [Duncan]. There might be more – it would depend on the **family** a bit, you know, their level of involvement and interest too. If they were taking time off and taking them down and felt that they were getting the best for their mother by having more treatments and surveillance in Victoria, that might be happening. So it can take various combinations of the two [centres] or one or the other. There is a wide spectrum of how that might look.”

Researcher: “Do you communicate directly with the [**Chemotherapy Nurses**] on the floor?”

D01:

“I think they would mostly be taking their direction from [the **Duncan Oncologist**]...”

Researcher:

“Would they call you with patient’s status - ‘we just saw them today and we are really concerned about X’? Or would that be [the **Duncan oncologist**] that calls you?”

D01:

“You know, it would be [the **Duncan oncologist**.]”

...

“The decision to defer chemo would be [the oncologist’s]. I might have some input if I was seeing a patient with febrile neutropenia in the [ER] or something like that. That would be a reason to defer [chemo], *I would be communicating with the **specialist [oncologist]** there who would make that final decision.*”

Researcher:

“In terms of communication and continuity, what works better for you: having patients going to see the Victoria group or having them connected up here locally?”

DO1:

“Hmm...My first reaction would be locally. I would be getting, likely, a little bit ...ah...more reliable communication. I think the flow of information is a bit slower coming from Victoria...”

Researcher: “Let me ask you about the two different societies. How do you get them engaged in the patient’s care? Do you do that or does somebody else do that?”

DO1:
 “I would be *often suggesting resources* like the **Cancer Society** and the **Hospice [Society]** when I am seeing the value of that and seeing the stress levels and coping abilities and just their resources that are in place for the patient and the family already. But they might also have that connection themselves or from others too. I could very well be someone suggesting this could be a good resource.”

Researcher: “Do you ever get information back from either of them?”

DO1: “*Not likely, no I wouldn’t.*”

Figure 22: Transcript from another portion of a participant interview with a family physician in Duncan. In this section, the participant is being prompted to better describe communication activities between providers that have been named as being involved with Mrs. Cann while she is ambulatory and living at home in Duncan. Providers are highlighted in bold. Communication activities are italicized. Transitions of care are underlined.

Third, the Clinical Case Presentations of each Patient Persona were designed to provide acute changes in a patient’s situation. These changes would likely trigger a transition of care (potentially changing providers, locations, or approach). Figure 23 shows the discussion around Mrs. Cann’s pain crisis. If the pain were severe, Mrs. Cann would be admitted to hospital. Also, the participant again mentions the role of the family. He also highlights the need to communicate changes in medication orders to better manage pain.

Researcher:
 “Let me just tell you a little bit more about our patient here. So she comes in to see you today. She’s your second to last patient of the day. And she’s definitely looking worse. She’s normally very well dressed, well kept. Today she doesn’t have make up on, looking a little disheveled. She’s developed a new pain in her back. She hasn’t had that before. It’s a new spot. The pain control that she’s been on – the MS Contin – is definitely not working. She’s actually been in bed for the better part of the last three days... What would do and who would you communicate [with] about that [change]. Is there anyone you would engage at this point?”

DO1:
 “Her **family**, whichever one that may be nearest at hand or most involved, like the spokesperson for the family... usually there would be one identified. And to make some *adjustments to her pain medications would be necessary* but also to determine if there is some role for radiation for a spinal met. If there is any concern about cord compression. If there were [neurological] signs and symptoms like weakness of legs or bladder. This has to be a hospital patient for CT scan. To get control of this pain there might be a role for an acute admission... direct admit for a palliative patient may be accomplished.”

Figure 23: Transcript from another portion of a participant interview with a family physician in Duncan. In this section, I described Mrs. Cann’s worsening scenario to see if the acute decline would prompt a transition in care, such as an admission, which it did. Providers are highlighted in bold. Communication activities are italicized. Transitions were underlined.

The Case Presentations continued to unfold as per the interview protocol. For brevity, the rest of the transcripts for the Mrs. Cann case or the Mr. Hart case were not included.

Forth, the interviews concluded with a series of additional reflective questions designed to provide the participants the opportunity to explore additional gaps and to discuss how clinical information systems supported care. This was part of the wrap up on the interview. In Figure 24 the same participant described some of his perceived needs for improved continuity for patients, with a focus on clinical information systems. He highlighted several clinical information systems: his own office based electronic medical record, the hospital PowerChart system, and the provincial PharmaNet system that contains medication-dispensing history. He also highlighted a gap around Advanced Directives and how information in his office is locked away from other providers who may be caring for his patients.

Researcher: “Alright. Well, those are my two cases.

D01: “Good cases”

Researcher:

“They are holding up... Let me ask you a couple of wrap up questions. We’ve spent a lot of time talking about the clinical side of things and the flow of information between providers. What we haven’t talked about is how the information systems can help this. Do you have any thoughts, now that we’ve gone through the two cases, of where you think an information system could actually help improve the flow and continuity?”

D01:

“Some linkage with our **home care nursing**. *Faxing* has been the standard for many years now but dealing with faxed documents in an electronic record is cumbersome. Opening those scanned documents – it would be better to have some electronic flow of information that is more direct. I think the use of PowerChart in the VIHA facilities – if our **oncology consultants** could be sending information in that route rather than paper and fax...

“There would be certainly some benefits if we had *electronic flow of information* not paper or fax. Whether is was through some arm of *PowerChart* or something that could communicate to the office *EMRs*.”

Researcher: “So you see really connecting up to your EMR, providing the documents you are getting in paper to be a big benefit”

D01:

“I would think that anything that allows that information to be pulled up and used without the scanning – scanned information is more time consuming and the information, you cannot draw on it as quickly. That’s probably the main, cumbersome, time waster.”

Researcher:

“Is there anything else – we mentioned communication, electronic distribution of documents – is there anything else that electronic systems could do to support continuity for these patients?”

D01:

“Landing in Emergency on the weekend after hours and **having that ability to know what those important end of life – the advance directives – in an electronic form**. That’s being talked about. Alberta had just got a repository system now for all Advanced Directives. I gather that’s a push they are going for. For the emergency physician to deal with an urgency or emergent oncologic problem where one isn’t quite at that ahhh - or even if one is totally on a totally pain / comfort care [plan]. If that comfort care need can’t be met and I am not on call on the weekend and my **cover physician colleague... how is he going to know what’s going on in my office** unless I send him all the information or something. I may *update him on things* as the weekend approaches, or at the *change over*. There would be of value for those unexpected things that we may not communicate at the start of a weekend, or a locum, or someone covering. To have *access to some of that information...* some of the lab data, the oncology consults, what’s happening in the progress notes. Certainly allergies and med lists. You can draw up the medications from *PharmaNet* if you’re connected and have paid your fee for that.”

Figure 24: Transcript from another portion of a participant interview with a family physician in Duncan. In this section, I described Mrs. Cann’s worsening scenario to see if the acute decline would prompt a transition in care, such as an admission, which it did. Providers are highlighted in bold. Communication activities are italicized. Transitions were underlined.

After the individual interview was analysed, the next stage was to compare other interviews from participants with the same role in each community. In the case of family physicians in Duncan, for example, two other participants were interviewed (transcripts not shown). Findings from participants of the same role were combined. For example, the lists of providers were compared within participants of the same role. A superset of the roles mentioned by family physicians (and other roles) was developed (see Table 13). Next, the appropriate illustrations were developed, as per the study methods.

Table 13: List of providers involved in Mrs. Cann's Care while she is ambulatory from the perspective of the family physician participants, with a summary superset of providers that was then used in the conceptual modeling.

Duncan family physician 1	Duncan family physician 2	Duncan family physician 3	Superset of roles named by family physicians in Duncan
Home and Community Care Nurse	Home and Community Care Nurse	Home and Community Care Nurse	Home and Community Care Nurse
	Community Support Worker	Community Support Worker	Community Support Worker
Duncan Oncologist	Duncan Oncologist	Duncan Oncologist	Duncan Oncologist
Duncan Chemotherapy Nurse	Duncan Chemotherapy Nurse	Duncan Chemotherapy Nurse	Duncan Chemotherapy Nurse
Radiation Oncologist	Radiation Oncologist	Radiation Oncologist	Radiation Oncologist
Medical Oncologist	Medical Oncologist	Medical Oncologist	Medical Oncologist
Cancer Society	Cancer Society		Cancer Society
Hospice Society	Hospice Society		Hospice Society
Family	Family	Family	Family
On Call family doctors	On Call family doctors	On Call family doctors	On Call family doctors
ER physician			ER Physician
		Pharmacist	Pharmacist
		BC Cancer Agency Pain Clinic	BC Cancer Agency Pain Clinic
	Pastoral Care		Pastoral Care

Findings were then triangulated *across* roles (not shown). This provided the ability to compare findings internally. For example, the view of the Circle of Care from the family physicians was compared to the home and community care nurses. The findings were represented in the conceptual models and repeatedly compared and refined during the interviews. See the upcoming chapters for the specific models.

This process was followed for the analysis of each of the aspects of this study. First analysis of individual interviews, followed by comparison amongst like groups, then between disparate groups. This led to the development of the Rich Pictures and Conceptual Models in this study. The illustrations were used in the IM/IT interviews and in the Structured Discussion Groups to explore solutions to gaps in continuity.

Structured Discussion Groups

Originally, two discussion groups were planned with members of both communities in attendance for both meetings. It was not possible to organize the Structured Discussion Groups for a time that would have allowed sufficient numbers to attend both of discussion groups, even with video conferencing. A compromise was needed and instead of one set of two discussion groups, two individual discussion groups were held: one for each community. This allowed for eight of the participants to attend the Structured Discussions Groups, not including the researcher. Five participants attended in Victoria and three in Duncan. There was representation from: family physicians, specialty practice, oncology and the Vancouver Island Cancer Centre, the Emergency Department, Home and Community Care, Hospice, Hospital Liaison, and IM/IT.

Chapter 11 Rich Pictures of Care

This chapter describes the analysis process that led to the study's Rich Pictures. The Rich Pictures of Mrs. Cann's care are described in some detail, followed by Mr. Hart's Rich Pictures. Mr. Hart's pictures are presented more briefly, highlighting the additional gaps in transitions that were discovered through the second Patient Persona.

The Rich Pictures were the starting point of my iterative analysis and so it is an appropriate place to begin the description of my analysis and findings. The development of the Rich Pictures was based on the details of the stories told by the participants; see Figure 25 for an illustration of the analysis process.

In each interview, a provider highlighted his or her own perspectives on how each Patient Persona would receive care. They would tell their stories of Mrs. Cann and Mr. Hart highlighting transitions, communications, and challenges in continuity. In my analysis of each interview, I focused on highlighting gaps in continuity during the key transitions. By iterating through the interviews, I found gaps that were corroborated in stories told by multiple participants. These were the aspects of the story that were then highlighted in the Rich Pictures. Over time, the Rich Pictures evolved to reflect a realistic story that highlighted key gaps in Continuity of Care. Draft versions of the Rich Pictures were shared in the Discussion Groups, leading some debate, refinement and confirmation.

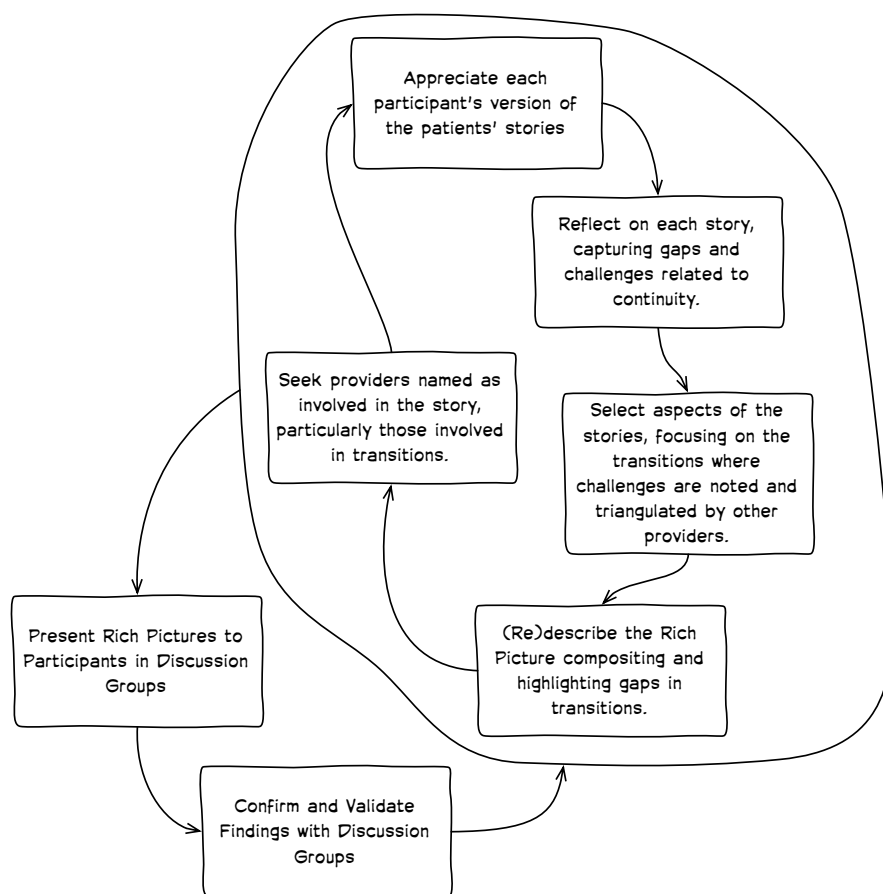


Figure 25: Approach to the development of the Rich Pictures that describe the care of Mrs. Cann and Mr. Hart in Victoria and Duncan.

An Introduction to Mrs. Cann

A brief description of Mrs. Cann, a 64 year-old widow with metastatic breast cancer, was provided earlier in the methods, and the specifics of the Case Presentation were described in the appendices. The case provided a skeleton from which each participant was able to describe – from his or her perspective – how Mrs. Cann’s story was most likely to unfold.

Mrs. Cann’s story was visited with each participant at four key points in her last year of life. These points reflected changes in her condition, some potentially requiring urgent transitions in care of some kind. These four points are illustrated in Figure 26.

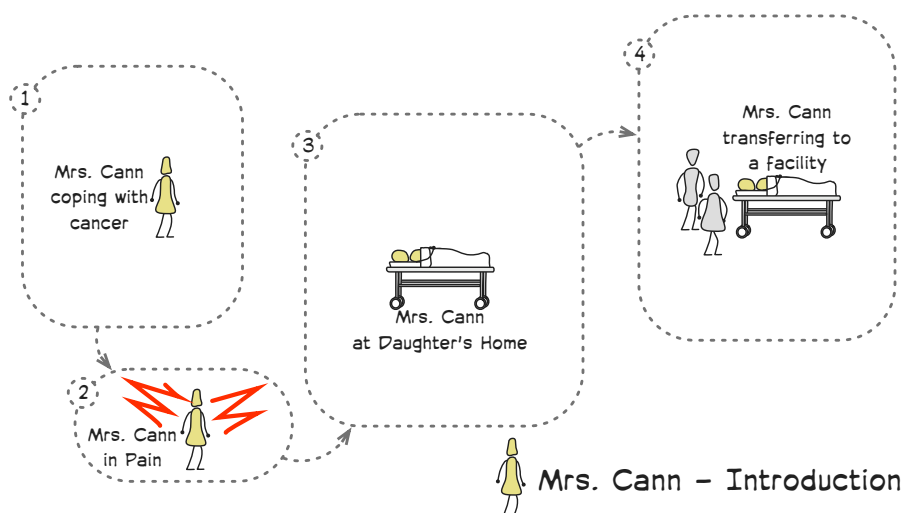


Figure 26: The skeleton framework of the case of Mrs. Cann, each provider participant filled in the details through the interview.

The framework of these four stages gave sufficient structure to focus and explore the key transitions, but still allowed each participant to create their story and provide their perspective on what worked, what did not, and what were the local resources, constraints, and ways providers communicated. Two composite Rich Pictures were developed to highlight a likely path for Mrs. Cann, one for each community. The paths were chosen from findings in the interviews. They were meant to highlight key findings / gaps for discussion. They were not the most frequent paths nor were they idealized paths.

Mrs. Cann's Rich Picture of Care in Duncan

The Rich Picture of Mrs. Cann in Duncan (Figure 27) captured the flow of her care and was based on the findings from the interviews as previously described. Each of the four stages is described in more detail below.

Gaps for each stage were highlighted. These were presented to IM/IT participants during their interviews and to the participants in the discussion groups. The Rich Pictures highlight key activities and flows; they are not exhaustive in illustrating all the providers or all the potential ad hoc communications.

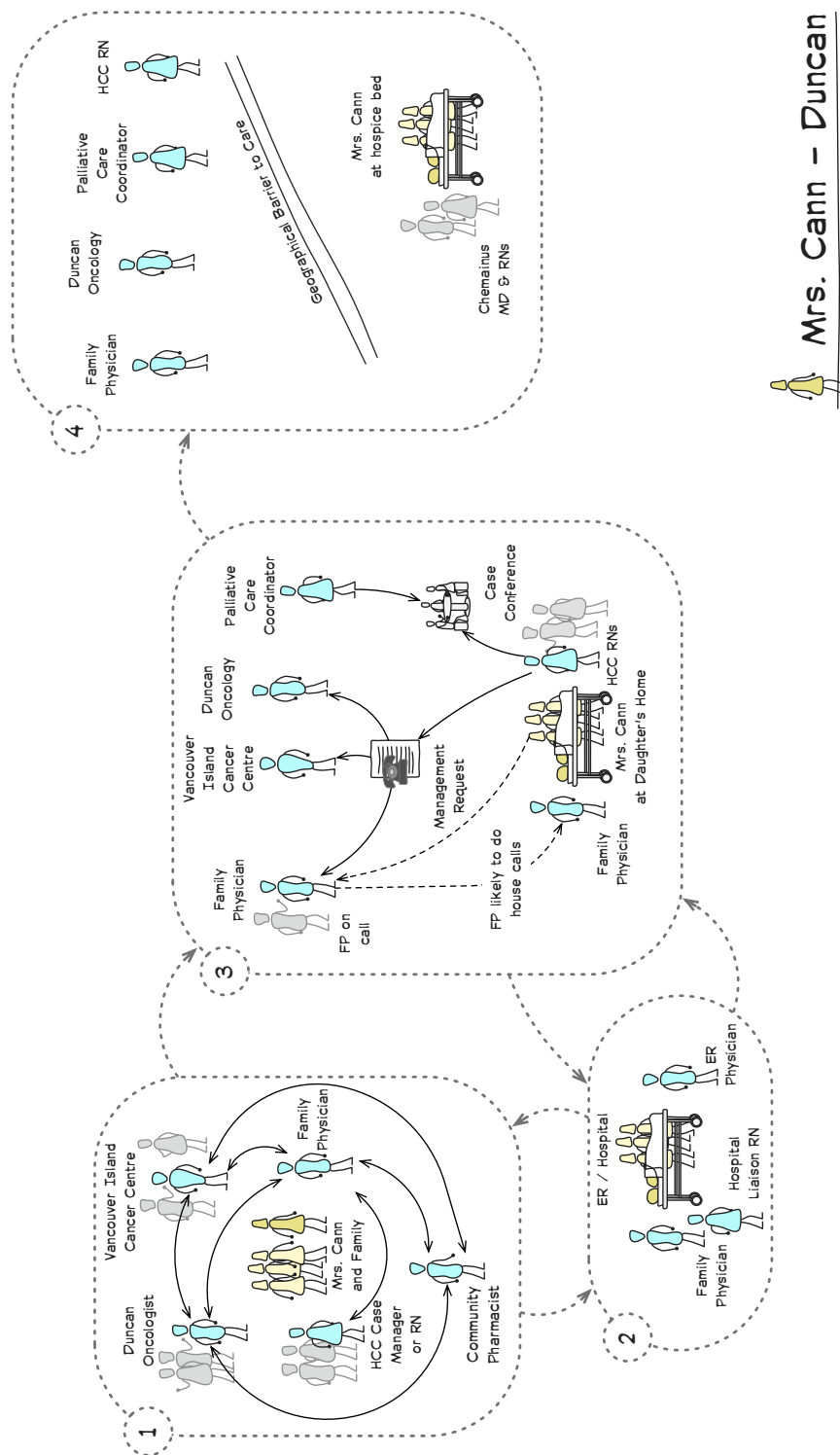


Figure 27: Rich Picture of Mrs. Cann's story in Duncan. Providers with significant roles in ensuring Continuity of Care ("Continuity Providers") are highlighted and other providers are hinted at as ghosted out providers (not all providers are displayed).

Stage 1 – Living at Home and Beginning Not to Cope (Figure 28):

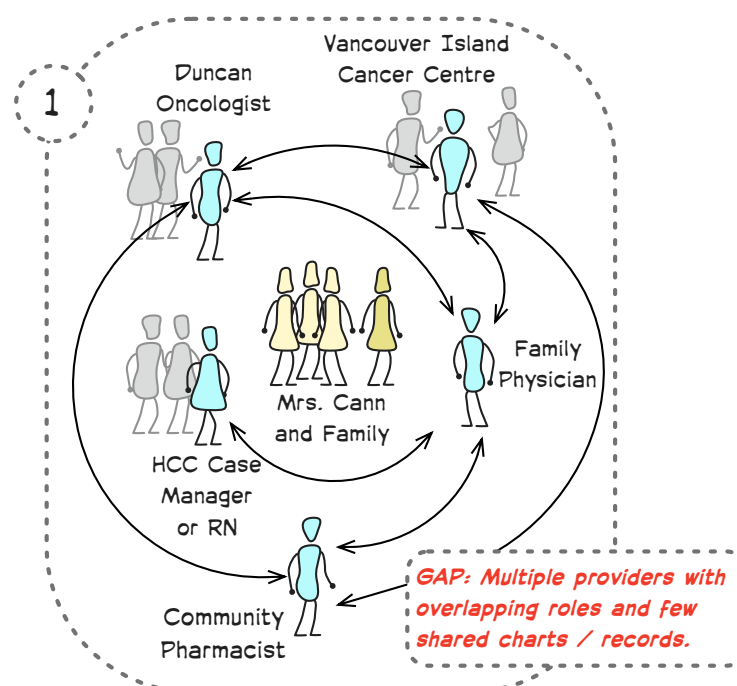


Figure 28: Mrs. Cann is in Duncan and she is living at home alone. There is a swirl of activity and communication around her. Her three daughters are actively involved in ensuring she gets to her appointments and has support at home.

As a person who was living at home alone in Duncan with metastatic cancer, Mrs. Cann would typically have had several providers, whom she would have seen regularly. She would have seen her Family Physician for overall care assessment, planning, and management. She would have been referred by her family physician to the Vancouver Island Cancer Centre, which is in Victoria. There she would have been assessed by the oncologist and received radiation therapy. She would also have follow up, post-radiation, at the cancer clinic in Duncan. This facility provides chemotherapy, but no radiation. Mrs. Cann was seeing the Duncan specialist for ongoing management and returned for acute issues while in Duncan. The family physician did the initial and ongoing coordination with Mrs. Cann, although the oncologists provided considerable support and medical management, such as managing acute pain if needed during a visit.

Mrs. Cann had three daughters in Duncan. Her family was very supportive and made sure she had company every evening. They also helped her get to her appointments in Victoria and in Duncan and did independently visit or call their mother's family physician or oncologist with questions or concerns on occasion.

Home and Community Care was engaged with Mrs. Cann at this point, mainly from a home support perspective. The Home and Community Care Case Manager coordinated these services. The Home and Community Care nurse assessed Mrs. Cann's symptoms, met with the family, and began the process developing rapport with the patient in preparation for what was expected come in the future (i.e. the nurse felt it was important to develop Relationship Continuity). Community Support Workers were be involved at this time as Mrs. Cann needed some additional help, particularly during her radiation treatment.

A Community Pharmacist in Duncan was involved, dispensing routine (non-cancer) medications. There was also a BCCA pharmacist who was involved with the chemotherapy while Mrs. Cann receives treatment in Victoria. When Mrs. Cann's oncology care was transferred to the Duncan Cancer Centre, the community hospital pharmacist received orders from the Duncan Oncologist to continue the chemotherapy protocols.

Gaps:

At this stage, Mrs. Cann's care was occurring in many locations with providers who were operating somewhat autonomously. For some activities, it was clear who provided care (e.g. chemotherapy management was the role of the oncologist). For other activities, it was not clear who is providing what service and it may have varied over time. This is particularly true for pain control, where nearly all of the physicians saw that as one of their roles.

There were few shared records and many isolated care plans on paper stored in various locations both in Victoria and Duncan. Even ensuring access to laboratory results was a challenge for some. For example:

“Difficulty is if a person has outpatient labs done that the outpatient labs don't show up in the Cerner system... having it in the Cerner system would be handy because the clinic is here” (D06)

Continuity was maintained, primarily, through point-to-point communications between providers. These communications were typically verbal (phone or face to face) or on paper (often faxed). There were many requests for information when providers discovered that they had gaps in their information. Home and Community Care would keep up to date by regularly asking for information:

“We do it by asking for information from the Cancer Agency” (D07)

Not all providers were aware of all changes in plans, as we discovered in Stage 2.

Stage 2 – Mrs. Cann in a Pain Crisis (Figure 29):

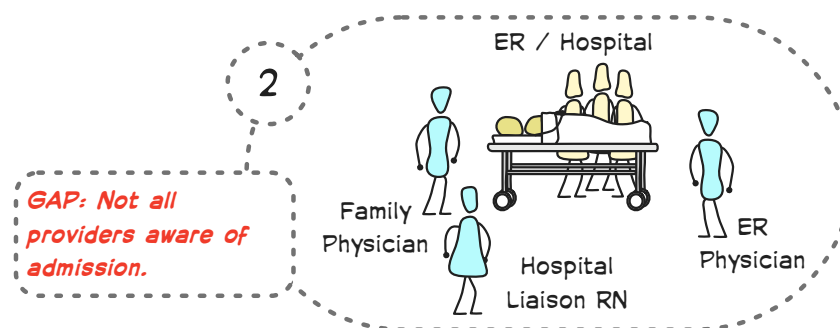


Figure 29: Mrs. Cann has a pain crisis and ends up being admitted through the Emergency Department.

Mrs. Cann was home by herself for a long weekend. When her family returned they found her in considerable pain and immediately phoned the family physician on call. The family physician on call did not know Mrs. Cann and did not have any of her records (as they were in her own family physician’s office that was not accessible to the on call physician). She suggested that Mrs. Cann’s family take her to the ER for acute pain management. They took her straight to the ER at the hospital where she was assessed and had some IV pain medication. The ER physician managed the pain acutely and admitted Mrs. Cann overnight under the physician on call.

Mrs. Cann's family physician was made aware of the admission in the morning before he left for the office (he received a call from the ER physician). The family physician arranged a CT scan in the morning after speaking to the radiologist to get some advice on what the best test would be. This was done to assess the cause of the pain, which was a second metastasis to the bone.

The Home and Community Care nurse was made aware of Mrs. Cann's admission through the Hospital Liaison nurse. The Liaison nurse had the hospital census list manually compared with the Home and Community Care roster (this was done daily) and saw that Mrs. Cann was admitted the night before.

Once her pain was back under control and she had the CT scan, Mrs. Cann was discharged home. The family physician copied the results of the CT to her oncologist in Victoria. Over the next few days, an appointment was made with the oncologist and Mrs. Cann was reviewed to see what treatment options were available for her.

Mrs. Cann had similar pain crises as her disease progressed, although these were not illustrated.

Gaps:

Most of Mrs. Cann's information was not accessible to the care providers who see her during the crisis. None of the records from the BCCA, the family physician's office, the Duncan oncology centre, or Home and Community Care were available to either the family physician on call or the ER physician. As this is one of Mrs. Cann's first encounters with acute care in some time, the regional record had very little information in it. The Duncan hospital paper records did not include the ambulatory Duncan cancer centre records. As was noted:

"One of the difficulties with respect to the charting system is that the charts are locked away in the Cancer Clinic so that if the patient winds up in the Emergency Department or something like that, they don't have access to any of it." (D06)

The records were not available even though that clinic was run out of the Duncan hospital, one floor above the Emergency Department.

Another gap that was discovered through the participants was that not everyone was immediately aware of the admission. The oncologists would not necessarily have known about the admission, at least not initially. Home and Community Care knew about the admission the next day, but only because of a manual review of the complete hospital census that occurred daily at each hospital, although on a long weekend, that will not happen until the Tuesday morning. The family physician was informed about the admission because the ER physician transferred care. If the ER physician had discharged Mrs. Cann directly, then the family physician might not know of the ER visit for a few days, until he was up at the hospital and looked in his mailbox to find a paper copy of the ER physician's note.

Stage 3 – Staying at Daughter's, Confined to Home (Figure 30):

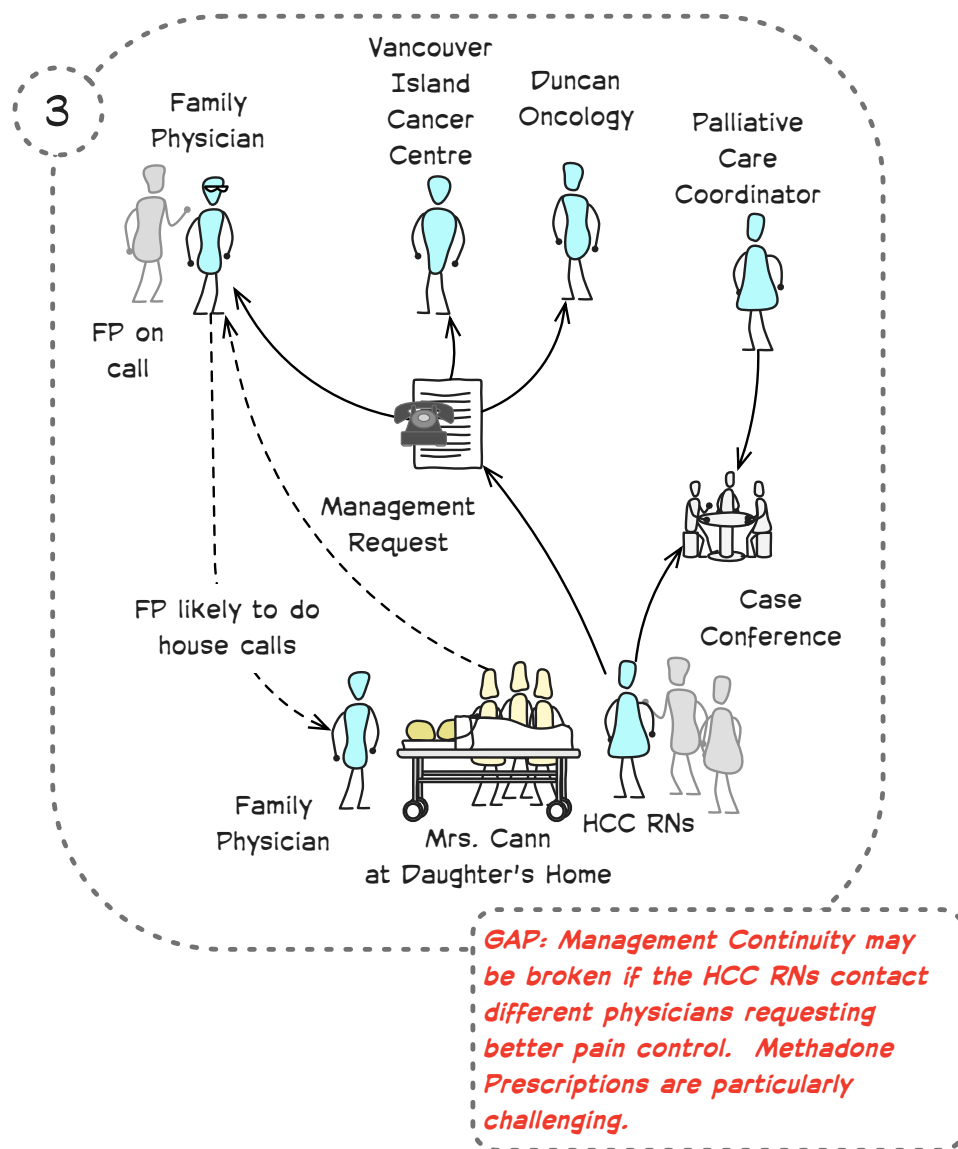


Figure 30: Some time passes since the last time we saw Mrs. Cann. She is now at her eldest daughter's home and too weak to attend appointments. Home and Community Care nurses are the main providers of care, seeing her daily.

Over the intervening months between Stage 2 and 3, Mrs. Cann's condition declined. She moved into her eldest daughter's home to get more support from her family and at this point rarely gets out of bed. Her daughter took a leave from work, even though they also

were receiving home support and home nursing from Home and Community Care. The Home and Community Care nurses were the primary providers for Mrs. Cann at this stage. There were multiple nurses who would rotate shifts through the week; they would see Mrs. Cann once daily. Her family physician attended when able or requested by the Home and Community Care nurse or family. The rest of the providers were only involved by phone consultation for advice (to the family physician or Home and Community Care nurse or family).

The Home and Community Care nurses in Duncan did not have extra training to manage palliative patients, but they were supported by the Palliative Care Coordinator, who met with the Home and Community Care staff regularly in case conferences. She was available to provide management advice to any of the Home and Community Care nurses in the community on the phone.

It was often up to the Home and Community Care nurse to assess the patient's function and pain. When necessary, the nurse contacted a physician of her choosing for a re-assessment or for a prescription change. Often this would be Mrs. Cann's family physician, but could be one of Mrs. Cann's other physicians. In this instance, this particular nurse felt that the family physician had been hesitant to increase Mrs. Cann's pain medication. So she contacted the Symptom Management Clinic at the Cancer Centre in Victoria (where she'd previously had good response) and requested a change in analgesic. The family picked up the prescription. A few weeks later the family physician was asked to renew the prescription by the local community pharmacist and it was different than what he had written previously. The prescription was for Methadone and the family physician was not licensed to prescribe it.

Gaps:

There were multiple Home and Community Care nurses providing care to Mrs. Cann at this time. They each might choose to contact a different physician when they needed to request an assessment and treatment. Typically this was for pain control, but could have been for other symptom management. The nurse may contact the family physician, the Duncan Oncologist, or the BCCA Symptom Management Clinic (Pain Clinic) in Victoria. The

choice was at the discretion of the nurse. If the nurse felt the family physician was not managing Mrs. Cann's pain well, then they could have called someone else:

"Clearly this patient isn't being well managed and so we phone the cancer agency... we are trying to advocate for the client" (D07)

This varied on personal preference and past individual experience with the providers. This level of variability could cause Mrs. Cann's pain management to become unnecessarily complicated and varied. This could be a source of confusion for the family. A very focused issue was raised by several providers (across roles): if the BCCA clinic prescribed methadone for pain, there are very few physicians in Duncan who were able to continue methadone prescriptions. Methadone may help with pain, but was challenging for the various providers in Duncan when they tried to get the medication renewed.

"This whole methadone [prescription issue] is needing a lot of work." (D07)

"There needs to be more communication with the family doctor...it feels sometimes like there isn't the same communication [around methadone and pain control]...then you have to take over and there hasn't been the same continuity that there could be with better communication." (D13)

The Home and Community Care services were only available approximately 12 hours a day. This can cause some gaps in care over night. Family physicians had call coverage for evenings and weekends, but the gap in nursing care was an issue, especially in acute declines and for planned deaths at home. Often the families filled this gap and would administer medications, some which are subcutaneous injections. Other times, nervous family members could take patients to the ER.

**Stage 4 – Mrs. Cann is in Her Final Days and moved to a Facility
(Figure 31):**

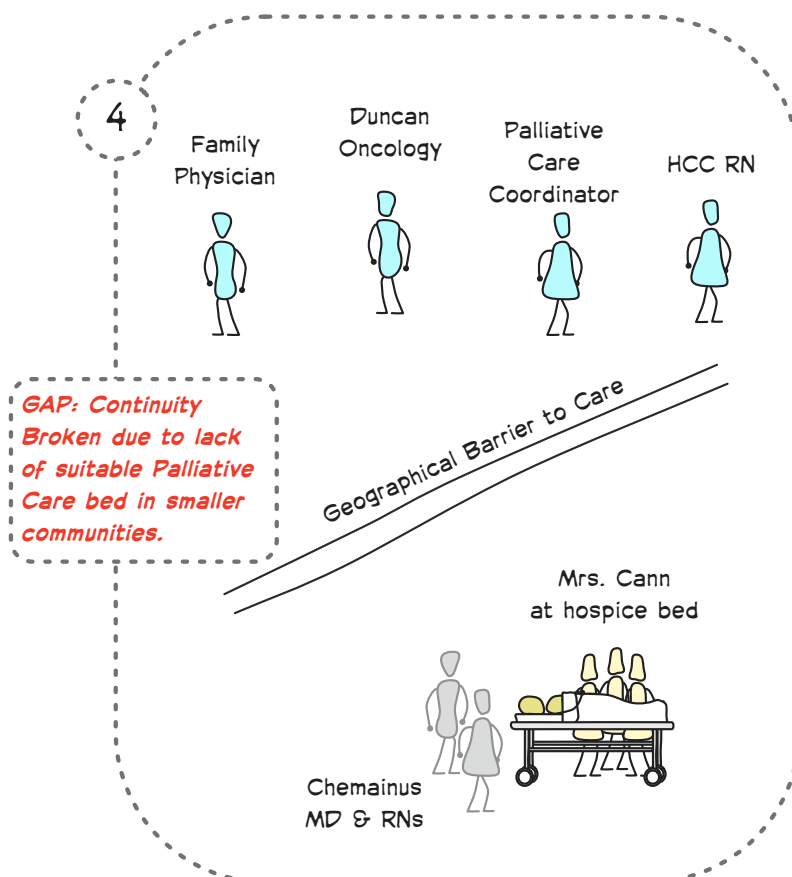


Figure 31: Mrs. Cann is moved to a hospice bed. The closest bed is in Chemainus, a neighboring town.

Mrs. Cann continued her decline at her daughter's home and was approaching her final days. She was not eating and was drinking little. In a moment of crisis, she decided that she did not want to further burden her family with her death in their house. She wanted to go to a facility to die. After a discussion with the patient and the family, which explored other options, the Home and Community Care nurse realized that this was the best option.³⁰ The

³⁰ Most providers were strong advocates of respecting Mrs. Cann's wishes to die at home and wanted to work through the crisis at home with the family. Dying at home, even though it is common and often preferred, was not an option for Mrs. Cann in this study, as the transition to a palliative bed was considered an important transition to explore.

Palliative Care Coordinator in Duncan facilitated Mrs. Cann's placement, triaging Mrs. Cann with other patients based on need.

Unfortunately, Duncan no longer had a palliative care bed for community palliative patients. The two options for Mrs. Cann were: to send her to the ER and place her in an acute bed at the hospital (providers agreed is not ideal), or to transfer her to a hospice bed in a neighboring community. It turns out that, after two days waiting, a bed became available in Chemainus,³¹ a community north of Duncan.

Mrs. Cann was transferred to the Chemainus palliative care bed. Her family physician transferred care to one of the family physicians in Chemainus. Mrs. Cann and her family had to meet a whole new Care Team in her final days. Her family made trips to see her every day until she died, but Mrs. Cann's other care providers from Duncan (her family physician, nurses, oncologist) did not.

Gaps:

The biggest gap at this stage was the lack of the proper palliative facilities in Duncan to support Mrs. Cann in her final days. Providers all struggled with this issue and were frustrated by the loss of palliative beds in their community. They noted this as a challenging transition for Mrs. Cann. As one provider put it:

"[This is] two more losses on top of everything else: her family doctor and her community." (D11)

This transition was hard for providers as well, especially those who had developed long-term relationships with their patients.

"If I had to transfer that patient to another physician outside of my catchment, in order to obtain a palliative care bed to meet the needs for that patient, that would be one of my greatest disappointments." (D01)

This concluded the case of Mrs. Cann in Duncan.

³¹ There are also two hospice beds in Ladysmith, which is a community further north, or the Victoria Hospice, to the south.

Mrs. Cann's Rich Picture of Care in Victoria

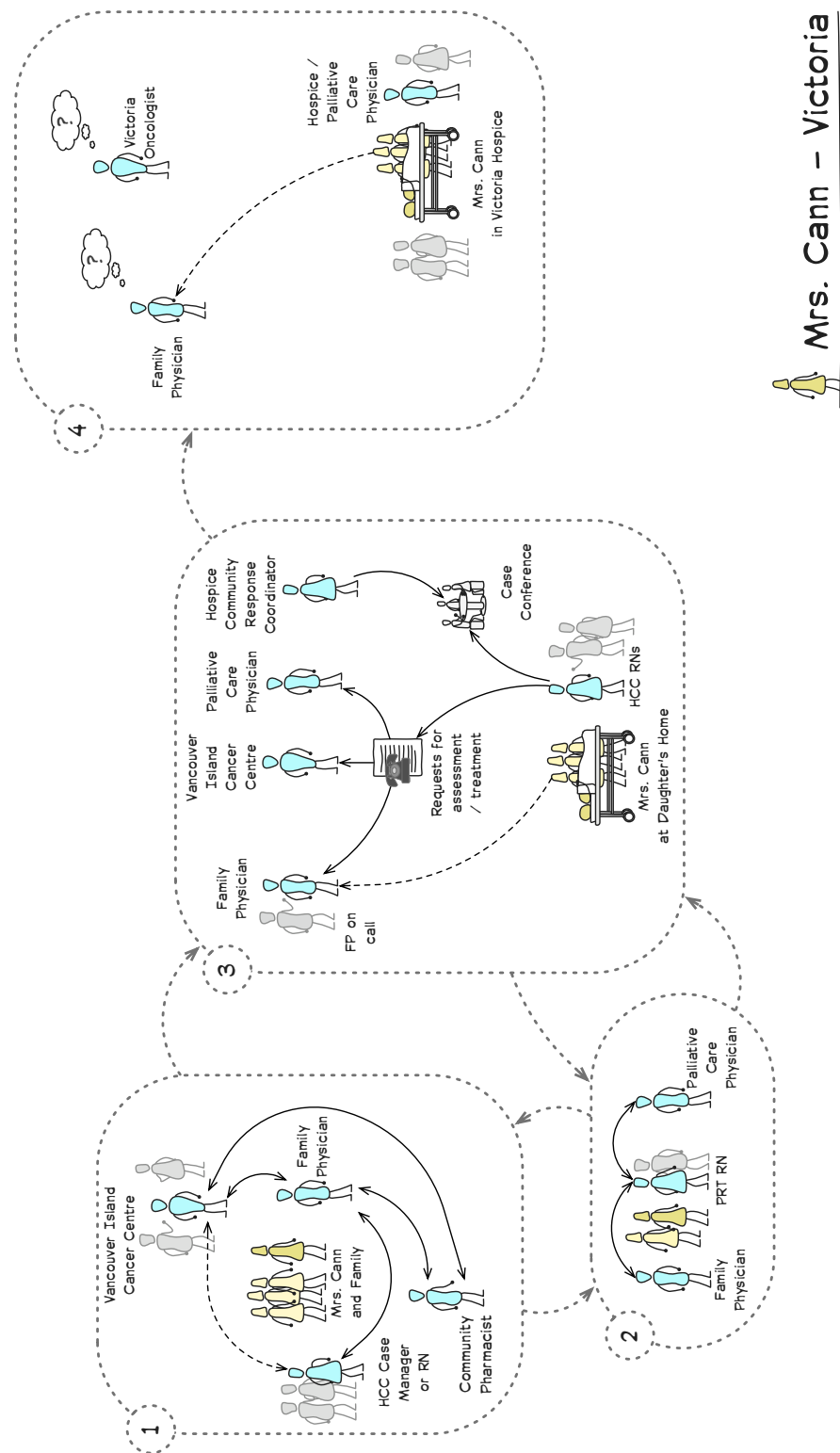


Figure 32: Rich Picture of Mrs. Cann's care in Victoria.

Mrs. Cann – Victoria

This Rich Picture (Figure 32) captures the story of Mrs. Cann in Victoria. It was developed in a consistent manner to the Mrs. Cann in Duncan Rich Picture. This facilitated comparisons between the two communities. Note that Mrs. Cann went through the same four stages. Instead of repeating Mrs. Cann's story in detail, this section highlighted the major differences to Mrs. Cann's story in Victoria, as compared to Duncan.

Stage 1 - Living at Home and Beginning Not to Cope (Figure 33):

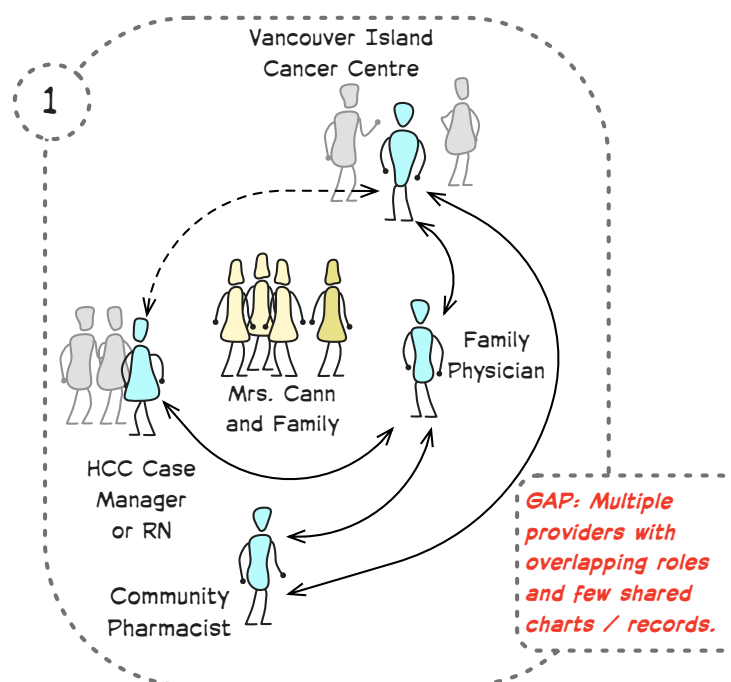


Figure 33: Mrs. Cann is living at home in Victoria. There are several providers in her Circle of Care, most of whom she does to see at their offices / clinics / pharmacies. Her three daughters are actively involved in ensuring she gets to her appointments and has support at home.

Care provision was quite similar in Victoria and Duncan at this stage for Mrs. Cann. The Circle of Care was not as complex in Victoria, the larger centre, as she only needed to visit the BCCA and not the second Cancer Centre in Duncan. The BCCA did, however, take on a more active role in her care, providing more services, as it was easier for Mrs. Cann to

attend the BCCA for additional support. Home and Community Care also registered Mrs. Cann for the Victoria Hospice, although she did not require any hospice services at this time. One other significant difference was that her family physician did not have admitting privileges.

Gaps:

The gaps at this stage were very similar between the two communities, overlapping roles and few shared records, particularly for care planning. Most communication was point to point. The lack of admitting privileges for Mrs. Cann's family physician had little impact at this stage.

Stage 2 – Pain Crisis (Figure 34):

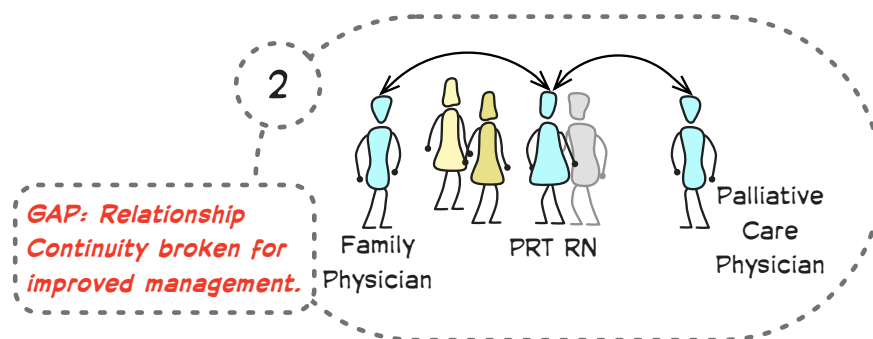


Figure 34: Mrs. Cann has a pain crisis. In Victoria, PRT is engaged from Victoria Hospice and this often averts an admission to the Emergency.

When Mrs. Cann had her pain crisis over the long weekend in Victoria, instead of being sent to the Emergency, the Home and Community Care nurse contacted the Palliative Response Team (PRT). This was the outpatient, urgent response team of Victoria Hospice. There was a highly skilled nurse and palliative counselor on call who were able to attend Mrs. Cann anytime, day or night. They had the back up of a Palliative Care Physician (family physician with additional training). They came in and assessed Mrs. Cann and quickly deployed a

management strategy, supporting the patient for 4 days (typically they stay involved for 3-7 days). They worked with the family physician over the phone, requesting medication changes as needed over that time. The Home and Community Care nurse transferred care to the PRT nurse and at the end of the intervention the PRT nurse transferred care back to the Home and Community Care nurse.

Gaps:

This transition appeared to work quite well. However, when PRT was engaged, this created a brief gap in Relationship Continuity. The Home and Community Care nurse stepped back and the PRT team stepped in. This gap was relatively minor and the Home and Community Care nurse and family physicians were kept engaged, daily, through phone calls and fax updates. This was a trade off between applying focused expert management and ensuring Relationship Continuity. The family physician was kept engaged where possible with faxes and calls and he was asked to write the prescription changes.

“The PRT works really hard keeping the communication between ourselves and the GP open. So when patients are on PRT, we send a fax to the GP, we call during the day to update. We try to use the GP as the first line for ordering medications. It is something we are very aware of, trying to kept the GP in the loop.” (V10)

This appeared to work well as family physicians were more responsive to PRT than to Home and Community Care nurses:

“It’s much easier to engage a doctor on the phone if I call and say I am a PRT.” (V06)

Another gap, which was not illustrated in this version of the story, was when patients were not registered with Home and Community Care³² or the Victoria Hospice. In this case, they could not access PRT. Patients would have gone to the Emergency Department instead of the getting support from PRT. In these cases, care would have been more fragmented, even compared to Duncan. Family physicians in Victoria were often not involved or immediately

³² PRT requires Home and Community Care be involved so they can Transfer Care to someone else after they engage.

notified when patients go to the Emergency. This could be a significant gap and patients like Mrs. Cann might have ping ponged between the Emergency and home in recurrent crises, taken in by different family members and seen by different ER physicians. This could have happened all without the family physician being involved. For this study, the PRT was highlighted to capture this important group of the patient's Circle of Care.

Stage 3 - Staying at Daughter's, Confined to Home (Figure 35):

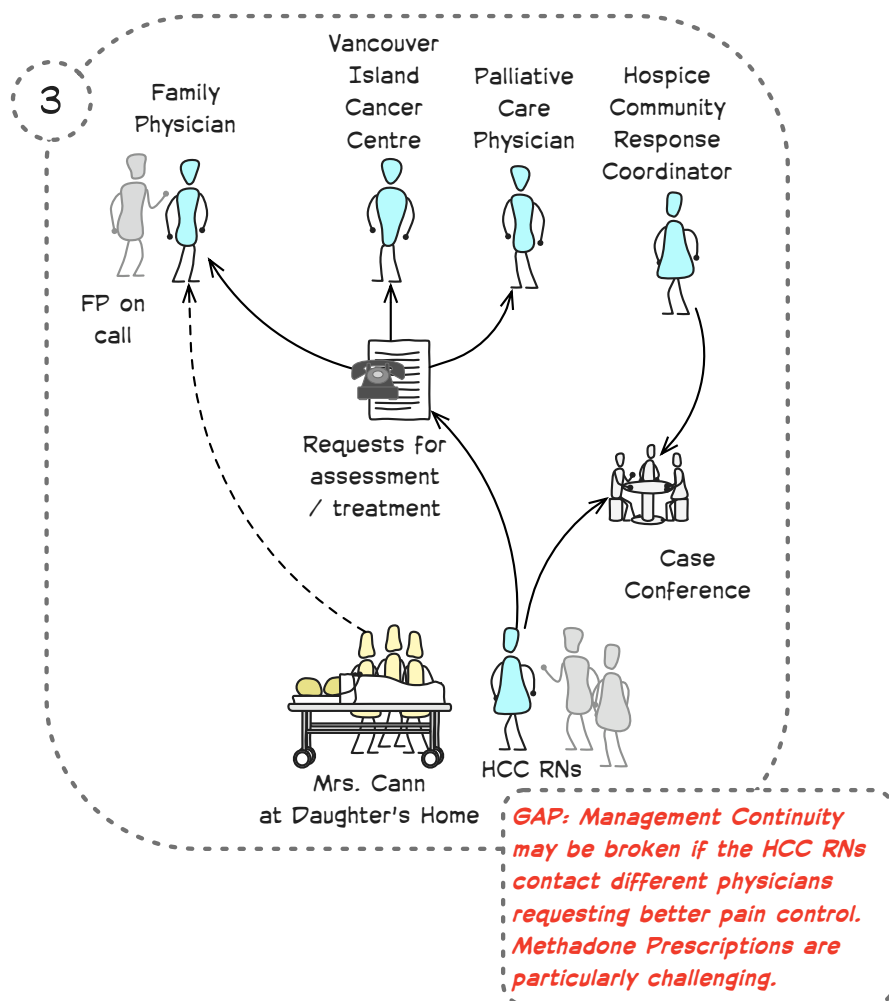


Figure 35: Mrs. Cann is now at her eldest daughter's home and too weak to attend appointments. Home and Community Care nurses are the main providers of care, seeing her daily.

In Stage 3, several months have passed since Stage 2. Mrs. Cann was in her daughter's house, mainly in bed. As in Duncan, the Home and Community Care nurses were now providing the day-to-day care and management for Mrs. Cann. There were several differences between Duncan and Victoria. First, in Victoria Home and Community Care and PRT were able to provide 24 hour / day coverage when needed. Second, family physicians were less likely to perform house calls in Victoria. Much more was completed by phone and fax between the Home and Community Care and the family physician. The family might have visited the family physician's office expressing concerns, such as concerns around pain or food intake, if they are not in regular contact.

Gaps:

As in Duncan, different Home and Community Care nurses may have contacted different physicians to address acute pain issues. They might have contacted the Palliative Care Physician, one of the physicians at the BCCA (oncology of Pain and Symptom Management Clinic physician) or the patient's Family Doctor. The request pattern varied based on time of day, previous experience, and whom the nurse knows. If the Home and Community Care nurse did not get an adequate response, (s)he tried another person. One Home and Community Care nurse felt frustrated, as she did not get a response to many of her faxes to family physicians:

"You request a response to a fax and I'd say at least 50% of the time you won't get any response" (V06)

Family physician support after hours in Victoria was an issue. It was difficult to contact some family physicians after hours. Many did not have on call groups and answering machines that would not accept messages. If this happened, nurses started to look elsewhere. As one specialist commented, supporting his nurse colleagues during the Discussion Groups:

"If I call at 5 o'clock - and I'm calling a family doctor - half the time I won't get them and I won't be able to leave a message...and so if it's a home care nurse calling, she calls someone she knows will respond." (V02)

Family physicians were much less likely to do home visits in Victoria, which was a gap in Relationship Continuity at this stage in Mrs. Cann's disease. The patient relied on other providers more.

Stage 4 - In Her Final Days, Moved to a Facility (Figure 36):

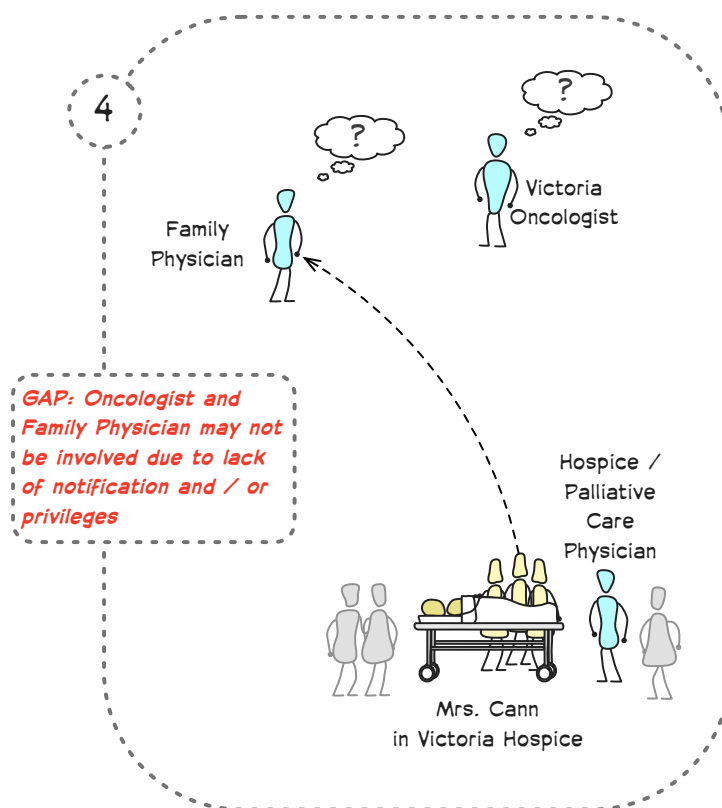


Figure 36: Mrs. Cann is admitted to Victoria Hospice in her final days.

In Victoria, unlike Duncan, there was a 17-bed hospice. Its priority was for community patients who were not coping. While it was busy and not all patients that needed to be

admitted to hospice could be admitted, it was an important service for patients in Victoria at the end of life³³.

When Mrs. Cann experienced her crisis, the hospice community response coordinator was engaged to facilitate the admission to hospice. It was felt that Mrs. Cann's decline could not be managed at home and an admission to hospice was arranged. Mrs. Cann was admitted to Victoria Hospice after a few days. Her Hospice Chart from PRT was available to the providers on the ward. Mrs. Cann's family physician did not have admitting privileges and so did not attend her while she was in hospice. Her oncologist was also not aware of the admission, even though the Vancouver Island Cancer Centre was on the same hospital campus as the Victoria Hospice.

Mrs. Cann's family was able to visit her regularly until she died.

Gaps:

Both family physicians and oncologists expressed that there were gaps in being notified when patients were admitted to hospice.

Family physicians, especially those without privileges, often would not be involved in the admission. Family members were one of the conduits to notify family physicians of these of admissions. Family physicians who were active in the hospital may visit their patients while in Hospice to maintain Relationship Continuity. Family physicians without privileges could also attend, but this rarely happened, according to participants.

"There is nothing to stop them from visiting, to keep the continuity." (V02)

Oncologists also felt that they are not regularly notified of admissions.

"Most of the time, I don't find out [of an admission to hospice]" (V02)

³³ Like in Duncan, patients needing a bed may end up in one of the acute hospitals, or they may end up in one of the private long-term care facilities in Victoria, where palliative rooms are available, if the family physician is comfortable managing them.

While not providing active treatment at this stage, some of the Oncologists stated that they would like to visit Mrs. Cann to provide some support and Relationship Continuity. In the discussion group, it was a surprise to the Victoria Hospice that the oncologists were not being notified.

“You know what, every single admission that comes into Victoria Hospice, I phone the Cancer Clinic and speak to the secretaries...every single admission is called to the Cancer Clinic.” (V10)

This gap was clearly noted by IM/IT:

“We know... that provider identification and relationship ID between patient and provider and who is actively the MRP - or the MRP oncologist - is not always standardized or correct.” (IMIT01)

This concludes the story of Mrs. Cann in Victoria.

Mr. Hart’s Rich Pictures

Mr. Hart was the second Patient Persona that was developed in this study. He was designed to complement Mrs. Cann’s case in several ways: he was male, a non-cancer patient, without family, and he moved to a residential care facility after having a stroke instead of dying at home. The Clinical Case Presentation of Mr. Hart was provided earlier in the methods. For the case of Mr. Hart, he was also revisited at four key points in his last year of life in the interviews.

However, during the interviews, it became clear that there was an important transition that the presentation did not quite capture. Specifically, several providers pointed out that Mr. Hart’s case would be *worse* if, after his stroke, he was discharged home. This was a more significant gap in care. Upon reflection, I decided this transition needed to be captured in the Rich Picture.

Therefore, as Mr. Hart's Rich Picture was being developed, an additional stage was added to highlight the gaps if Mr. Hart was discharged from Emergency back to the community. The five points in his last year of life were:

1. Mr. Hart has Stage III Congestive Heart Failure, Diabetes, and lung disease. He is coping somewhat poorly in the community, fairly isolated.
2. Mr. Hart has his **initial stroke**; it is managed in the ER and **discharged home**.
3. Mr. Hart then has a **second stroke**, managed in the ER and requiring transfer to Long Term Care.
4. Mr. Hart is transferred to Long Term Care facility as rehabilitation not successful enough to safely discharge home.
5. Mr. Hart has his final heart attack while in the facility in the middle of the night and is transferred to the Emergency.

These five stages were illustrated in Figure 37 and were used to describe the story in both communities.

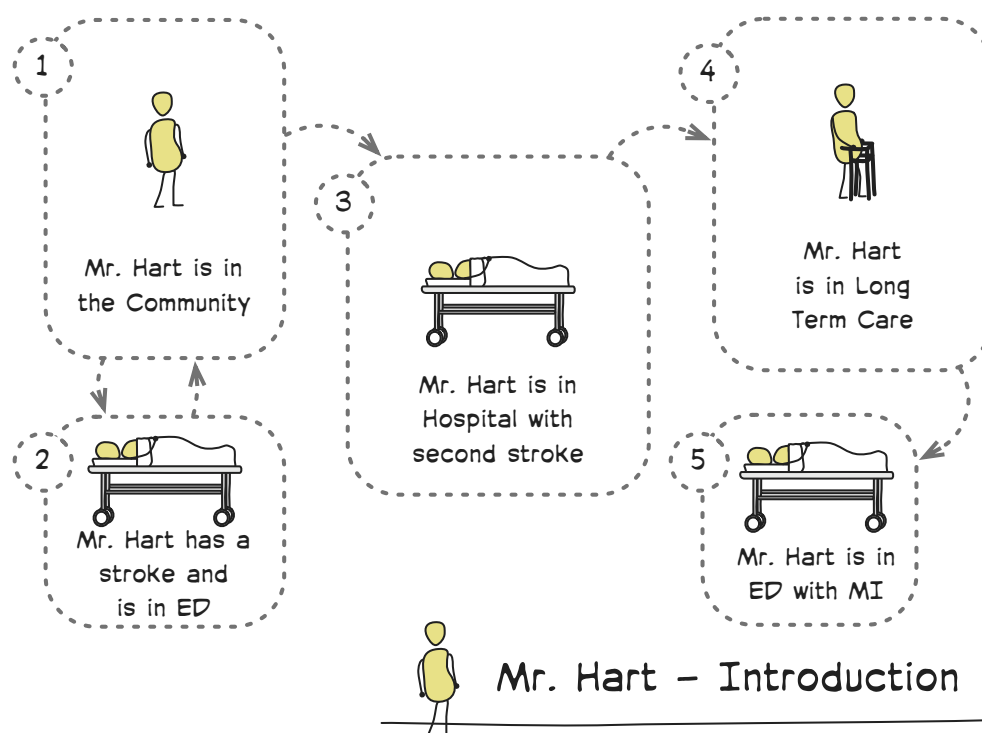


Figure 37: The skeleton framework of the case of Mr. Hart, each provider participant filled in the details through the interviews.

Mr. Hart's detailed Rich Pictures were completed for Duncan (Figure 38) and Victoria (Figure 39). The analysis and descriptions of Mr. Hart's Rich Pictures were detailed in Appendix I. Mr. Hart's Rich Pictures highlighted several other aspects of Continuity of Care for end of life patients that were not apparent in the Mrs. Cann scenario and thus it was useful to have two cases to review with participants.

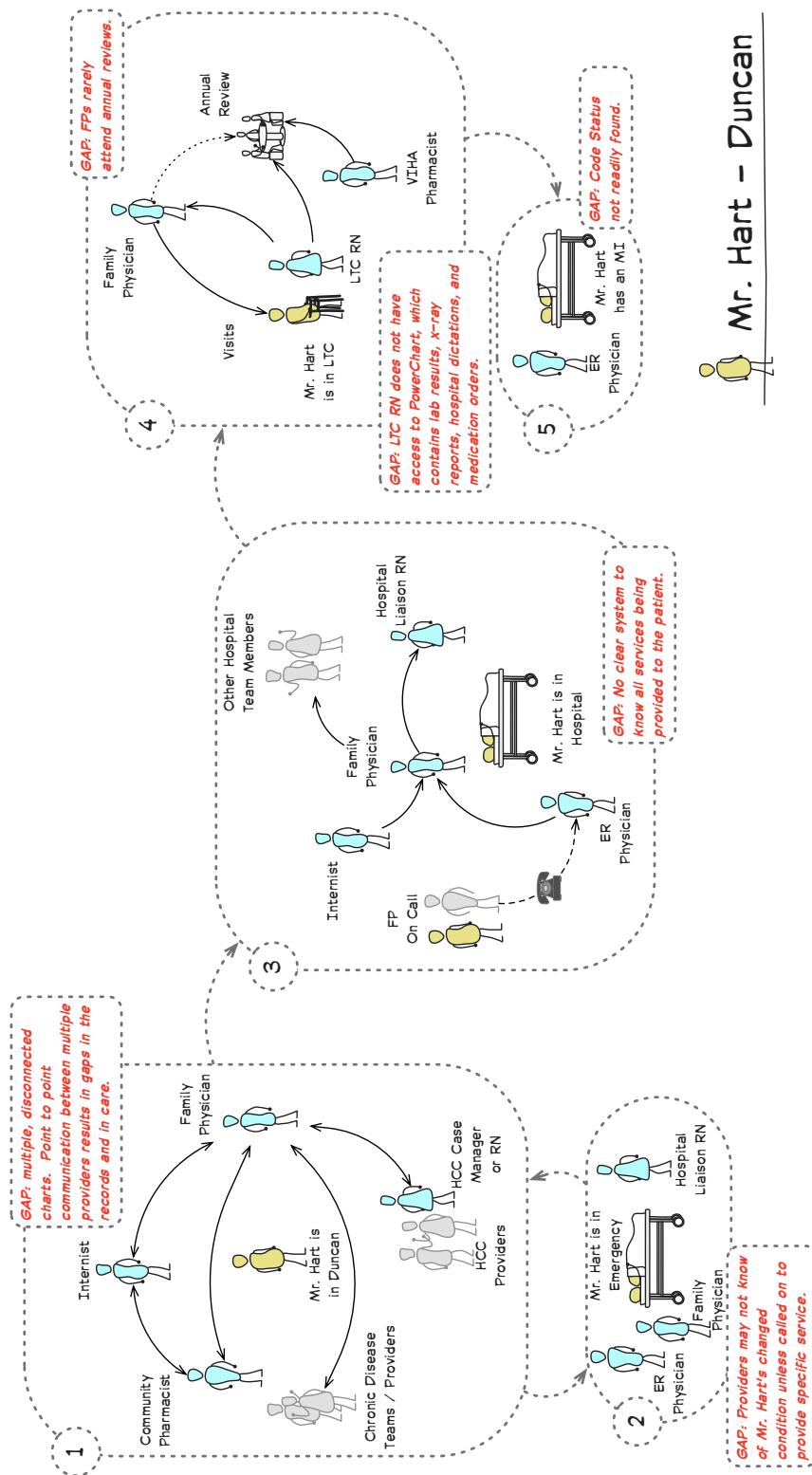


Figure 38: Rich Picture of Mr. Hart in Duncan. Note the lack of nurse access to Cerner PowerChart in Long-term Care and challenges with code status / advance directive availability.

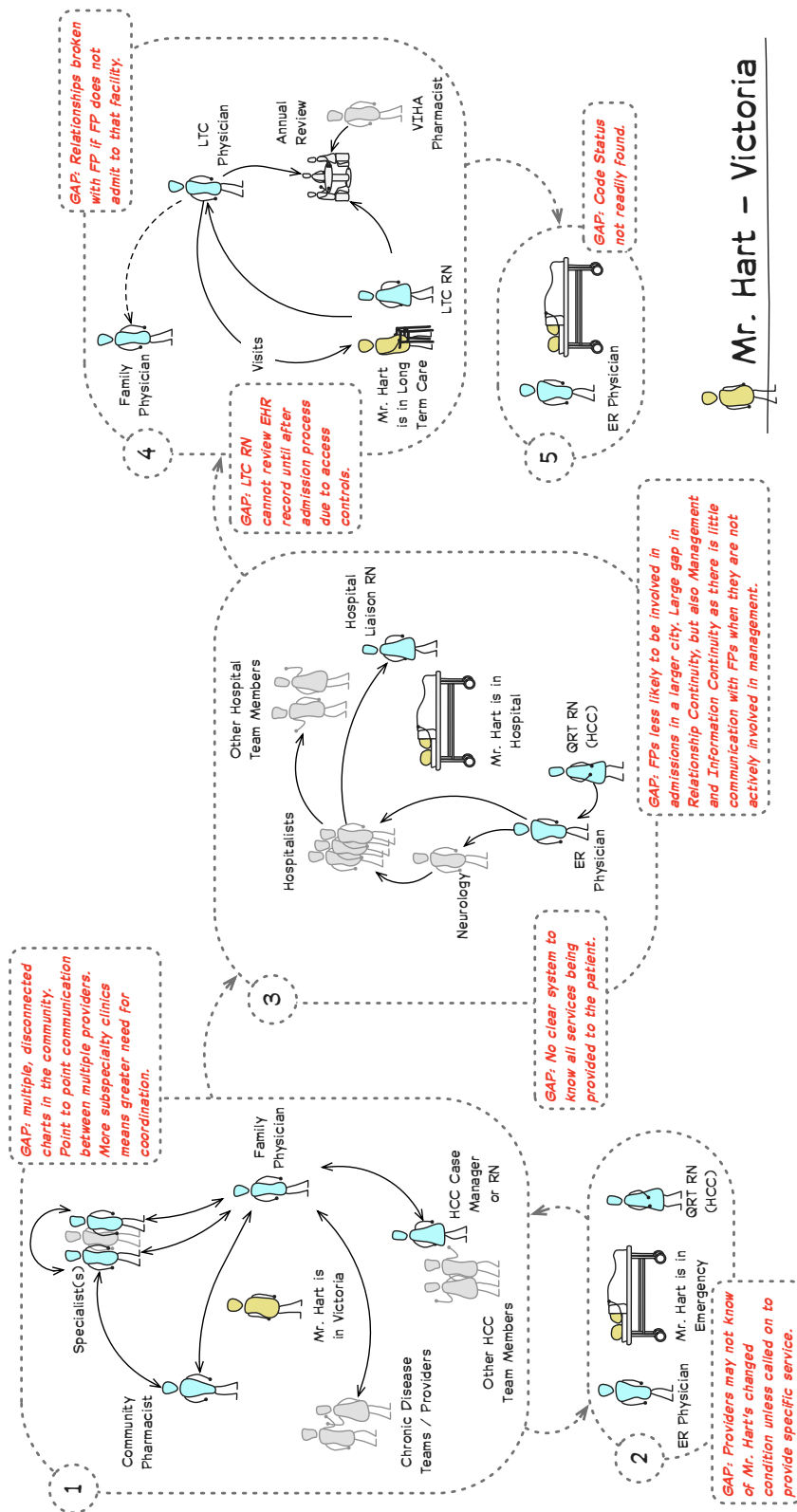


Figure 39: Rich Picture of Mr. Hart in Victoria. Note the lack of family physician involvement in facility care (hospital and long-term care) and challenges with code status / advance directive availability.

When Mr. Hart was ambulatory and living in the community, the gaps were very similar to the Mrs. Cann story – independent charts without a great deal of access – although the particulars of the providers and the charts varied (i.e. no oncologists, but other specialists were involved). The most common form of communication was point-to-point communication. When Mr. Hart was admitted to Emergency, the issue of not knowing the providers in the Circle of Care is similar to Mrs. Cann’s case. However, Mr. Hart’s case highlighted a greater potential variation in providers. There can be, particularly in Victoria, a much greater array of providers in different Care Teams involved in Mr. Hart’s medical care that was seen in Mrs. Cann care. The Cancer Centre was effective in consolidating many of Mrs. Cann’s providers into one team. This made it harder for the ER physicians to try to gather information or notify the correct providers of Mr. Hart’s admission. In Duncan this was less of an issue as there were fewer specialists and subspecialists in the smaller community.

When Mr. Hart accessed hospital care in Victoria in Stage 3, a more significant gap was highlighted. As many family physicians no longer admitted in Victoria, Mr. Hart was not under the care of his own physician, but under a hospitalist. Relationship Continuity, Information Continuity and Management Continuity would have been impacted. This occurred as there was poor communication between the hospital and community based family physicians. This gap was not highlighted with Mrs. Cann as her case was primarily based in the community. However, when she moved into hospice, this gap was noted.

In Stage 4, when Mr. Hart was transferred to Long-term Care (Sunset Lodge), several additional gaps were highlighted. Again, the issue of family physicians not engaged in facility care was apparent in Victoria. Mr. Hart’s family physician transferred care to another physician who provided care to long-term care patients at the Sunset Lodge. This broke Relationship Continuity in order to improve Management Continuity. There were also gaps in physicians attending annual reviews and other case conferences in both communities.

Also, Stage 4 highlighted that long-term care nurses were restricted in their access to information in Cerner in a way that impacted their ability to properly assess patients on admission. The Cerner access model blocked long-term care nurses from accessing charts for patients that were not in their facility. However, for any patient admission, the nurse

needed to assess that patient *prior* to them arriving in the facility. As they were not able to access Mr. Hart's electronic hospital record during the admission, the nurses needed to phone the hospital and speak to the staff there. They also requested received faxes of information that they needed to review Mr. Hart's information during the assessment for admission process. Much of this information could have been available to them in Cerner, with the right access model. This information on Mr. Hart was available to them *after* he was accepted and transferred.

Stage 4 further highlighted that long-term care nurses in Duncan did not have access to the Cerner at all. This meant that they could not get ready access to laboratory results, medical imaging reports, or operative notes on their patients, even when the patients were admitted in their facilities. This was a very significant gap in Information Continuity that challenged the participants in providing care. This gap had been ongoing since the implementation of Cerner in Duncan approximately 8 months prior to this study.

Mr. Hart's final trip to the Emergency with a heart attack brought out, strongly, issues related to the challenges of accessing Advance Directives when they were needed. This gap in Management Continuity was felt acutely by both ER physicians and the long-term care nurses. Both groups commented on the difficulties in finding Advance Directives when needed and also in interpreting them in a timely manner once they were found. This was less of an issue with Mrs. Cann, perhaps because hospice and palliative care were more involved, although the ER physicians felt that lack of access to Advance Directives in the Emergency was an issue for all end of life patients, including cancer patients.

Chapter 12 Continuity of Care

This section highlights how participants in this study viewed Continuity of Care in the context of caring for end of life patients. First, the role of families is highlighted. All three levels of Continuity of Care were supported by findings in the study, plus a fourth level was clearly articulated by the participants, that of Inter-Provider Continuity. This chapter concludes with a reflection on some of the environmental context that impacts continuity.

During the finding out phase of this study and through into the discussion groups, providers and IM/IT participants spoke about Continuity of Care. Sometimes they spoke about continuity in the abstract, but more often they spoke about its importance through actions related to the care that was being provided to our two simulated end of life patients.

Here we appreciate the role of families in end of life care as well as four aspects of Continuity of Care that were highlighted by participants in this study. The first three aspects corresponded to the Haggerty and Reid definition of continuity: Information Continuity, Management Continuity, and Relationship Continuity. There appeared a fourth aspect of Continuity of Care: Inter-Provider Continuity.

As part of the social and political reflection during this study, several aspects became apparent that impact Continuity of Care. These are described in the final section of this chapter on the Environmental Context of Continuity.

Families and End of Life Care

In the study design, I excluded real patients and families from being participants in this study. I did this, not because they are not key members of the Circle of Care, but because of the potential ethical challenges in recruitment. It was simpler to use the simulated patient scenarios and highlight differences in provision of care when there is a family (Mrs. Cann) and when there is not (Mr. Hart) than to try to recruit patients and families matching the profiles. However, participants in this study were clear that families were important to continuity and to care delivery in several ways.

First, providers relied on families for information. This is especially important when patients are making transitions to new Care Teams. When a patient is admitted to a long-term care facility, for example, the nurses rely on patients and families:

“We will get the information from patient and family usually – primarily.” (DO4)

Families were relied on to help with decision making. In the interview, when Mrs. Cann requested to go into a facility, most participants described how they would have recruited at least one of Mrs. Cann’s daughters:

“I’d ask the patient if I could talk to the daughter and get the daughter involved [in the decision to go to hospice]” (V01)

Involvement of some family, especially at end of life, was so intense that some providers noted the importance of counseling about balance. Family members needed to maintain a balance between being a caregiver and being a family member:

“At some point having discussions with them about being care giver vs., you know, daughter in this sort of role.” (D02)

Sometimes, it was difficult for providers to not rely on families, as was the case with Mr. Hart. Providers wanted to contact his lost son or give Mr. Hart some family:

“I’m just thinking generally, rather than Mr. Hart, I was going to say sometimes we’ll get like families who are the advocate, but in his case he doesn’t [have family].” (DO5)

Two participants also related very strongly – and emotionally – to the story of Mrs. Cann. These two participants shared that they were daughters who lost their mothers to cancer. The story resonated strongly for both of them. They shared the strains, the challenges, and tears of providing care. The burden on families at end of life was striking:

“It’s exhausting, for months and...I wasn’t working... that’s what you kind of have to do to be able to do it. Unless you have the supports that will say, ‘You know what, we’ll bring a nurse in for nighttime and you guys can sleep.’ Which is not available.”
(ID REMOVED)

Although excluded from the interviews, patients and families were very much a part of this study and the findings related to Continuity of Care.

Information Continuity

Information Continuity (from Haggerty and Reid’s Continuity of Care model, see Chapter 2) was an important aspect to providing care. Providers were very clear that there were real challenges to maintaining Information Continuity for our two Patient Personas. There were gaps in Information Continuity in multiple locations where care was provided in both communities. Family doctors working outside of VIHA were challenged to get the information they needed:

“Sometimes you get the lab and diagnostics [from the ER] and sometimes you have to go and track them down... I obviously prefer to get the information.” (V01)

Providers within VIHA were also challenged by information gaps:

“The difficulty is that if a person has [private] outpatient labs done, then the outpatient labs do not show up in the [VIHA] Cerner system.” (D06)

A lot of work was done daily to help ensure Information Continuity. Family physicians, specialists and nurses regularly requested copies of old records. Hospital Liaison Nurses pulled daily hospital census records and had them reviewed manually to make sure Home

and Community Care staff were alerted of any Home and Community Care patients that had been admitted or discharged from hospital.

A large information gap existed between VIHA and the BC Cancer Agency. VIHA administrative staff tried to track down cancer care information routinely,

“The [hospice] secretary has to phone medical records at the cancer clinic – which she does, multiple time every day... and then you have to wait.” (V07)

Interesting, this particular gap tended to be felt more from the VIHA side as few VIHA providers have access to the BCCA’s CAIS system. Most BCCA physicians also had VIHA privileges and so had access to VIHA’s Cerner PowerChart. When VIHA providers had multiple roles, sometimes that resulted in improved access to information, such as one provider who had access to systems at both VIHA and BC Cancer agency. One VIHA provider has access to both systems, which had a clear benefit to Continuity of Care and Information Continuity for patients at Victoria Hospice. But that also concerned one of the participants:

“Isn’t that random? It’s too random... it’s a huge gap [not having access to the Cancer Agency information system] because patients assume you have access to that. That it is part of their medical record. They are highly insulted that you don’t have automated access to that.” (V07)

Some providers felt there was a benefit to having an integrated record across domains:

“If we had access to all the written information through one [system], like PowerChart, it would be beneficial for our clientele.” (D07)

IM/IT was aware of some of the information gaps between care settings. They were also aware of the benefits of improved access to information. They had seen these benefits from their of the single, regional, integrated approach to acute care already. They realized, however, that while transitions between hospitals were more integrated, there were still gaps across other care settings:

“There are gaps across the continuum about how those systems and how that information is going to follow a client or patient as they go from home to acute care and back home or to residential care...the strength is that at least the acute care information, the episodes of acute care, are all in one location. Electronic information is available in one location, PowerChart. There is still information that is not available in PowerChart...[lists many kinds of information]...so it is not complete.” (IMIT01)

The information gaps were also nuanced and it was not always clear that something was missing or, if the information was known to be missing, where the missing information could be found. Laboratory results, as an example, a physician’s office record would contain *some* of the results from both private and VIHA labs, but likely was missing some other results (i.e. if they were not copied on the results they would not have received them). VIHA’s Cerner PowerChart, in contrast, had all VIHA labs, both inpatient and outpatient, but none of the private outpatient labs. The VIHA hospital (or VIHA long-term care) paper record might have contained *some* private outpatient labs. This only occurred if someone manually copied results from their office charts. It might also contain copies of some of the results accessible in Cerner PowerChart.³⁴

Hospice dictations were available in Cerner PowerChart, but only for inpatient consultations. If the same physician were to have seen the same patient at home 24 hours prior to an admission, then the consult would be transcribed privately and not be in PowerChart. It would only be available in a Victoria Hospice chart, which is paper and only accessible to a members of Hospice.

Information Continuity was important and there were gaps, participants particularly noted the gaps between settings and organizations. There was considerable activity to help maintain information continuity, but important pieces were often missing.

³⁴ To further complicate the web of results, this manual copying might also have partially duplicated the information in PowerChart when the physician copies portions of his record that contain VIHA results. The chart, then, could contain unique and duplicate results.

Management Continuity

Being able to ensure there were consistent care plans in place (e.g. pain control, congestive heart failure care plans) – and that they were being followed – was another important aspect of continuity. Providers supported the need for better sharing of management plans. However, the current clinical information systems in the region did not support sharing of care plans, as they did the sharing results. Care plans and computerized provider order entry were not available in Cerner or any of the regional clinical information systems.

There were challenges to Management Continuity in both communities and for many of the groups. Plans might not be well communicated and they were not easily available to the providers, even on paper. This was particularly true for providers of unplanned care, such as emergency physicians:

“I don’t know how many times I have to make plans for people, first time I meet them. That frustrates me. I point out to the patients – why isn’t there a plan? Why are you directing traffic yourself?” (V13)

To help ensure that people know the management plans, information was often communicated in many ways, often on paper or verbally and stored in various charts and records. Hospice, which appeared to do this well, spent considerable time ensuring people knew their plans, particularly for outpatient care where they are not continuously involved:

“There is a lot of overlap. You write plans in a lot of different places...and then you go back to the office and dictate a letter.” (V07)

Patients registered with hospice were also given a binder where providers are asked to write plans down (as well as everywhere else). Patients were meant to bring this binder to all appointments and to the hospital so management plans are shared. This was helpful, but not always used: patients might not have remembered to bring the book with them and providers might not have had time to review or document in the binder as well as their own charts.

There was also a lack of understanding of the services provided by different groups. Home and Community Care, in particular, suffered from this.

“The [hospital] nursing staff just seemed to be amazed that we’d been seeing her... I don’t know why they should have been amazed, a lot of them have no idea what we [Home and Community Care] do.” (D07)

Without knowing the scope of practice of one’s colleagues, it is difficult to ensure management continuity.

Most of the orders / care plans were captured on paper. Some plans were captured in transcribed letters that were kept electronically in the regional clinical information systems (e.g. in the Cancer Agency’s Information System or in VIHA’s Cerner). These plans were somewhat buried within documents and not readily accessible without searching for specific authors or documents.

There were no accessible electronic tools to capture advance directives. Although these, too, were also sometimes embedded in different consult letters and transcribed assessments.

Relationship Continuity

For end of life patients, Relationship Continuity was particularly important, or at least it was perhaps more easily observed with this patient population. As patients shifted from the medical treatment model to a symptom management and quality of life model, provider roles changed. Many providers commented that they no longer have a “medical role” in care when patients transition to end of life or to hospice. Still, many wanted to stay involved - for Relationship Continuity, although they described it differently:

“Once they are in hospice...I will go in periodically and see the patient, that’s more for moral support and leave the ordering to the hospice physician” (V01)

“I try to stay involved...I don’t want them to feel abandoned...I often just like to drop in to say hello. I’ve been involved throughout.” (V02)

Relationship Continuity was not only important at end of life. There was significant value when those who know the patient were still involved during many of the transitions of care.

The Emergency Department was one place where this loss of Relationship Continuity was felt, particularly in the larger centre of Victoria. When family physicians did not admit:

“The patient is the loser. The person who really should be there is not there and this is part of this continuity issue. There is nobody in charge anymore.” (V13)

Casual nurses (who rotate shifts and do not stay with patients), walk-in clinics, and hospitalists, were examples raised by many of the participants as system issues that disrupt this kind of continuity.

Capturing the relationships was an aspect that is important to IM/IT:

“Information is critical to understanding the relationships – who is who to the patient and family and who are they in relationship to each other and what roles do they play.” (IMIT01)

PowerChart itself was able to document various patient-provider relationships, which could help other providers in coordinating care. Technology cannot replace Relationship Continuity, but it may help facilitate maintaining the connections between providers to better ensure that providers can play their roles for a patient to their fullest potential.

Inter-Provider Continuity

As the study continued, participants repeatedly mentioned another type of Continuity of Care, which I have named “Inter-Provider Continuity”. Inter-Provider Continuity was related to the relationships *between* specific providers that were caring for the same patient(s). These relationships, specifically between providers in different locations, were seen as an important aspect to supporting the other three types of Continuity of Care. It made communication more effective. Inter-Provider Continuity did seem to be lacking in Victoria:

“There is the more social aspect of the Continuity of Care, ...there seems to be a large disconnect between members of the medical community [in Victoria] in general... Speaking as a community family doc, in terms of cohesiveness... Cohesiveness of the

medical community seems to be missing... I think size is the main problem... you are lost in the shuffle.” (V03)

Duncan appeared more cohesive, even in the Discussion Groups, where people knew each other.

Several participants were very clear that they had activities they do to help maintain Inter-Provider Continuity. One family physician walked through the hospital in a certain way so he can maintain Inter-Provider Continuity:

“I try to have a good relationship with them [the ER Physicians]... when I go to the hospital, I always go through Emergency. That’s my routine. I just say hello to all the guys there, because when I call them, I know who they are. Most of them will call me back.” (V11)

One home care nurse tried to have face-to-face conversations with family physicians, particularly if they shared a complex patient, such as a palliative patient:

“I’ll just drop by [the GP’s office]...so that he knows me... You want the GP to know at least who you are. Understand that I’m not the home support worker.” (D09)

Some relied on relationships developed through previous roles they have had and the relationships developed in those roles. One nurse relied on her previous work at the BC Cancer Agency:

“When I phone one of the oncologists... they know [me], they trust my assessment.” (V06)

The same participant also acknowledged the challenge when you do not know other providers who were providing care to the same patient. This impacted the trust needed to provide care as a team.

“We don’t know each other and so it becomes very impersonal. With this kind of work, there has to be a really high level of trust between professionals and it’s much harder to trust someone you don’t know than somebody you do know.” (V06)

Taking time to develop Inter-Provider Continuity could benefit other members of the care team. Support and education can be provided, for example. Providing support to other members of the Circle of Care was important to at least one participant:

“We [Home and Community Care nurses] don’t have a lot of communication with the [community support] workers... some people are more aware of sussing things out. We had one support worker who was in a panic when she was with somebody who was going through some really bad stridor.³⁵ How do we support them? That’s a huge thing that needs to be re-looked at... when I am in there I try to touch base with them and ask them how comfortable they are with this [supporting a dying patient]. If they tell me they haven’t ever been around somebody who’s died, I can speak to their leader.”
(D12)

The organization of healthcare itself challenged maintaining Inter-Provider Continuity. As family physicians are less likely to admit patients to hospital (due to, in part, financial constraints), there are not the same physical spaces to meet and develop relationships with other physicians. As Home and Community Care relied more on faxes – and family physicians received them from multiple nurses – there was less of an opportunity to develop those relationships. Casual nurses did not have regular patients that they covered. Even separate records and information systems could reduce Inter-Provider Continuity, to a degree.

“The effects of not paying attention to those relationships – because that’s really what our models of care are built around – I hear that all the time...and realizing ‘oh my goodness, we’ve fragmented this journey in a way that’s going to be really hard to piece back together.’ Of course that’s my professional and personal angst around disparate information systems.” (IMIT01)

Process changes were discussed as ways of improving Inter-Provider Continuity. More local, interdisciplinary continuing education events were thought of to get providers out together, face to face. One participant in the discussion group suggested that his community start a

³⁵ Breathing sounds, typically high pitched, due to some level of obstruction or swelling.

series of education sessions for providers, or rounds. These rounds would be set up to help improve provider knowledge of services and would also for a way for people to see and meet each other. He called these “*Know your Community Rounds*” (D02). This was seen as a way to improve Inter-Provider Continuity. Also in the discussion group in Duncan, the participants were very keen to look at how to improve Inter-Provider Continuity between Home and Community Care and family physicians by changing organizational structures.

Environmental Context of Continuity

As part of my analysis, I highlighted some of the social and political issues that were raised, or became apparent, during the interviews and discussions groups. This was part of Soft Systems Methodology. The various contexts were captured in the details of Genre models (see appendices). These were aspects of the clinical community, the organizational structures, or the broader provincial systems that could influence or impact Continuity of Care. These were beyond the control of the study participants and outside the Circle of Care, but they could impact planning and activities that would support Continuity of Care.

Ten aspects of the environmental context became apparent through my social and political reflection; they are described in Table 14. These contexts were important to consider when making suggestions for improvement. They hint at the feasibility – or infeasibility – of certain improvements.

Table 14: Aspects of Environmental Context developed while reflecting on participant interviews during the study.

Aspect of Context	Description	Examples
Availability of Providers	Availability of providers was variably limited in each community.	No palliative trained nurses in Home and Community Care in Duncan providing 24-hour care. Few family physicians with admitting privileges in Victoria at time of study.

Privacy issues and Legislation	Privacy legislation in BC can have a large impact on the use of shared information systems. There were two sets of legislation in BC that relate to private providers (e.g. physician offices) and public providers (e.g. health authorities).	Privacy issues could challenge creating a single repository with records from all providers in the region. This was particularly true when public, private and aboriginal jurisdictions are crossed.
Funding	Funding in many forms impacts Continuity of Care.	There was funding in BC that encourages the adoption of EMRs in the private practice, but these EMRs are not linked to the other systems to share more than laboratory results. Fee for service fees discourage family physicians to continue to admit patients. Organizational budgets restrict 24-hour coverage for Home and Community Care in Duncan. Budget reductions can limit availability of services or IM/IT projects.
Organizational Boundaries	Organizational boundaries impact care and the flow of information.	Despite being on the same physical campus, the Vancouver Island Cancer Centre and the Royal Jubilee Hospital were part of separate organizations, with significant barriers that result. Depending on bed availability, a patient may be admitted to a VIHA long-term care facility or a non-VIHA facility. This can dramatically impact Continuity of Care, both in terms of Information Continuity (no access to PowerChart, for example) and Relationship Continuity (family physician may not have admitting privileges to the VIHA facility but may at a non-VIHA facility).
Professional Practice Standards	Standards often encourage specific communication patterns.	Registered nurses were much more likely to speak with physicians on the phone than other providers (e.g. in Home and Community Care or long-term care) as they can take verbal orders. Physicians prescribe medications and therefore are made aware of pain issue more often than some other challenges in order to change medications.
Local Scopes of Practice	The scope of practice varied in the two communities based on local needs and skills.	Family physicians had admitting privileges more often in Duncan than in Victoria. Family physicians were more likely to do house calls in Duncan.
Physical Proximity of Care / Resources	Not all resources were available in all locations. This was more so in the smaller community.	Radiotherapy was only available in Victoria. Urgent stroke centre only available in Victoria or Nanaimo.

Technical Infrastructure	Technical decisions impacted functionality at different points of care.	Results and reports could be printed in the hospital, but not printed remotely. The technical design precluded allowing printing in private offices, where it was needed. The security design of remote login was perceived as too onerous for some providers to log in routinely.
Organizational Strategies / Priorities / Resources	There are many demands on health services and limited resources. As such, the organizational priorities can impact local projects.	During this study, VIHA was rewriting its Strategy. It was not clear how this might change the priorities of the organization.
Access Policies	The policies around who can access information, what they access, and where they access it from can enhance Continuity of Care, or it can be a barrier.	Not having appropriate access to perform certain duties (e.g. admissions) impacted Information Continuity for long-term care nurses. Remote access to PowerChart or CAIS, when available, was very positively received.

Continuity of Care Summary

Despite not interviewing patients or families, their voices were heard clearly throughout this study and were key to Continuity of Care. Two participants shared their own stories, they each very much lived the experience of being Mrs. Cann's daughter and worked to support their mothers' cancer care and helped navigate the Vancouver Island healthcare system.

Participants supported, through telling their own stories, the three levels of Continuity of Care in the Haggerty and Reid model. They also highlighted to me a fourth form of Continuity of Care that was important to the communication within the Circle of Care, Inter-Provider Continuity. This type of continuity based based on the relationships individual providers had with each other, knowing each other through previous working relationships and other shared patients. It was important aspect to smoothing out processes and enhancing communication to support the other types of continuity. Provider trust was part of Inter-Provider Continuity.

Also, several aspects of the environmental context were found to support or challenge Continuity of Care as patients moved across care settings during their journey of care. These elements were not part of the Circle of Care, but could influence the system. These findings helped inform our understanding of Continuity of Care for end of life patients and for continuity in general.

Chapter 13 Abstracting Genres

This chapter describes the process of reviewing the specific Genres in the study and developing a set of Abstract Genres. Detailed examples of three Abstract Genres are provided, followed by a summary of the complete set of ten Abstract Genres, with examples descriptions of how the ten Abstract Genres are unique to each other.

Abstracting the Genres

One of my objectives for this study was to create a Genre collection and map of the various Genres used to support Continuity of Care. As the study progressed, many individual Genres were discovered. Participants described their communication with other providers and I reviewed the various catalogues of pre-printed paper forms that were made available. It became increasingly clear to me that a large catalogue of individual Genres might not be as useful to others as originally thought. It would have been exceedingly large. Many Genres were ad hoc with an informal structure, but with a clear purpose. Many of these individual Genres had similarities.

In order to make sense of the findings, for the modeling process initially, I attempted to abstract the commonalities of the specific Genres. This generated a set of Abstract Genres related to maintaining Continuity of Care. These proved useful in the modeling of communication (see Chapter 14 on Conceptual Modeling). I thought that the Abstract Genres would be more useful than an exhaustive catalogue.

The process to derive the Abstract Genres was captured in Figure 40. As part of the interview analysis, the specific Genres of communication were captured. Those were

collected into groups of similar Genres based on *purposeful activities*. Purposeful activity was a concept from Soft Systems that was used to break down analyses into appropriate systems and it proved to be an effective way to abstract Genres. By grouping specific Genres by purposeful activity, I developed a set of Abstracted Genres. During the development, constant reflection on the set of Abstract Genres was required to confirm the differences between the Abstracted Genres. Abstract could continue until there was a single Genre. The abstraction goal for this study was to develop a manageable set of seven (plus or minus two) communication patterns. until there was a single Genre. The abstraction goal for this study was to develop a manageable set of seven (plus or minus two) communication patterns. These Abstracted Genres categorized the individual activities into recognizable patterns of communication that supported Continuity of Care. Ten Abstract Genre were developed.

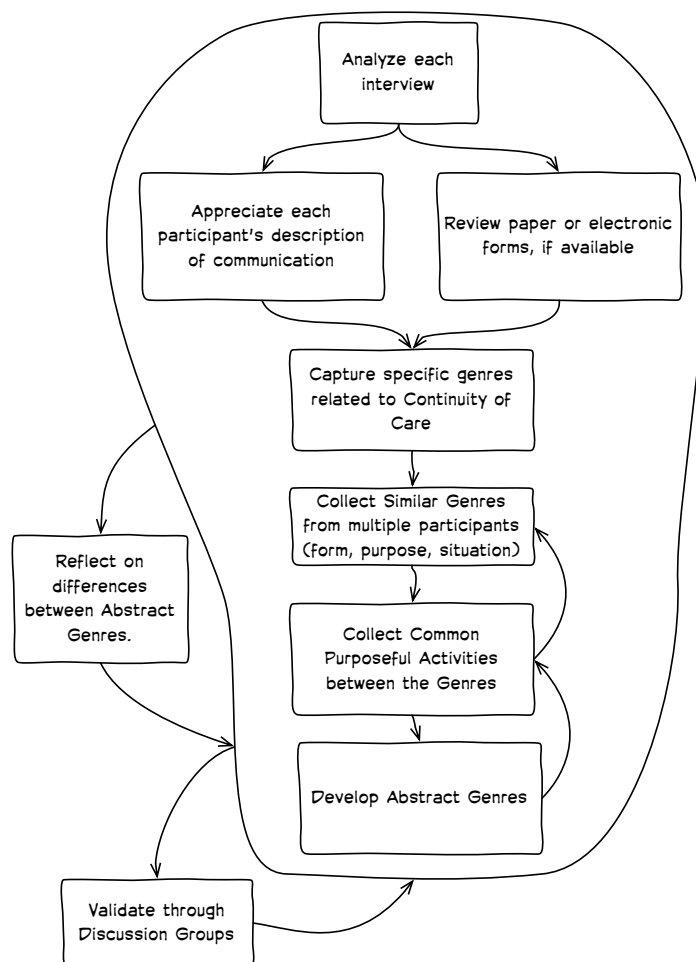


Figure 40: Process for developing the Abstract Genres. Note that this was happening in parallel with other analyses during the interviews.

Development of Three Abstract Genres

The complete set of Abstract Genres is described in detail in Appendix J. The development process followed is illustrated here using three Abstract Genres. This section was designed to provide the reader details from the development process outlined in Figure 40. The three Abstract Genres described here are *Request Assessment / Treatment, Order, and Transfer Care*.

Request Assessment / Treatment

All analysis began with reviewing the participant interviews and any paper forms that were made available. The family physicians were interviewed early and they collectively described some specific Genres. For example, they were consistent in what they would do with Mr. Hart's suspected acute stroke:

"I'd be calling the Emergency Physician here and saying there is a patient of mine coming in for assessment - suspect stroke." (D01)

"I would pick up the phone and speak to...the ER Physician and say 'look I have got here Mr. H. and here is his history and he seems to have experienced a neurological event and may need a CT scan and he has unsteady gait and I am going to send him in.'" (V11)

This was a common communicative act between providers, not just for family physicians, but also for other providers who would see Mr. Hart with an acute stroke:

"I would phone the GP and then send [Mr. Hart] to Emerg, because the GP would say send him to Emerg...we do try to give them the heads up...I would phone them and just say I am sending you this gentleman. This is what's going on, he lives alone, and this is what the findings are and they would take it from there." (D08)

In each case in the scenario, providers would have communicated with Emergency, providing information about the patient and requesting that the ER physician assess and treat Mr. Hart and his suspected stroke.

Other similar situations in both scenarios resulted in similar types of communication between providers. There are similar referrals to Home and Community Care:

“There’s the 1-877 number in Nanaimo...that you phone and do a referral and they do an assessment [for home care].” (D13)

“Usually the referral [requesting Home and Community Care] would come from the GP” (D08)

When a member of Home and Community Care needs to consult another member of the Home and Community Care Team, he / she uses a specific “Client Update” form (Figure 41).

There were several other similar forms of communication. They were applied in different settings and varied in form (e.g. phone, paper forms, written notes), but these specific Genres were similar to each other in their intent. Their intent, or *purposeful activity*, was to request that another provider examine a specific aspect of the patient’s condition and, through their interpretation either provide an assessment or treatment. These were collected together to then describe the Abstract Genre *Request Information / Treatment*. There were several other requests to other providers that did not fit into this Abstract Genre.


		Home & Community Care CLIENT UPDATE Revised May 2008		Affix Client Information Label Here Client Name: _____ Client Number: _____																			
<input type="checkbox"/> Information Only <input type="checkbox"/> Consultation Only <input type="checkbox"/> Demographic Change <input type="checkbox"/> Client Grouping Change > > > > > > > > <input type="checkbox"/> ACTION REQUESTED				<table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="text-align: left;">Current</th> <th></th> <th style="text-align: right;">Change</th> </tr> </thead> <tbody> <tr> <td><input type="checkbox"/></td> <td>1A Acute</td> <td style="text-align: right;"><input type="checkbox"/></td> </tr> <tr> <td><input type="checkbox"/></td> <td>1B End of Life</td> <td style="text-align: right;"><input type="checkbox"/></td> </tr> <tr> <td><input type="checkbox"/></td> <td>1C Long Term Supportive</td> <td style="text-align: right;"><input type="checkbox"/></td> </tr> <tr> <td><input type="checkbox"/></td> <td>1D Maintenance</td> <td style="text-align: right;"><input type="checkbox"/></td> </tr> <tr> <td><input type="checkbox"/></td> <td>1E Rehab</td> <td style="text-align: right;"><input type="checkbox"/></td> </tr> </tbody> </table>		Current		Change	<input type="checkbox"/>	1A Acute	<input type="checkbox"/>	<input type="checkbox"/>	1B End of Life	<input type="checkbox"/>	<input type="checkbox"/>	1C Long Term Supportive	<input type="checkbox"/>	<input type="checkbox"/>	1D Maintenance	<input type="checkbox"/>	<input type="checkbox"/>	1E Rehab	<input type="checkbox"/>
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TO All involved clinicians: _____			Client's Physician: _____																				
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Priority (refer to Priority Setting Guidelines on back) <input type="checkbox"/> High (0-2 days) <i>Client unstable</i> <input type="checkbox"/> Med (3-7 days) <i>Client is stable but may be at risk</i> <input type="checkbox"/> Low (8-21 days) <i>Client is stable and not at immediate risk</i>				<input type="checkbox"/> Phone <input type="checkbox"/> Visit by Date:																			
Rationale for Priority: <input type="checkbox"/> Falls risk: high risk of sustaining injury <input type="checkbox"/> Low PPS score: rapid deterioration; urgent symptom management <input type="checkbox"/> Acute Care discharge requiring follow-up <input type="checkbox"/> Skin Integrity risk: break down/worsen without intervention <input type="checkbox"/> ADL or <input type="checkbox"/> IADL: difficulty / unsafe <input type="checkbox"/> Caregiver: decreased capacity <input type="checkbox"/> Cognitive Status: rapid deterioration <input type="checkbox"/> Nutritional risk <input type="checkbox"/> Abuse or Neglect: suspected or evidence of: <small>Mark priority as High. Implement <u>HCC Response to Suspected Abuse, Neglect, or Self-Neglect</u> guideline.</small>																							
Reason for Referral: _____																							

Figure 41: Portion of the Home and Community Care Client Update form, which is used by the nurse to Request Assessment / Treatment from another member of the Home and Community Care team, such as the social worker or occupational therapist. Note that this form can also be used just to provide information.

Order

In the analysis of the interviews, another form of communication that occurred was the *Order*. Order was similar to the Request Assessment / Treatment; however, it was distinct in that it was more explicitly focused on the delegation of specific tasks to be performed and not about requesting providers develop an assessment or treatment plan. Instead of requests for assessment, this communication pattern contained specific elements of a treatment plan. They were the result of an assessment by the initiating provider. Physicians wrote prescriptions for pain medication that were sent to the pharmacists. Oncologists wrote chemotherapy protocols that were then run by pharmacists and nurses. Home and Community Care nurses would delegate care tasks to community support workers (Figure 42):

“We would put a Care Plan in, she [Community Support Worker] would have very specific things she would be doing...they read their Care Plan and know what they are supposed to be doing.” (D09)

“If we have somebody in the home who can’t remember to take their medications and have their medications in blister pack. I can delegate a CHW [Community Support Worker] to give the medication out of the blister pack at breakfast, lunch, and supper and bedtime as per the blister pack...I write up an order for them to do that.” (V08)

To: Administrator _____	Request Date _____
Agency Name _____	Fax# _____
FOR:	
<div style="border: 1px solid black; padding: 5px; width: fit-content;"> <p>Affix Client Label</p> </div>	Able to Direct <input type="checkbox"/> Unable to Direct <input type="checkbox"/> Care Level _____
Your Agency has agreed that home support staff will provide the Nursing, Rehabilitation or Nutrition function(s), transferred according to the Ministry of Health Guidelines, Section II, which are for the exclusive use with the above client and shall not be modified, nor used with another client. It is understood that the home support worker providing care will be given client specific teaching. The Agency will provide continuity of care through the assignment of specific caregiver(s). Section II Tasks must be taught directly by the Health Care Professional to the specific caregiver(s) providing the care in the presence of the Agency RN Supervisor/Group Home Manager for HSCL clients, and physiotherapy, occupational therapy and nutrition tasks.	
1) _____ _____	
2) _____ _____	
3) _____ _____	
(Detailed Care Plan attached if applicable)	

Figure 42: Section of the Delegation / Transfer of Function Home and Community Care form.

The community support workers, pharmacists, and nurses in these examples performed these tasks based on the explicit delegation or request from another provider. Notice in Figure 42, the statement “*shall not be modified*”. These specific Genres were related in their

intent to delegate specific tasks to other providers.³⁶ *Order*, then became another Abstract Genre, based on the purposeful action to delegate tasks to more appropriate providers.

Transfer Care

The third Abstract Genre is *Transfer Care*. Most of the physical transitions of care required some handover between some or all of the providers. *Transfer Care*, then, was about releasing one's own care responsibility for that patient to another provider. Where as Request Assessment / Treatment engages another provider in care and Order delegates tasks, this Abstract Genre is about releasing overall responsibility and transferring to another provider. The ER physicians, once they stabilize patients, like Mr. Hart, they would request an admission under another provider:

“He’s [Mr. Hart after his second stroke] a fairly slam dunk hospitalist patient...what we would do is speak to the intake hospitalist...[to admit].” (V12)

When Mr. Hart is transferred to a facility where his family physician does not admit, there is transfer to a family physician who does have privileges at that facility:

“They usually have the house physician, who will then assume care [of Mr. Hart]...discuss him by phone, send him critical or relevant records from the chart.” (V03)

Transfers could be permanent or temporary, such as handover for nursing shift changes or from the family physician to the on call physician. The intent of each of these specific Genres is to hand off responsibility to another provider and step away from providing care.

³⁶ Clearly patient safety should supersede an Order and this was seen in the discussions with participants. Delegated providers were expected to follow tasks, but not at the obvious risk to patients. Pharmacists would review prescriptions and, if there was a dosing error they would call the physician for clarification or change, as an example.

This is different to either of the other two Abstract Genres described above where the initiating provider is still involved in the care of the patient.

A Set of Abstract Genres

From the analysis, a set of Abstracted Genres was developed. The details of these Abstract Genres were captured in the appendices. The set of Abstracted Genres were summarized below in Table 15, with examples from the interviews were also included. These Abstracted Genres covered several types of communication, including: person-to-person information sharing, sharing information through shared records, requesting advice or service, and developing common mutual understanding and plans. The differences between the Abstracted Genres are highlighted in Table 16.

Table 15: Summary of the Abstracted Genres discovered in this study with their purposeful activities and examples.

Abstracted Genre	Purposeful activity	Examples
Communicate with Patient / Family	Communicating with the patient to examine the patient's condition, share information, educate, and to develop a common understanding or plan.	<ul style="list-style-type: none"> • Mr. Hart visits his family physician • Home and Community Care nurse Home Visit with Mrs. Cann and family. • Phone conversation from Mrs. Cann's daughter with the on call family physician when patient is in pain crisis. • Medication reconciliation by a pharmacist or nurse. • Duncan Home and Community Care's "Keeping In Touch" program of phoning isolated patients like Mr. Hart before they require significant Home and Community Care services.
Request Historical Information (PMHx) ³⁷	Seeking additional information from a particular provider, care team, or organization.	<ul style="list-style-type: none"> • Specialist requests previous bloodwork on Mr. Hart from family physician. • Home and Community Care or Hospice requests previous consult letters about Mrs. Cann from Cancer Centre.

³⁷ PMHx = Past Medical History

Provide Information	Ensuring other providers are aware of current findings and plans by sending information directly to named members of the Circle of Care.	<ul style="list-style-type: none"> Follow up letter to family physician from Oncologist on change in chemotherapy. ER Physician note to GP after patient is seen in the Emergency. Home and Community Care Case Manager fax to the family physician to inform the family physician that Mrs. Cann is receiving 4 hours per week of home support.
Document in Shared Record(s)	Documenting findings/plans as part of care delivery that is also in a location that is accessible to other members of the Circle of Care ³⁸	<ul style="list-style-type: none"> Neurologist documenting in Mr. Hart's Hospital chart. Family physician documenting in Mr. Hart's long-term care paper chart. VIHA Laboratory placing a result into Cerner.
Review Shared Record	Review information shared by other members of the Circle of Care to increase knowledge of patient's condition	<ul style="list-style-type: none"> Family physician reviews Mr. Hart's paper record when rounding on patients in long-term care ER Physician reviews PowerChart prior to seeing Mrs. Cann in the ER. Oncologist reviews BCCA records (electronic and paper) prior to seeing Mrs. Cann for follow up visit. Pharmacist reviews Mrs. Cann's PharmaNet profile.
Request Advice	Request information and advice about options related to a patient case without engaging an additional provider into the Circle of Care (i.e. through a Request for Assessment / Treatment)	<ul style="list-style-type: none"> Call to palliative care hotline to discuss medication options and conversion doses. Call to see what services might be available for particular type of patient. Call to Palliative Care Coordinator to discuss palliative care bed options without naming patient.
Request Assessment / Treatment	Contact another provider to request an action to assess and/or provide treatment/recommendations to a patient based on their assessment.	<ul style="list-style-type: none"> Family physician consults geriatrics for Mr. Hart in nursing home to assess behavioural issues. Home and Community Care nurse sends Internal Referral to physiotherapy and occupational therapist to assess what can be done to make house safer for Mrs. Cann. ER Physician calls neurology to assess Mr. Hart when he has had a stroke.

³⁸ Not all shared records were shared amongst all providers, indeed in this study there were multiple shared records but these were variably available to members of the Circle of Care depending on role, physical location, and privileges. No shared record was available to all members of the Circle of Care in this study.

Order	Request specific activity be delegated to / performed by another provider	<ul style="list-style-type: none"> • Prescription for Mr. Hart from MD to pharmacist. • Home and Community Care nurse delegated medication administration to Community Support Worker for Mrs. Cann. • Mr. Hart's Advance Directive to any provider in the future.
Transfer Care	Handing off care responsibilities between care providers of a similar capability.	<ul style="list-style-type: none"> • Nurse handover of Mr. Hart at shift change in long-term care. • Family physician to family physician transfer of Mrs. Cann, when on call. • ER physician transfer to family physician admission in hospital once Mr. Hart is stabilized, post stroke.
Coordinate as Care Team	To review, in real time with more than two individuals, the status and plans for the patient from multiple viewpoints.	<ul style="list-style-type: none"> • Long-term care Annual Review of Mr. Hart. • Breast cancer Oncology Rounds to discuss Mrs. Cann's treatment options. • Palliative Care Rounds at Victoria hospice to discuss pain control for Mrs. Cann. • Meeting with family physician, Home and Community Care nurse and family to discuss Mrs. Cann's prognosis.

Table 16: A description of the key distinguishing factors of the Abstract Genres.

Abstracted Genre	Key Distinguishing Factors
Communicate with Patient / Family	This captures all communications with the patient and or family. All other Genres are related to seeking information / sharing information with other providers. <i>Coordinate as Care Team</i> is the only other Genre that explicitly includes the patient or family and that includes additional providers.
Request Historical Information (PMHx) ³⁹	Requesting from a specific organization, historical information. Distinct from <i>Review Shared Record</i> in that the request is explicit and is reviewed by someone from that organization for appropriateness. This also, typically, creates delays that were a common issue.
Provide Information	Sending information specifically to one or more other named providers or groups. Unlike <i>Document in Shared Record</i> , this provides a level of control and requires forethought into who in the Circle of Care would benefit from having access to this information. Information is often tailored to the recipient.
Document in Shared Record(s)	Recording information in a common location. In this Genre, sharing is implied not explicit, unlike other Genres (e.g. <i>Provide Information</i>). Another provider may access information in a Shared Record without your control.
Review Shared Record	Accessing a record that is shared. This is the compliment to <i>Document in Shared Record</i> . This is the only Genre where a provider can collect information, such as previous observations or current plans without either <i>Communicating with Patient</i> to learn, or explicitly <i>Requesting Information</i> from another provider. Access to the shared record is based on previously established role or position.
Request Advice	Request information and advice from another provider. This Genre is unique as it is an important aspect to establishing consistent diagnoses and plans, but it does not involve communication with a provider within the Circle of Care. It may well lead to <i>Request Assessment / Treatment</i> , but it does not have to.
Request Assessment / Treatment	Request another provider engage in management decisions with a patient, typically around a specific issue (e.g. consultation to a cardiologist from a family physician). Unlike <i>Orders</i> , this Genre is more focused on engaging providers to assess and manage a specific issue. <i>Request Assessment / Treatment</i> is also different from <i>Transfer Care</i> as the requesting provider does not stop their relationship or hand over all responsibility to the other provider.
Order	<i>Order</i> describes a specific activity that is to be performed by another provider. While somewhat similar to <i>Request Assessment / Treatment</i> , <i>Orders</i> are task focused vs. assessment focused. <i>Order</i> has less context, typically, and are more explicit in the activities expected.
Transfer Care	Signing over care responsibilities to another provider, either temporarily or permanently. <i>Transfers</i> are often between similar providers (e.g. handover of patients between nurses at end of shift). Unlike <i>Request Assessment / Treatment</i> , with <i>Transfers</i> , the provider removes him or herself from an ongoing or at least active care responsibility for the patient.
Coordinate as Care Team	Real time discussion between at least three providers, or two providers and patient / family. This allows more cohesive discussion from multiple viewpoints. This is the only Genre that includes more than two providers. It may be followed by any of the other Genres to further ensure continuity, such as <i>Document in Shared Record</i> , <i>Request Assessment / Treatment</i> , and <i>Orders</i> .

³⁹ PMHx = Past Medical History

Mapping Abstract Genres to VIHA's IM/IT Regional Infrastructure

As part of the Finding Out phase of this study, VIHA IM/IT documentation was reviewed to understand current and planned functionality (VIHA, 2007) (VIHA, 2009c). This included functionality currently included in VIHA's primary regional CIS, Cerner, but other regional components were also reviewed (e.g. regional PACs, VIHA's regional telehealth program). One of my study objectives was to compare the Genres to the current IM/IT CIS implementation. This was an important step to developing the suggested improvements. The Abstract Genres were compared to current IM/IT Infrastructure (Table 17). This provided a framework from which to discuss with IM/IT and other providers when we could develop Suggested Improvements.

Table 17: A description of how the VIHA CISs, at the time of this study, support the Abstract Genres.

Abstracted Genre	Support in VIHA's CISs (as deployed at the time of the study)
Communicate with Patient / Family	GAP - At the time of the study there were no tools implemented that support communication with patients / families.
Request Historical Information (PMHx) ⁴⁰	GAP - Requests were made through phone / fax / paper in VIHA. However, as the regional repositories are developed, more information is available through shared records (see Review Shared Record).
Provide Information	The VIHA system allowed for certain information to be distributed to other providers. Outpatient laboratory results, medical imaging, and transcribed documents (such as procedure note, consultations, discharge summaries) can be provided to others. Some was electronic, some was distributed on paper.
Document in Shared Record(s)	Select providers could document in the regional clinical information system, Cerner. This was limited to a variety of transcribed documents ⁴¹ and twelve specific electronic forms ⁴² . VIHA planned a Clinical Documentation Strategy that was beginning in 2009 and will last at least three years.
Review Shared Record	Through the clinician user interfaces, e.g. PowerChart, most providers had the ability to review the shared record. Some did not, as noted in the recommendations for improvements.

⁴⁰ PMHx = Past Medical History

⁴¹ Not all transcription is stored in Cerner. Several outpatient services use other dictation services. BCCA uses their service. A private company transcribes outpatient consultations as Victoria Hospice. Neither is placed in Cerner.

⁴² Only the ER Nurse Triage Form was relevant to the scenarios developed in this study.

Request Advice	GAP - There were no implemented features within the current installation of Cerner to support this Genre. There were tools that would support ad hoc communication between providers that could, in the future, support this Genre. Email could be considered a tool for this. Interestingly, one of the participants in the study has developed and was running a set of telehealth rounds to provide a forum across the region between family physicians and medicine sub-specialists to discuss cases in the abstract, directly supporting this Genre.
Request Assessment / Treatment	GAP - There were no orders within the existing CIS where providers can request assessments / treatments. This was planned for future release future as part of a CPOE project. Telehealth was being used to support some requests for assessment. Specifically, a new telestroke project was started during this study where ER physicians can request a remote consult with the Neurologist on call in Victoria from several remote places on the Island.
Orders	GAP - There was no computerized provider order entry currently in VIHA, although this can be supported by the Cerner application. Orders were written on paper. They were re-keyed into Cerner by departmental technicians (in lab, medical imaging and pharmacy).
Transfer Care	Currently transfers of care were completed in person and orders were written (if needed). For inpatients, data entry clerks updated the Cerner encounter record to reflect the changes.
Coordinate as Care Team	The developing telehealth program provided some virtual case conferencing.

Abstract Genre Results Summary

This chapter described the set of Abstract Genres that was developed by grouping related specific Genres discovered in this study by *purposeful activity*. I felt that this was an important step for this study to better support the analysis of communication between providers.

These Abstract Genres proved useful for keeping the complex figures comprehensible to the IM/IT participants and to the participants in the Discussion Groups (see Chapter 14). They also provided a description of the set of communication patterns that were used to support Continuity of Care in my study. Although they were developed from this single study and need further refinement, they may have descriptive and predictive power in other settings (see Chapter 19). The VIHA IM/IT infrastructure only covered a portion of the Abstracted Genres, this suggested possible areas where there could be improvements.

Chapter 14 Three Conceptual Models to Describe the Circle of Care

This chapter describes the three conceptual models of each patient's care system that were developed through this study. The three models were developed to support the three views of the Circle of Care: the Provider View, the Communication View, and the Information / Repository View. All models are patient centric and, thus, they all have the patient in the image.

Modeling The Provider View

I developed a picture of the members of the Circle of Care for each Patient Persona in each community; these were the Provider Views of the Circle of Care. Modeling was iterative and began with the first interview. The modeling process has been described in Figure 43.

First, each participant described whom he or she saw in the Circle of Care as part of the interview. Each participant was asked to describe each patient's Circle of Care as each patient's story progressed. I collected the findings from participants of the same role (e.g. family physicians). Each role's perspective of the Circle of Care was modeled as a simple view of the members of the Circle of Care. In Soft System's terminology, these diagrams described that provider role's *worldview* of the Circle of Care.

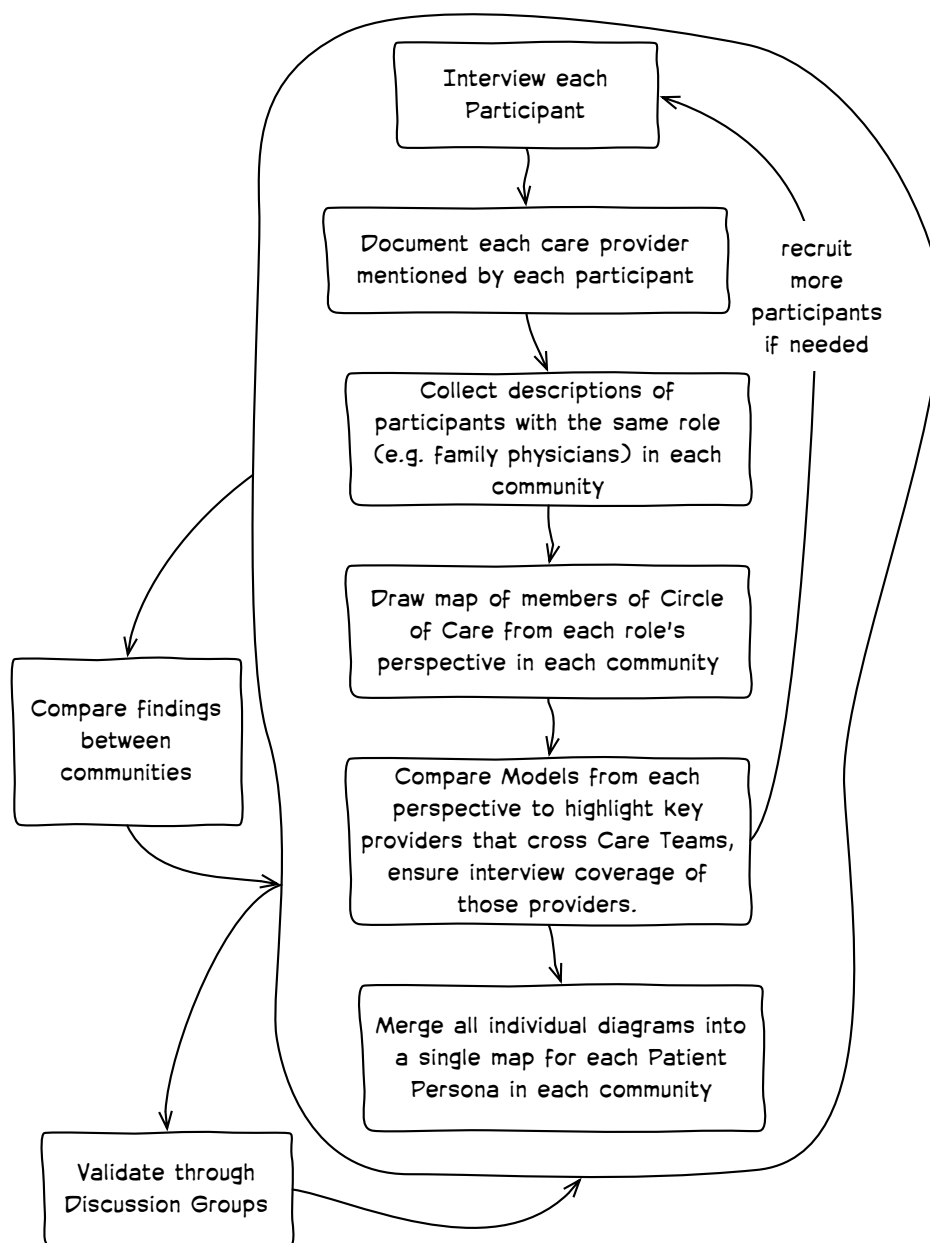


Figure 43: Process to model the Members of the Circle of Care.

For example, Figure 44 shows how the membership of the Circle of Care was perceived the family physician perspective in Duncan while Mrs. Cann was ambulatory. This view was compared to Figure 45, the perspective of the same Circle of Care, but from the Victoria based oncologist. The family physician was only aware of a few members of the Cancer Centre's Care Team, whereas the oncologist was very aware of the members of the Cancer

Centre's Care Team. By contrast, the Victoria oncologist was not aware of several of the resources in the Duncan community, which the family physicians knew well. For brevity, I have not illustrated each role's view here, as there are over twenty-five unique models (see Appendix K). No one role knew all the other providers in the Circle of Care.

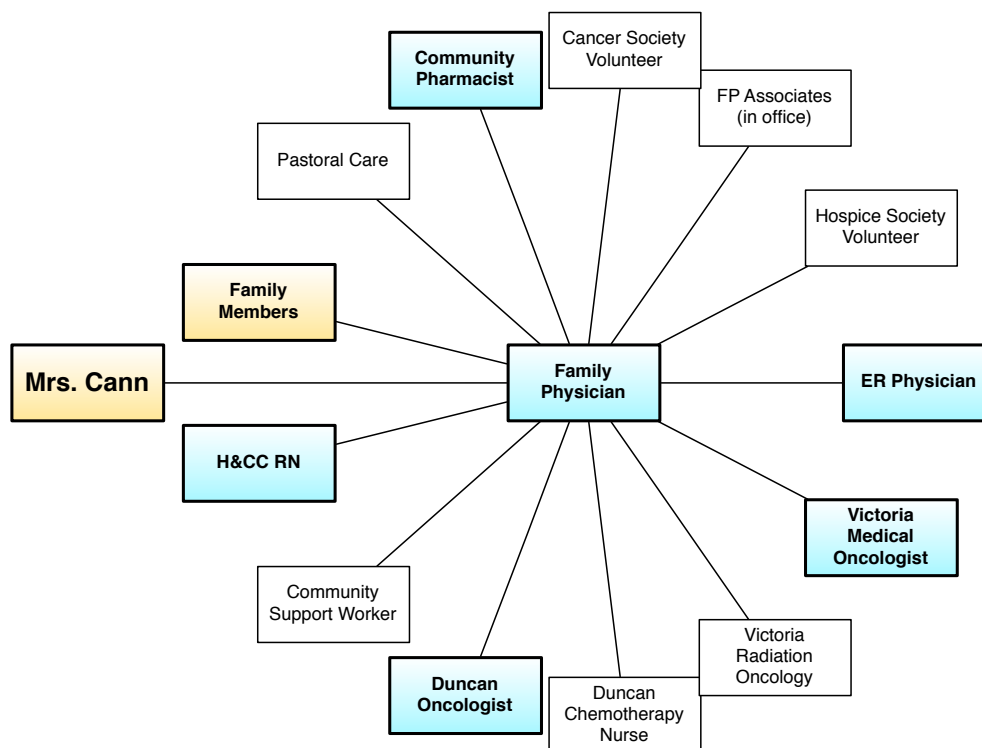


Figure 44: The view of the Circle of Care Provider View from Mrs. Cann's family physician in Duncan while she is ambulatory.

As the various views were constructed, some provider roles began to stand out. They were mentioned by most interviewees and were involved frequent communication *across* Care Teams. These were termed the “Continuity Providers” in the study. Continuity Providers had strong roles in communicating across the Care Teams, according to the participants, and would be some of the main providers who could impact Continuity of Care. The Continuity Providers are highlighted the diagrams in bold. As the size of the Circle of Care became apparent, it was clear that it was not possible to interview all providers, so the focus was on the Continuity Providers and understanding their communication patterns.

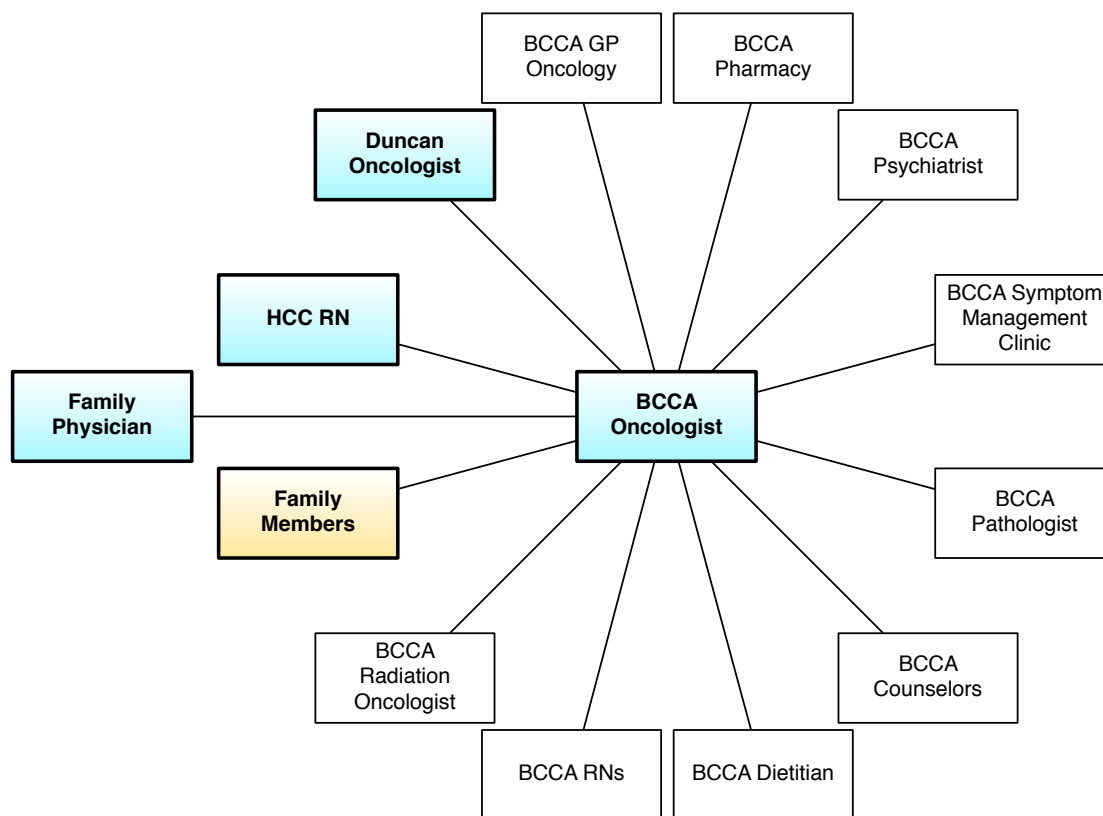


Figure 45: Mrs. Cann's Circle of Care Provide View while she is ambulatory living in Duncan, from the perspective of her Victoria based Oncologist who was involved in her care.

Once all individual views were complete, they were mapped together into a single diagram that illustrated each patient persona's complete Circle of Care. Redundancies were removed and members were grouped into Care Teams, groups that worked more closely together through organizational connection (e.g. all members of Home and Community Care) or physical connection (e.g. worked in the same office). There are two diagrams for Mrs. Cann (Figure 46 for Duncan, Figure 47 for Victoria).

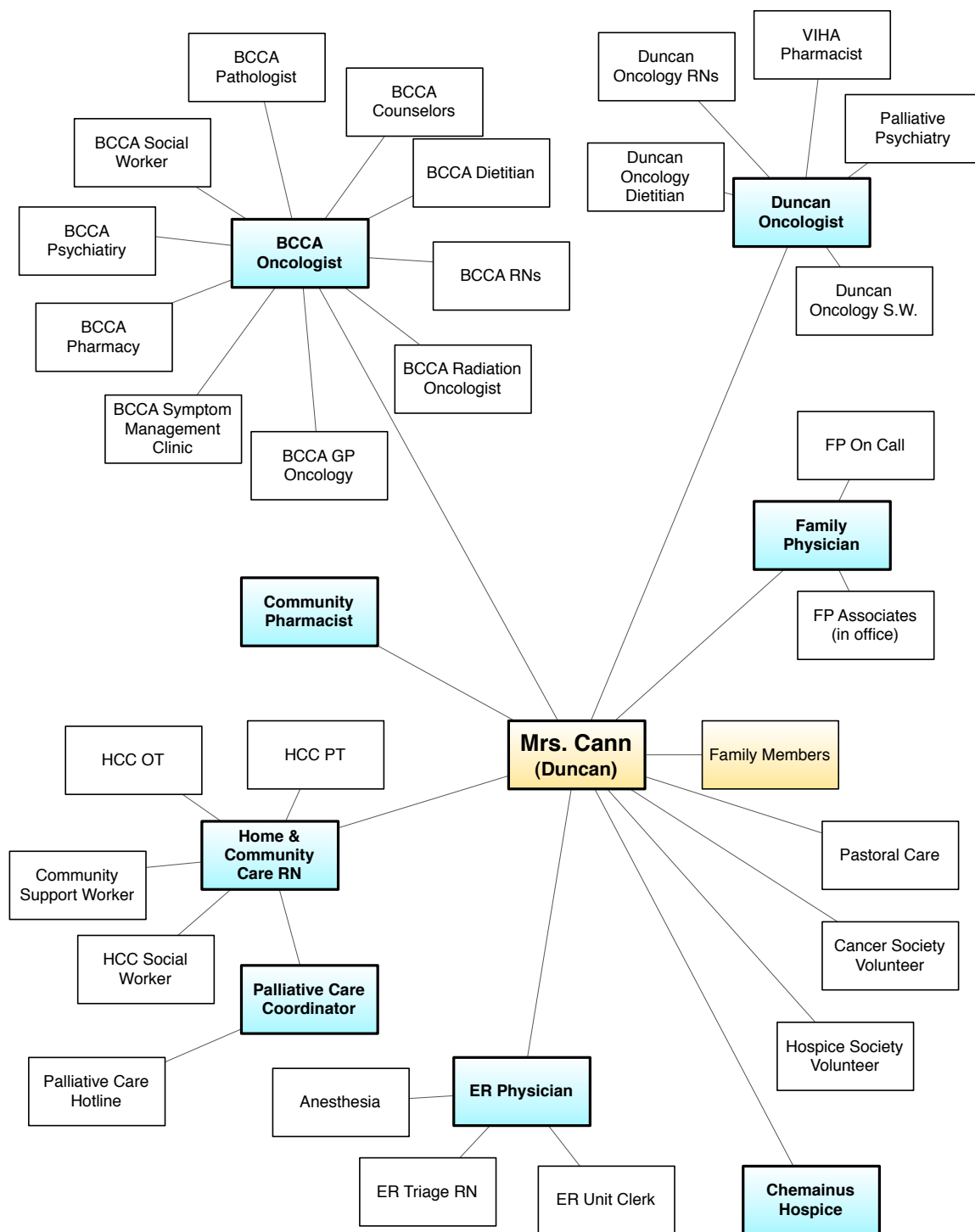


Figure 46: The combined Provider View for Mrs. Cann (Duncan). Continuity Providers, bolded, are responsible for the majority of communication between teams.

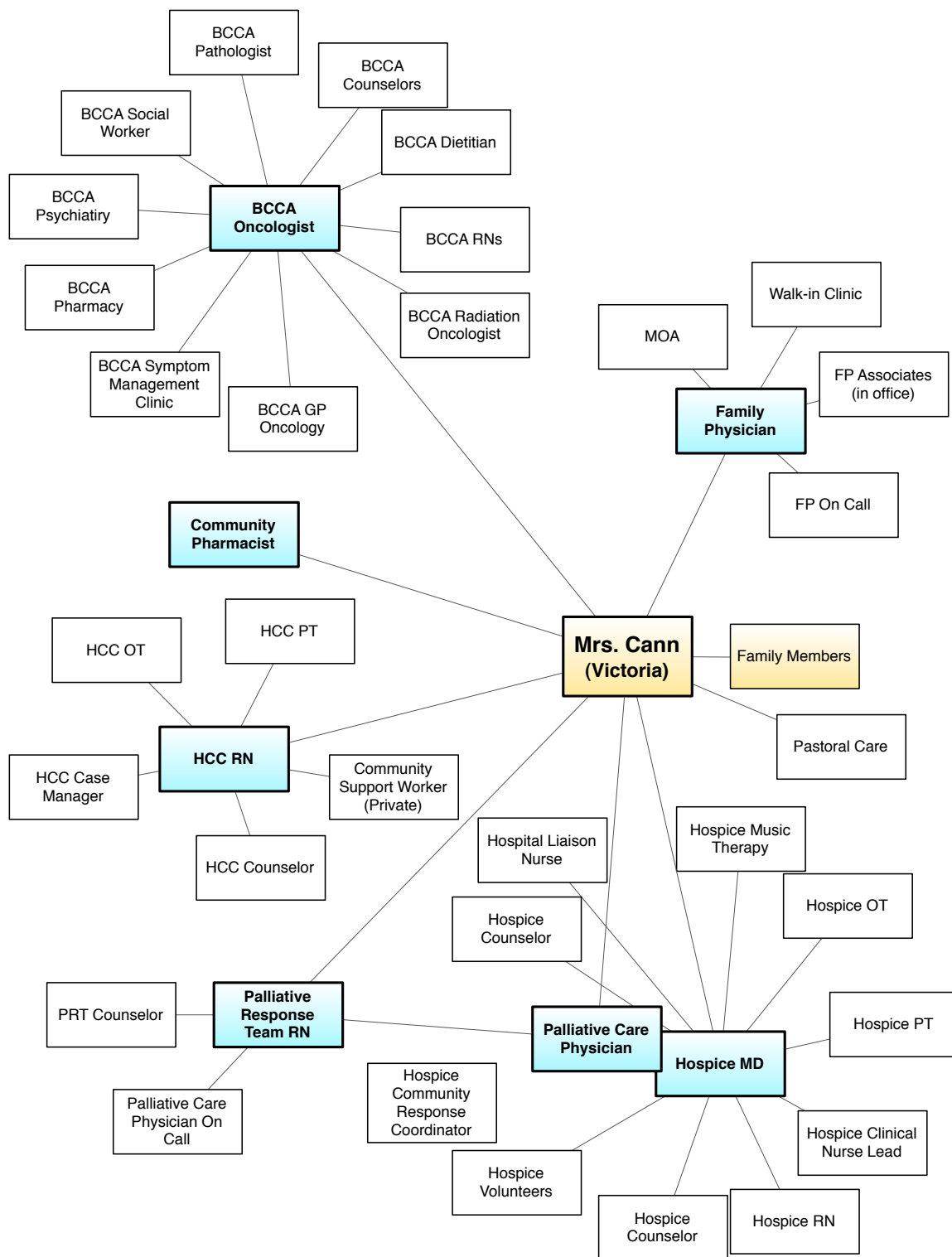


Figure 47: The combined Circle of Care Provider View for Mrs. Cann (Victoria). Continuity Providers (bold) are responsible for the majority of communication between teams. The Palliative Response Team and Hospice are an extended team, working together and sharing a chart.

These Provider Views highlighted the complex web of providers who were involved in Mrs. Cann's care over her last year of life. There was some redundancy in roles and skills within the various teams. Counselors, for example were available to Mrs. Cann in Victoria from several agencies, including the Cancer Centre, Home and Community Care, and Hospice (inpatient and outpatient). It was unclear from participants which one would be recruited and when.

Several aspects of Mrs. Cann's Provider Views were different between the two communities. First, care in Duncan was more fragmented than in Victoria, which was surprising. That the complexity of the members of the Circle of Care does not directly relate to the size of the community was an important observation and one that needs to be considered by health planners. As Duncan was a smaller town with fewer providers, it was expected that the care provided was simpler. In fact, Mrs. Cann's care, when she was living in Duncan, was spread out across three *different* communities on the island. In Victoria, all resources were available locally. Further, the larger hospice in Victoria was able to provide both outpatient and inpatient services. This fragmentation of care challenges Continuity of Care as the patient or the provider may not be able to travel to each other to maintain continuity. This was a gap that was also highlighted in the Rich Pictures in Duncan.

The Provider Views for Mr. Hart appeared quite different to Mrs. Cann (Figure 48 for Duncan and Figure 49 for Victoria). Several of the same Continuity Providers were involved, such as the family physician, community pharmacist and Home and Community Care case manager. But for Mr. Hart, there was a greater set of specialized providers and programs that did not appear to be well connected. There were specific programs and specialists that were recruited to provide management on certain aspects of Mr. Cann's care, such as the rapid stroke clinic, the diabetes education clinic, or the adult day program. There was some variability in the interviews as to which of these programs might be recruited (or which, the participants felt, Mr. Hart might actually attend). Much of this depended on the family physicians own comfort level in providing medical care to complex patients, such as Mr. Hart. Some family physicians would have managed his symptoms themselves. Others would have actively referred Mr. Hart to multiple specialists or programs for additional support. The larger number of providers meant more work was needed to actively maintain continuity. It could also become challenging to determine who was responsible for

managing which aspects of care. There were more members of Mr. Hart's Circle of Care in Victoria than in Duncan. In Victoria, the number of specialized services and sub-specialized services was greater than in Duncan.



Figure 48: Members of the Circle of Care of Mr. Hart in Duncan. Note the number of groups that are providing very focused care. Continuity Providers are highlighted.

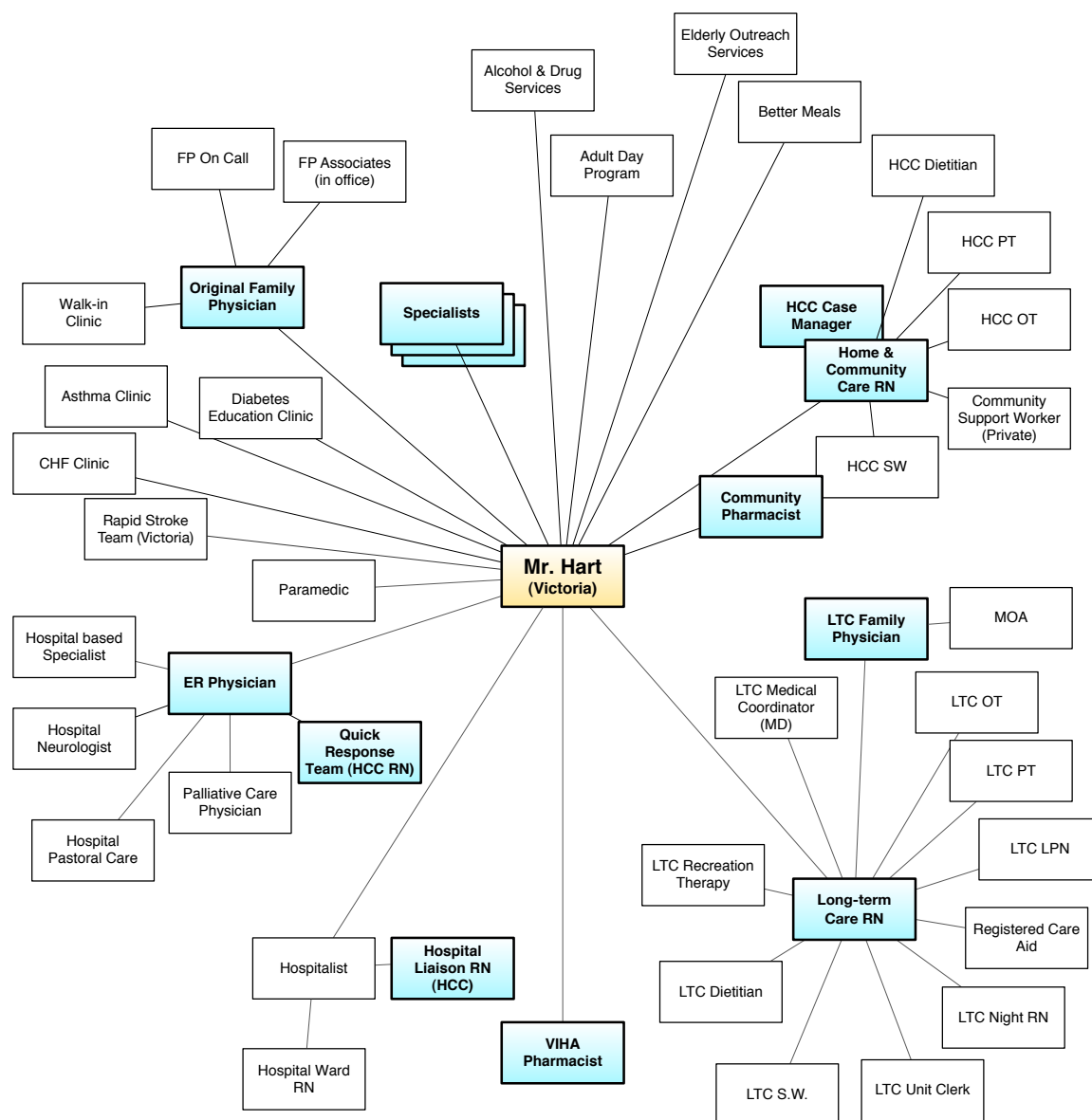


Figure 49: Members of the Circle of Care for Mr. Hart in Victoria. Note the number of smaller, specific services that could be engaged in Victoria. Continuity Providers are highlighted.

The members of Mr. Hart's Circle of Care changed more than Mrs. Cann's over the course of his scenario. This was most obvious in Victoria where Mr. Hart had, effectively, three different sets of providers with little overlap in who was providing care as he transitioned between settings. The groups were based on where Mr. Hart was, physically: in the community, in acute care, and in long-term care (Figure 50). Groups would transfer the patient from one setting to the next. Mrs. Cann had members of her Circle of Care actively involved for more of the scenario, as illustrated in the Rich Pictures. There was a greater

overlap in providers for Mr. Hart in Duncan, as his family physician was more likely to attend in both hospital and long-term care. In Duncan, the family physician was a strong link for continuity. This was not seen in Victoria.

This lack of Relationship Continuity could have significant negative clinical outcomes for patients like Mr. Hart. Patients with chronic conditions with low Relationship Continuity have poorer quality of care, increased ER visits and hospitalizations (Cabana & Jee, 2004). With complex webs of providers, as were seen with both of these patients, there is a risk that gaps in continuity cannot be effectively bridged and this has been seen as a safety issue (R. I. Cook, et al., 2000).

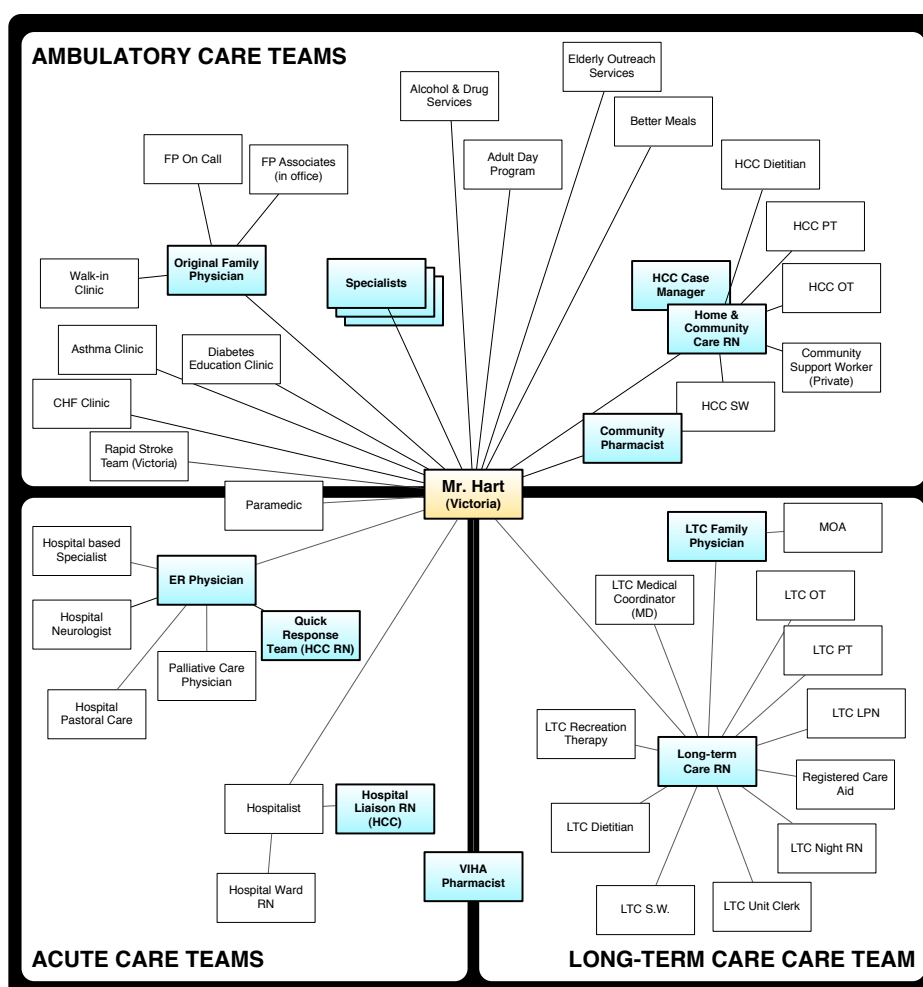


Figure 50: The members of Mr. Hart's Circle of Care were broken into three distinct groups in Victoria with minimal overlap.

Modeling The Communication View

The process that was followed to develop the communication diagrams is shown in Figure 51.

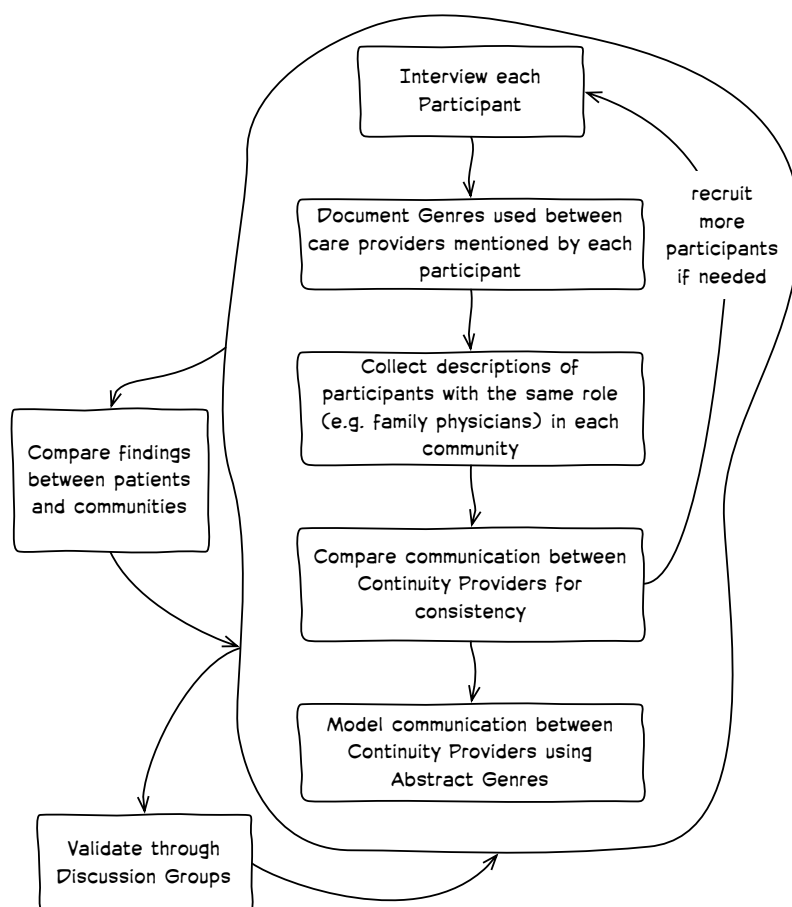


Figure 51: Development process for the Communication Models.

In the interviews, the participants described the communication between themselves and the other members of the Circle of Care. The specific Genres were captured and, when possible, paper copies were obtained. Comparisons were made between participants of the same role, to ensure all various types of communications were captured. Further comparisons were made between roles (where possible) to triangulate findings. For example, the communication between family physicians and Home and Community Care nurses captured in Table 18. The different perspectives between participants and between the two roles

supported that, once recruited into the Circle of Care, home care nurses were the primary initiator of communication and this was related to needing assessments or changes in treatment, for example a change in medication. The Communication Views were developed using the Abstract Genres (Chapter 13), so these would be “Provide Information” and “Request Assessment / Treatment”. Family physicians would send an “Order” to the nurse, often as part of the fax back response to a nurses “Request Assessment / Treatment.”

Table 18: A set of quotes from participants discussing communication between family physicians and Home and Community Care nurses.

<p>VO1 (Family Physician)</p>	<p>Researcher: “Would you notify community care, if they already are involved?”</p> <p>VO1: “I might. I might, quite honestly it depends on how busy you are. And I find, most of the time, if they are involved in community care, the nurses will obviously – most of them are <i>pretty good at seeing ‘here’s a change’ and they’ll give me a call... I won’t necessarily call them</i> to say there’s been a change. Typically <i>I will call if there is a medical change that is going to impact what they are doing. A medication change, that sort of stuff...</i> Generally, as you know, a lot of these patients are involved in community care... [Home and Community Care nurses] are pretty good about <i>calling me when there is some change that they need some orders on or something to update me on.</i>”</p>
<p>V03 (Family Physician)</p>	<p>“[Home and community care nurses will] send notes. <i>Faxed notes... usually when there is a concern that a change in management is necessary. They need more resources or the pain isn’t controlled, etc... usually comes down to clinical issues.</i> They take care of the rest of it automatically.”</p> <p>“Depending on the severity. If it was something minor, I would probably <i>fax them a note back.</i> If it was something more significant, I would probably call and talk to the nurse myself.”</p>
<p>VO6 (Home and Community Care Nurse)</p>	<p>“Most of the time we don’t call family doctors, OK. This is the part where I have had a lot of struggles in home care, just because I am used to working in other places where I feel so much better supported. So if I have a problem with a client... say Mr. Hart. Is it urgent? Most of the time it’s not, so you wouldn’t call the family physician because you’re not going to drag him out of his office on a non-urgent situation. So <i>there is something I need to report to him, like increased shortness or breath or increased angina</i> or whatever it happens to be. I have to go back to the office and have to go ‘dear doctor so and so, I saw Mr. Hart today and these are the things I assessed...’ and I have to fax it...then a copy of that fax goes into the chart.”</p>

<p>VO8 (Home and Community Care Nurse)</p>	<p>Researcher: “How do you communicate with the GP?”</p> <p>V08: “<i>Phone, fax, some nurses email – I don’t email.</i>”</p> <p>Researcher: “And how does the GP communicate with you?”</p> <p>V08: “<i>Often by fax back, just answer back on our faxes. Depends on the GP. There are a couple in town that call you back, but a lot of times it is fax.</i>”</p> <p>Researcher: “When do you get the GP involved? Are there particular cues if you are seeing this patient?”</p> <p>V08: “Yeah when anything is out of sorts, right – the medical management side of things...I would be engaging [Mrs. Cann’s] GP, because initially we’re supposed to go through the GP for any, <i>any medication management</i>, even pain medication management. So I would be doing my pain assessment, reviewing what medications she’s been in on, what level of pain she’s at, how many breakthroughs she’s been using, assessing where this new pain is. Then <i>I would be phoning the GP and communicating that.</i>”</p>
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Eight Communication Models were created in this study. Two models were developed for Mrs. Cann, one for each community and six for Mr. Hart. All Communication Models are available in Appendix L. Two models are provided here to illustrate the communication flow and to highlight the differences between the two patients (Mrs. Cann in Figure 52 and Mr. Hart in Figure 53).

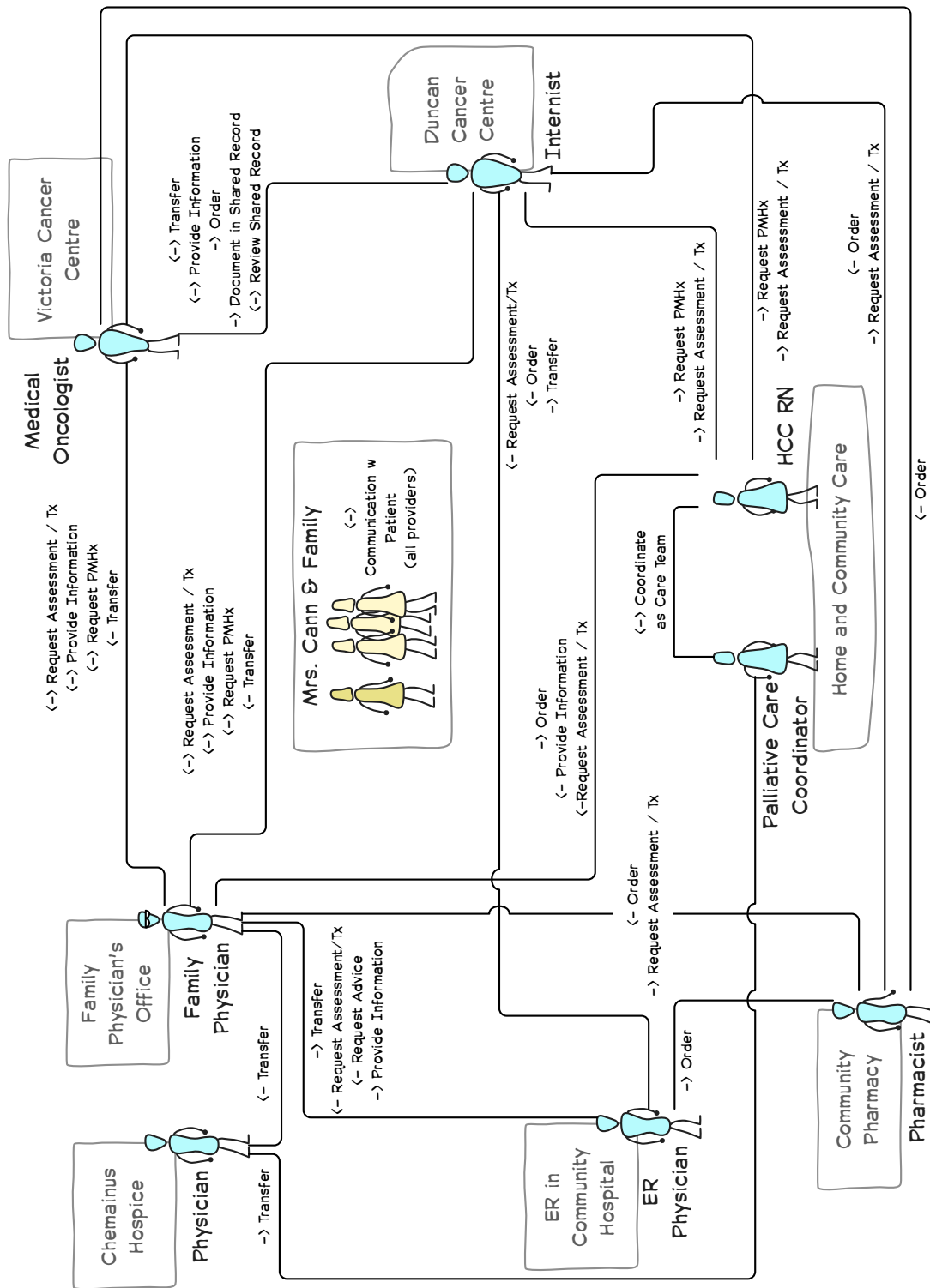


Figure 52: A modified communication diagram showing communications between Duncan Mrs. Cann's Continuity Providers. Arrows indicate flow of the communication; double-headed arrows indicate flow can happen in both directions.

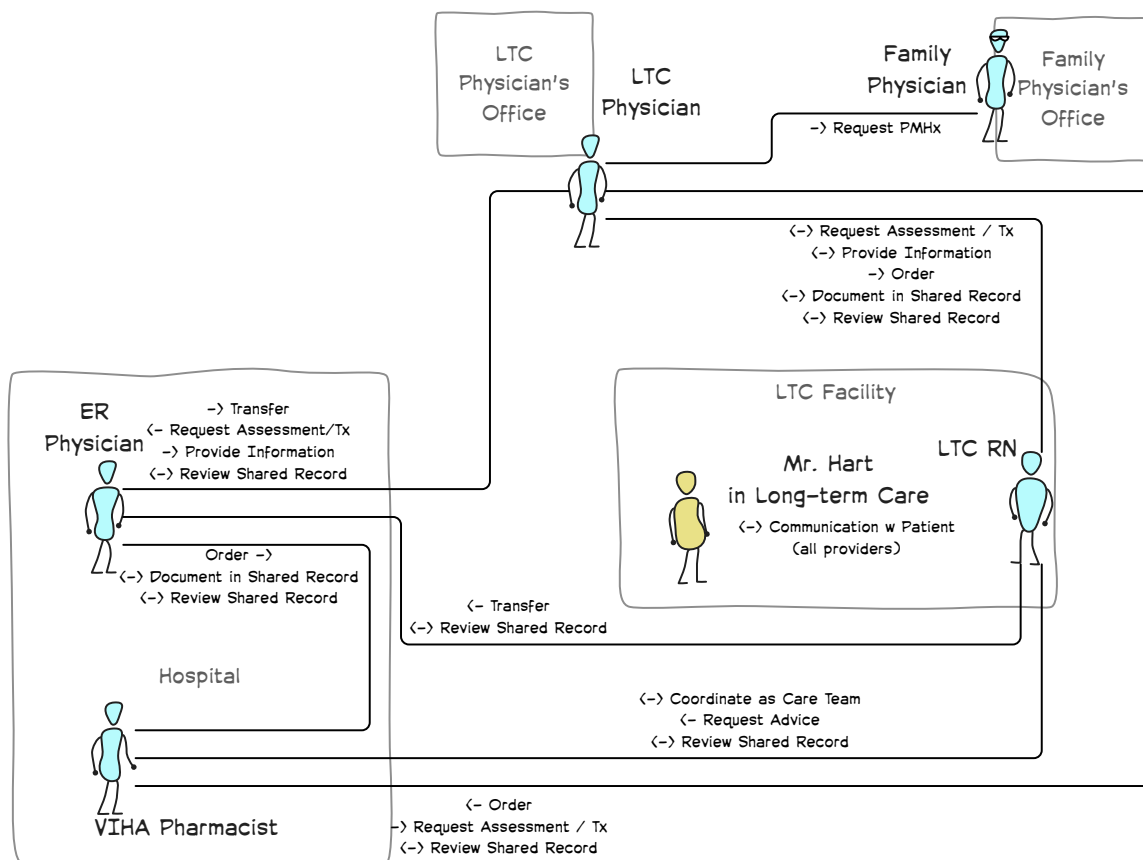


Figure 53: Communication Model showing key communications between Mr. Hart's Continuity Providers while he is a Long-Term Care facility in Victoria.

Three aspects of the Communication Views were worth highlighting here.

First, nearly all communication - in both communities – was ad hoc and point-to-point. Changes in patient condition usually spurred the communication between providers. Thus, much of the work and care planning was in response to acute changes. Regular case conferences to review and proactively plan were rarely used outside of individual care teams.

Second, with the Mrs. Cann scenarios, there was limited use of shared records for communication between Continuity Providers. The main exception was the cancer centre's shared electronic record. Victoria Oncologists dictated into the electronic record and the Duncan Oncologist could review those dictations as transcribed notes and letters. However, no other providers had access to the Cancer Agency's information system. PowerChart was not actively used by any of the providers involved in Mrs. Cann's care for communication, only to look up results. The Communication Views for Mr. Hart illustrated a greater dependency on shared records for communication between providers; however, this was due in part the third issue below.

Third, Mr. Hart's case unexpectedly required additional models, as the communication patterns were so different when Mr. Hart was in each setting. There was such a gap in Relationship Continuity, particularly in Victoria (as previously shown in the Rich Picture and in the Provider View of the Circle of Care), that there was minimal communication between providers in each setting. The individual teams in the facilities appeared to be acting quite autonomously to the rest of the Circle of Care. The Communication View in Figure 53 highlighted just what a small role Mr. Hart's family physician played in his care after admission to the facilities. People contacted him only to request past medical history. This was due to the fact that the family physician did not admit to either hospital or to the long-term care facility where Mr. Hart was placed⁴³. This was not the case in Duncan. The family physician was involved in each stage of his care. Again this kind of gap in Relationship Continuity can lead to decreased quality of care (Cabana & Jee, 2004).

⁴³ As per the scenario. This is not always the case in Victoria but was consistently described as an issue and, thus, became part of the Rich Picture and subsequent models.

Modeling the Information / Repository View

The final model that was developed was an Information / Repository View. These models illustrated all stores of patient specific information that were in use by the providers. Figure 54 describes the process for modeling the Repository View. IM/IT participants were particularly useful in reviewing information flows between repositories for this view, as not all providers were aware of the information flows.

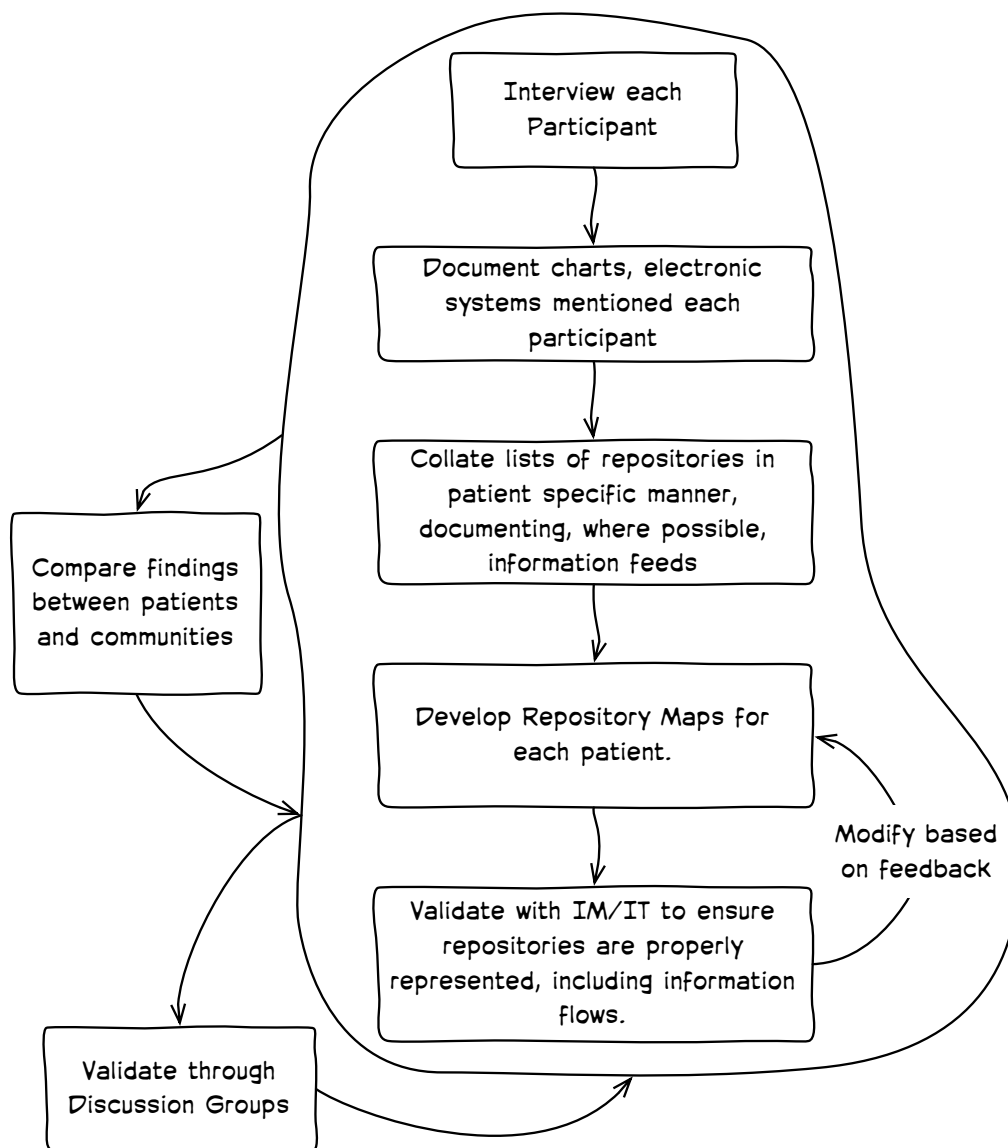


Figure 54: Process to develop the Repository Maps for each Patient Persona in each community.

Figure 55 describes the repositories that were in use for Mrs. Cann in Duncan over the course of her story. Most repositories were paper, although several were electronic. According to the findings from the interviews, there were nearly 30 active repositories that contained specific information on Mrs. Cann in her last year of life.

Figure 56 captured the Repository Map for Mr. Hart in Duncan. In the Duncan scenario, Long-Term Care also had an additional local clinical information system that was available to providers in the facility. This electronic record was not available to Mr. Hart's family physician, even though he attended Mr. Hart at that facility. This was due to lack of interest, access (sign on), and training. There were at least 25 different repositories for Mr. Hart's information over the course of his story. In Victoria there were more specialist and disease specific education centre charts. The information flows were similar between all groups.

Three repositories have no connection points in the diagrams. This was purely to make the diagram more comprehensible. Two patient repositories (the Cancer Centre's patient booklet and the Patient's Palliative Binder) could receive information from anyone in the Circle of Care and, thus, would be copied from any of the repositories (although the Cancer Centre's booklet typically only contained patient education material about specific cancer treatments). Email, too, was used by most of the care teams, to varying degrees, and connections would have made the diagram very cluttered. Email messages were sometimes printed and placed in paper charts or notes were transcribed into the chart.

There were a limited number of electronic lines of communication between systems in all Repository Maps. Most information was physically copied or manually transcribed (in whole or in part) between repositories. These figures did not describe the detail of what information was copied between systems or if it is transformed (e.g. summarized). The practices were too variable and the detail level too great for this level of analysis.

These figures (both for Mrs. Cann and Mr. Hart) triggered the most visceral responses from participants, both IM/IT (Health Records is part of IM/IT in VIHA) and providers alike. Gasps, nervous laughter, and shrieks were common as these pictures were revealed to participants.

“The only thing I can think of, seeing this graphically is – Oh my God!... and the whole issue, you know, around what’s shared between people...[pause, looks over the map again]...it’s incredible [sigh]” (IMIT05)

What is the impact of this level of disparate records, one nurse in IM/IT said it well as she looked over the picture:

“There would be a lot of duplication on that, but there would be a lot of stuff missing. So what the family physician might have would not be the whole picture. The oncologist wouldn’t have the whole picture. Nobody would have the whole picture - you need somebody who has the entire picture.” (IMIT03)

Despite the complexity of these pictures, they were not exhaustive views of all repositories in the region. They were only an illustration of what the participants were aware of and what they recalled during the interviews. In reality, there were more repositories, such as those used by data entry clerks in Home and Community Care to capture and send data to the provincial government, abstracting databases, business analysis systems, and feeder systems from laboratories that are not described in these maps.

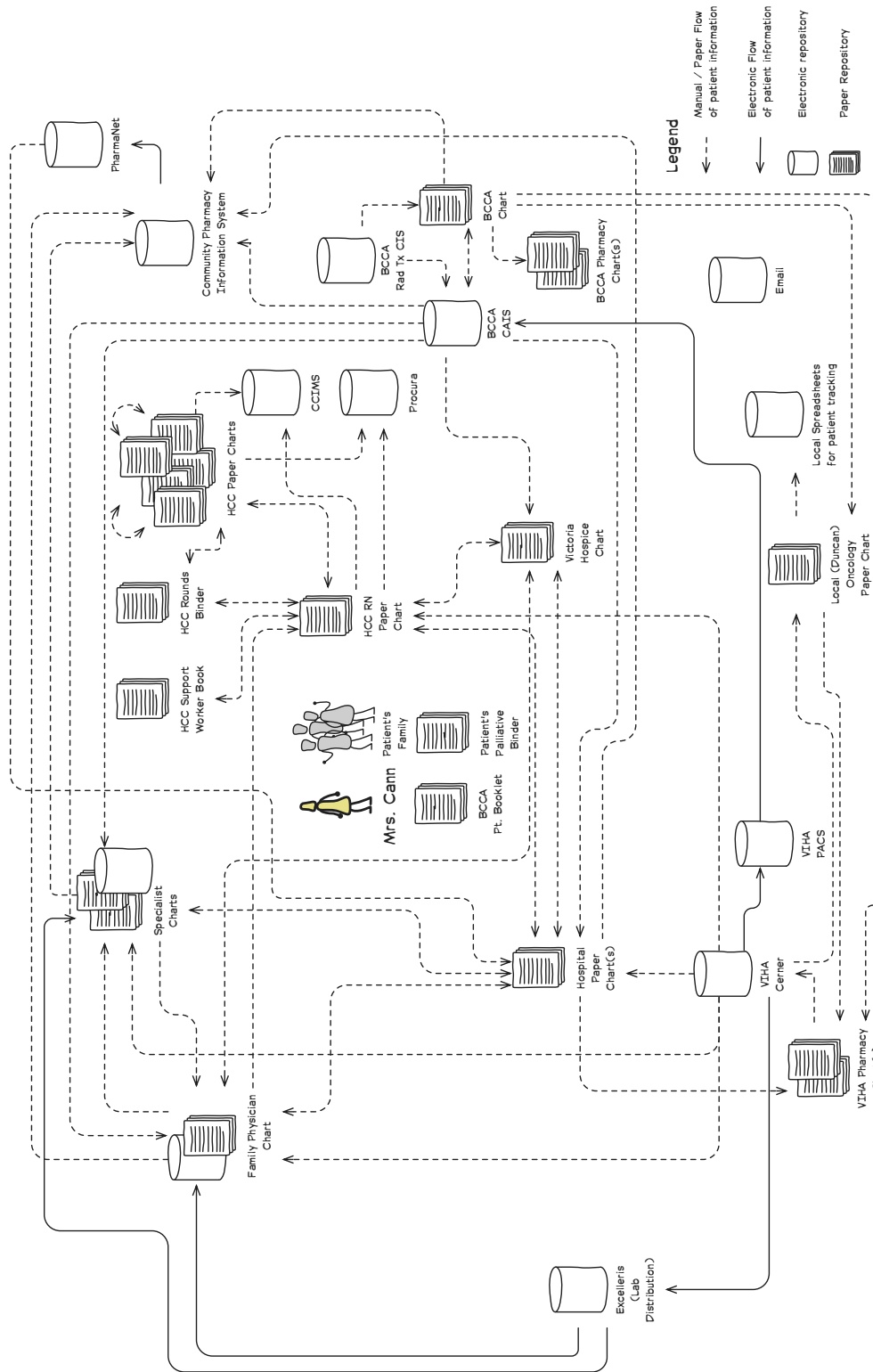


Figure 55: Duncan Mrs. Cann Repository View. Major persistent records are illustrated, with records containing information about Mrs. Cann.

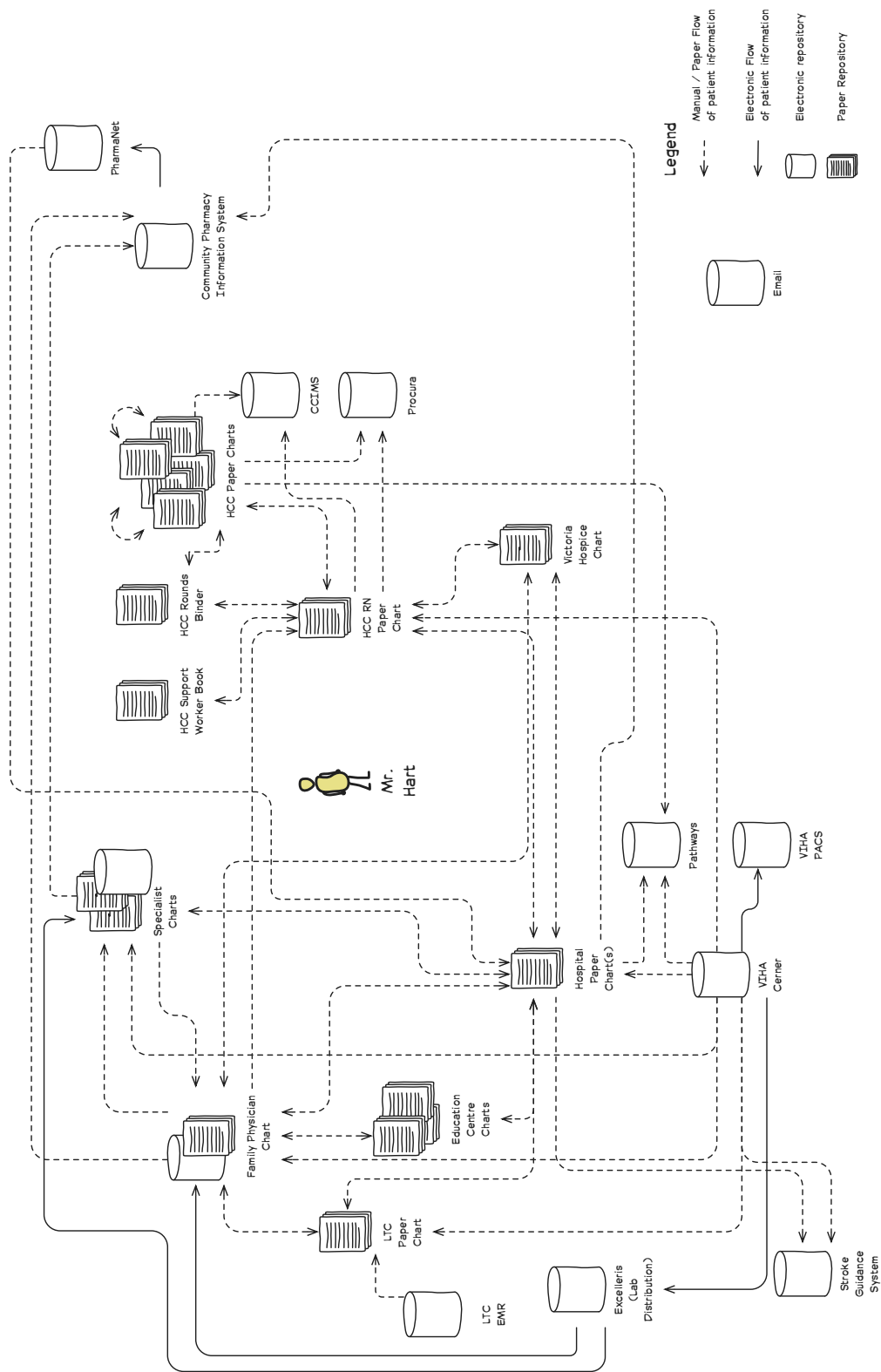


Figure 56: Duncan Mr. Hart Repository View. Note that Mr. Hart may have multiple specialist charts.

The complete set of Repository Views for Mrs. Cann and Mr. Hart in Victoria are in Appendix M.

An additional diagram was created, containing all of the information repositories discovered in this study. It was a master list of the various repositories described by all participants (Figure 57). UML classes were then developed to describe the typical content that is stored in each repository (Figure 58). This was a useful reference to review scope of content in each repository. The content types were based on (P Tang & McDonald, 2006), as described in the methods section. This diagram, while very high level, highlighted how much material was potentially repeated or overlapping between repositories. The bulk of the repetition was the result of manual processes, suggesting that information could have errors due to copying and become out of date or unsynchronized easily.

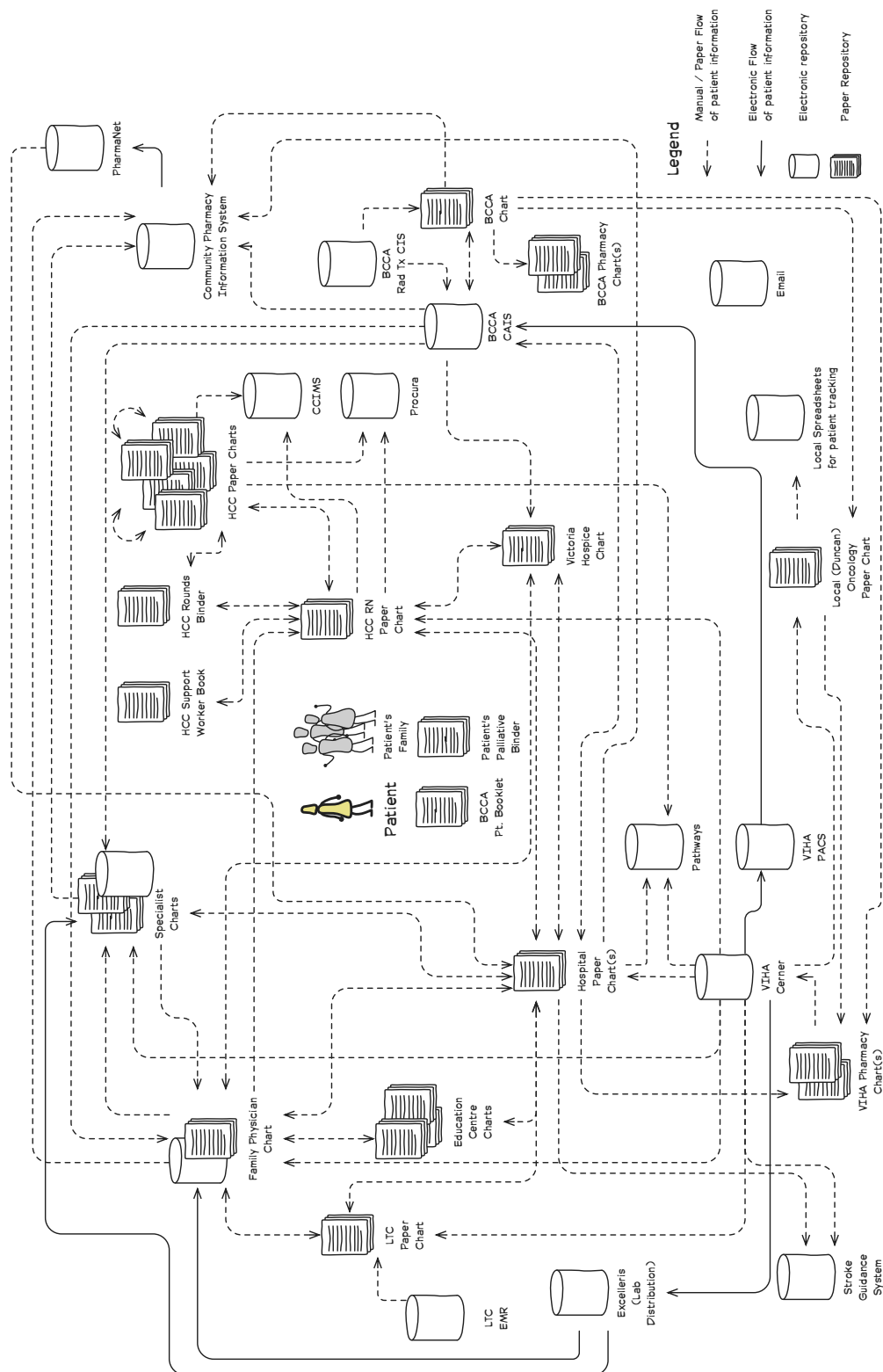


Figure 57: Composite Repository View containing all patient records across both Patient Personas and both communities.

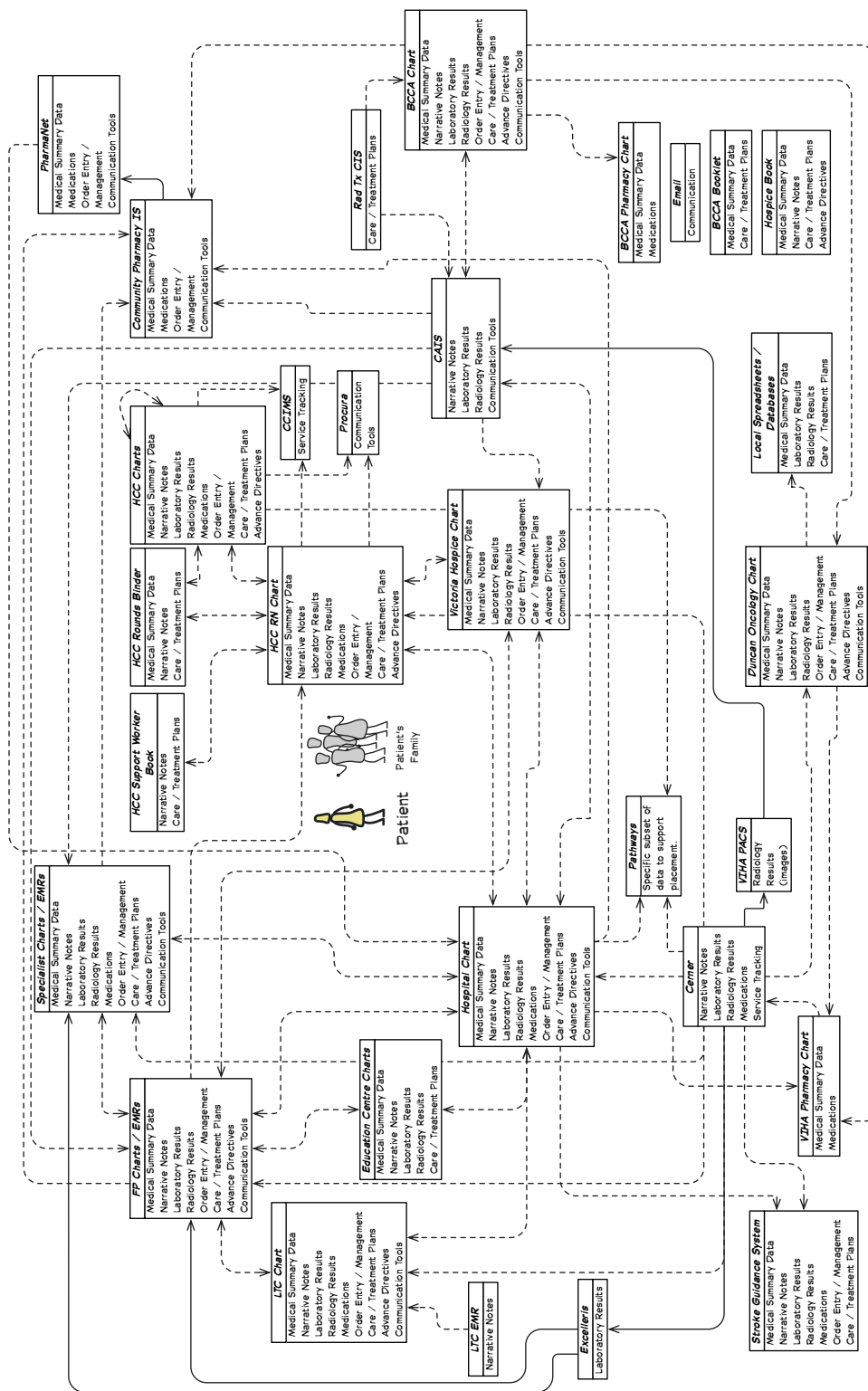


Figure 58: UML classes diagram with typical types of patient information stored in each repository.

Conceptual Modeling - Summary

Mrs. Cann and Mr. Hart were typical and not overly complex patients with chronic illnesses that would be seen in British Columbia in their last year of life. The Conceptual Models of these two patients' Circles of Care highlighted how complex the care systems were for patients like these. The models highlighted several challenges, such as how to manage information and plans across such large and disparate Circles of Care, that is, how to ensure there was the access to the right information by the right providers at the right times. The differences between the Circles of Care of the two patients highlight the challenges of approaching wicked problems in healthcare (Churchman, 1967) (Periyakoil, 2007). Based on the size of the two communities, one would have expected that the Circle of Care in Duncan would have been less complex. Duncan's population was one-tenth the size of Victoria. What was seen was that one Circle of Care (Mr. Hart's) was only slightly less complex and the other (Mrs. Cann's) was more complex, with her Circle of Care scattered across three communities.

The models complemented the rich pictures developed in this study by showing different views of each patient's care system. They were used to reason about potential changes and improvements to the system.

Chapter 15 Suggested Improvements

This chapter describes the six Suggested Improvements that were generated as part of this study. The process for developing these Suggested Improvements is described, as are the findings that led to the recommendations. The chapter concludes with mention of infeasible improvements.

Formation of the Six Suggested Improvements

The following six suggested improvements were developed through the study and were meant to address challenges raised by participants. The process to developing these suggestions for improvement with participants was captured in an SSM conceptual mode (Figure 59). As background, VIHA's current IM/IT capabilities and their proposed directions were appreciated through a review of the VIHA IM/IT strategy. During the analysis of the interviews, common clinical gaps were discovered, as were raw suggestions for improvement from the participants. The main gaps were captured in the Rich Pictures and Conceptual Models. The issues were discussed with the IM/IT participants through the use of the pictures and models. Feasible improvements were sought with the IM/IT participants. Six suggested improvements were drafted based on these findings. Each of the draft suggestions was raised with participants in the Discussion Groups (both provider and IM/IT participants); the options were explored in more detail. The Suggested Improvements were modified and refined based on their feedback.

There were many clinical areas where there were gaps in continuity. These six improvements were selected as they met several key criteria:

- They improved the gaps described by participants, particularly inter-team challenges;

- They had regional (or greater) application;
- The participants, both providers and IM/IT, agreed and considered them feasible.

Feasible, for this study, was defined as activities that could be incorporated into the currently planned activities (i.e. IM/IT activities, VIHA organizational activities, and care delivery) and completed within one year, as confirmed by both IM/IT participants during interviews and by participants in the discussion groups.

There were many more issues that were discovered through the study than were addressed by the suggested improvements. These were often local issues, relating to a particular local nuance within the various care teams interviewed. Some of these were not incorporated into the six suggested improvements described here. The intent was to share these findings with potential local improvements back with the participant groups and various administrative leaders as part of closing the feedback loop with all the participants after this study is concluded. Other issues, such as lack of 24-hour home nursing coverage in Duncan, were problems that were considered infeasible.

The six suggested improvements that were endorsed by participants in both discussion groups were:

1. Improve Access to appropriate CISs
2. Develop an Advance Directives Repository
3. Enhance documentation of Pt-Provider Relationships within the regional EHR
4. Notify Providers of Transitions
5. Improved Use of Case Conferences
6. Design a Regional Clinical Communication Tool

What follows in this section is the description of each of these six suggested improvements developed by this study.

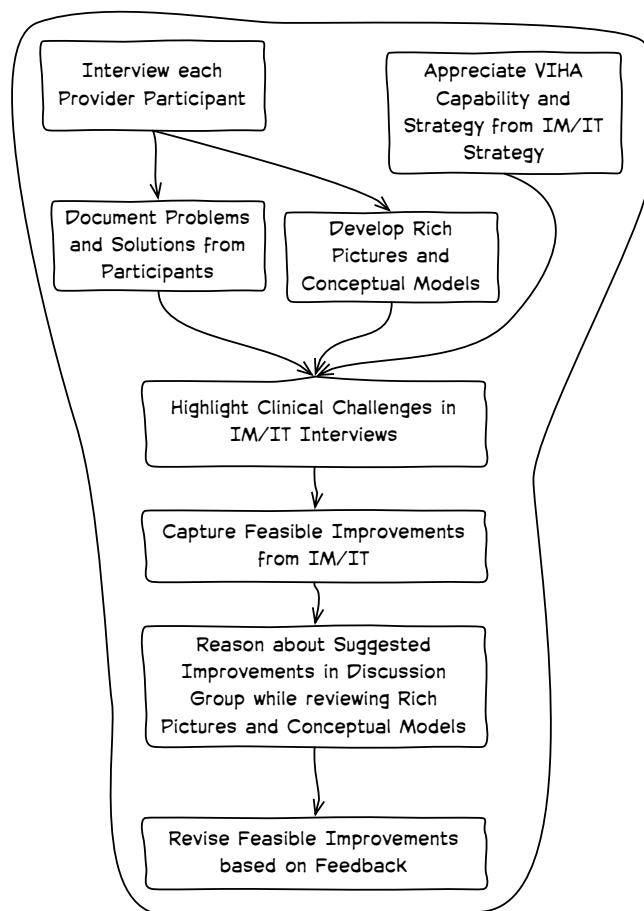


Figure 59: Process for developing Suggested Improvements with participants in this study.

1. Improve Access to Appropriate CISs

Several gaps to Information Continuity that were discovered could be addressed through improved access to information that was already stored in the existing regional Clinical Information Systems (CISs). Many providers described challenges in accessing information in these electronic repositories. Even without changing / enhancing content in the CISs, there was perceived value in providers having better access to the information already in these systems.

Improved access was thought of in two ways. First, providing access to the major, regional CISs for those that did not have access. The major, regional CISs were VIHA's regional hospital system, Cerner PowerChart; Cancer Agency's Information System; and the

province's medication repository, PharmaNet. These contained important information on patients. Information from these systems was being sent or copied into multiple other records or it was not being accessed. Second, small changes to existing access models to Cerner would have better supported care delivery. There were four specific improvements to access that were suggested as improvements to Continuity of Care for end of life patients.

Access to PowerChart for all Family Physicians

Many family physicians interviewed had access to PowerChart and accessed it remotely. Despite some frustrations in the time it took to log in, access to the information was thought to be very helpful:

“PowerChart is probably the single most important piece of patient information, better than the chart. Because the chart is not clear – where is his diabetic sugar levels, what is his level of care. PowerChart is very clear and I can access it from home.” (V11)

These were clear benefits, but these benefits were not available to all family physicians in the region as not all family physicians in the region had access to PowerChart.

Family physicians without VIHA admitting privileges (e.g. hospital privileges) did not have access to PowerChart. Clinical benefits were clear - although they did not admit patients to VIHA, their patients did often go to VIHA facilities. Continuity needs were greater for those not directly involved in the admissions. As one participant without privileges said about gaining access to PowerChart: *“It's a no brainer”* (V03). The group of family physicians without access to PowerChart was a particularly large in Victoria.

Two approaches would support this: an information sharing agreement could be established between the physicians and VIHA, or associate privileges could be granted to any family physician who wants access to PowerChart, without the requirement to admit patients. The latter was felt to be straightforward by the IM/IT leadership. This would provide ready access to inpatient results, consultation reports and other documents when patients return to their family physicians after discharges from the hospitals.

Design Projects with Appropriate Access and Training to CISs

Another group that did not have access to PowerChart was the long-term care nurses in Duncan. These were VIHA employees and worked in a VIHA facility in Duncan. Long-term care nurses in Victoria did have access. It was discovered that the Duncan long-term care nurses were not trained when PowerChart was deployed in Duncan. Cerner and PowerChart were deployed Duncan about six months prior to this study. The scope of the project for implementation was focused on acute care (hospitals). The long-term care clinicians were considered out of scope. However, there was a lot of information in PowerChart that was important for long-term care nurses, including all bloodwork and medical imaging reports for long-term care patients, like Mr. Hart.

What was discovered in this study was that Duncan long-term care nurses relied on other people to get access to what is in Cerner PowerChart, which was limiting to practice.

“Our Unit Clerks [have access to PowerChart] but we don’t. If it is after 3:30 or on a weekend -- too bad” (DO3)

That limitation caused frustration and considerable extra work for the nurses:

“Not being on PowerChart when everybody else is, is very difficult. I get no lab results, so I basically have to watch what’s drawn and get all the results I need. I have no access to medications.” (DO3)

One of the long-term care nurses in the same facility did have access to Cerner PowerChart (as she was trained elsewhere in VIHA in another role and had an active account), and by comparison, she was pleased and found it very helpful:

“I have access to PowerChart so I can find out what they did with him, but not everybody has that information...I find it very helpful...the admitting history... and lab work in there and it lets us know where they are” (DO5)

This lack of access was due to a gap in proper scoping of a project, which limited the access to training and login accounts for these nurses.

“That was one of the, what I consider – on the record – not well coordinated pieces of the Island eCare Core Clinicals⁴⁴ roll out. So it was, from a Continuity of Care perspective, it was not well thought out - and because of keeping [project] scope, only a certain number of residential care places were given PowerChart access and some were not at all... I feel that scope needs to be not just project scope, but information [continuity] scope... That’s a feasible change, that’s just education and building the right access.” (IMIT01)

This issue was not limited to Duncan, but to many communities across the region. Island eCare Core Clinicals⁴⁴ project spanned the entire region, with the exclusion of the south Vancouver Island (e.g. Victoria). When this gap was raised with IM/IT, it was thought that training would take:

“Probably for two years, these people will not have access to even simple INRs⁴⁵ and potassium results.” (IMIT01)

I was pleased to hear that by the time of the discussion groups – that is, during the course of a few months – this issue that had been rectified and all long-term care nurses across the region had been trained and given accounts to access Cerner PowerChart. This significantly improved Information Continuity for patients in the VIHA long-term care facilities.

While this example has been rectified, it highlighted the importance of understanding a patient’s care system prior to defining the scope of implementation projects. Cerner was deployed to all hospitals in VIHA and that completed in Duncan in October of 2008. The project focused on acute care, as a setting. It made sense to exclude residential care nurses were out of scope of a *hospital* implementation. Yet, VIHA lab results, medical imaging reports and medication orders were in Cerner for VIHA patients in long-term care facilities. The recommendation here, as the training had occurred, was to ensure that access was reviewed appropriately in future projects to ensure that information was not inappropriately placed in inaccessible silos.

⁴⁴ This was the name of the VIHA project to implement Cerner in all the regional hospitals in VIHA.

⁴⁵ INR is a common blood test for people on blood thinners.

Increase VIHA Provider Access to PHSA's CAIS

A select group of VIHA providers would benefit from being able to access the BCCA's CAIS system. Specifically, palliative care providers (physician and nurses), ER physicians, hospitalists, and some specialists and family physicians. This was noted as a significant gap, especially for ER physicians, who work only a few hundred feet away from the Vancouver Island Cancer Centre.

"The oncology documents are ridiculously difficult to get and it's the same in both regions that I have worked. Cancer Centre charts are not accessible and that's problematic... you get them on Monday, you know - you get them in the light of day."
(V12)

ER physicians often saw oncology patients in crisis and did not have access to information inside CAIS. This was noted particularly at night and on weekends, as highlighted in Mrs. Cann's story. Records were more accessible *"in the light of day"* (V12) as administrative staff were present at the BC Cancer Agency during normal working hours and could respond to requests for information from the ER physicians and others. They were not available at nights or on weekends.

Family physicians also felt timely access to cancer clinic information would have been a benefit to them as well; not having the information, or getting it later, impacted the care they gave.

"All the time I'm asked – people come back ... and they don't want to wait five weeks [to have the letter with the family physician]. I think most docs want [access to the Cancer Agency's information system]... what a savings for them [oncologists] obviously at the same time. You can say 'I've looked at Joe's note and have this specific question about it', not 'What is Joe's note?'" (D02)

Having access to the consultations would change the conversations between providers, making the conversations more informed and effective, rather than repeating what was captured in the consultation letters.

Hospice requested old BCCA consult letters on all cancer patients as part of a routine admission. But there were gaps, especially for outpatient palliative patients, and the majority of hospice patients were outpatients. As a palliative care clinician said,

“The biggest gap for me is the cancer clinic... we have no access to it [consultation letters] and it is unfortunate that it is not part of PowerChart.” (D12)

Integrating notes from CAIS into PowerChart was likely to be too large of a project. That was considered infeasible; however, providing access is something that is feasible.

Providing training and access for select clinicians would allow them to provide better care to their patients with access to the consult letters that are available in CAIS. This could speed up time to access the information while decreasing demand on Cancer Centre’s Health Records. It would require the completion of Information Sharing Agreements as well as setting up accounts and training, for those interested providers in VIHA. This was felt to be possible by both BCCA and VIHA IM/IT participants.

Interestingly most oncologists on Vancouver Island also had privileges at VIHA and, therefore, have access to PowerChart, so this gap was not felt in the reverse.

Recommend Changes in Access to PharmaNet

PharmaNet was the provincial repository that contained most outpatient medication dispensing in the province. VIHA developed a viewer interface to PharmaNet within PowerChart. It was available to physicians while they in hospital. Due to provincial policies at the time of this study, the VIHA tool was restricted to physicians in hospital treating inpatients. Physicians outside of hospital were not able to access through the free VIHA viewer. Instead, they were expected to pay for private, third party products. The payment to access a public resource had stopped several physicians from using this resource:

“There is something that says, ‘Why am I paying [for PharmaNet] to help my patient?’... I just couldn’t see myself going that route. Then when I heard it was coming on PowerChart, but the months keep going and it’s not [there].” (D01)

Further, access to PharmaNet was restricted by provincial policy to pharmacists and physicians. Nurses, some of whom had medication reconciliation as part of their scope of practice, did not have access to PharmaNet. One nurse questioned this:

“So we [nurses] are meant to do the med reconciliations at the home, but we’re not allowed to access PharmaNet?” (D11)

Clearly, there was a perceived benefit for anyone responsible for medication reconciliation to have appropriate access to PharmaNet.

While VIHA did not control PharmaNet policy, findings from this study could help VIHA lobby the province to change their access models to better support care delivery. With a PharmaNet viewer already integrated into PowerChart, improved access would very easily be achieved in VIHA, once the policies were revised. The recommendation from the discussion group was for VIHA to further lobby the BC Ministry of Health to change the access policies to better support the care processes.

Modify Cerner Nurse Access Models to Better Fit Care Delivery

Finally, the access models within the Cerner system should be reviewed to better support care delivery. Specifically, several nursing positions were not able to see patient records when their practice dictated that they should have had access. Cerner’s access model was developed in a way that blocked nurses from viewing patients that were not located on the ward where the nurses were working. This was a useful privacy protection; however, it limited the value of having PowerChart during transitions of care. All admissions and transfers to a ward, for example, were impacted by this access limitation.

The specific example in this study was admission to long-term care from acute care. The long-term care nurses (those who were trained in Victoria and had access to PowerChart) were not able to see information on any patients during their admission process. The long-term care nurse had access to the record only after the patient had arrived in the facility. They did not have access during the process of assessment and admission. They relied, instead, on receiving information through phone calls and faxes. This was a slower process, prone to errors, and tied up two nurses in the process.

“For the admission process, it would be very helpful [to see PowerChart]. Because if I had access right away... then a lot of sending back of faxes would be unnecessary, because I could to read them right online.” (V05)

A review of the access control model may provide additional benefits, improving appropriate access to information would allow for the admission processes to be streamlined and that could free up additional nursing time across the region to provide care. The VIHA access model was due for review at the time of this study, so these findings could be factored into the redesign efforts. Thus this was felt to be a very feasible activity in IM/IT.

Caveat to Improving Access to CISs – Sustainability of Access to Too Many CISs

There was one significant caveat to this recommendation: the more systems that a user has access to, the more difficult their use of those systems becomes. Time spent learning and searching through multiple systems becomes unreasonable when there are too many systems. For some providers, having access to multiple records (such as PowerChart (with embedded PharmaNet), the Cancer Centre information system and their local chart (paper or EMR)) was considered a benefit. For others, having their local chart and then having to access PowerChart was felt to be too cumbersome and they were not regularly reviewing both even though they had access. Providing access to even more electronic systems would not scale to include all the various local systems in the region.

The longer-term solution that would also improve Information Continuity would be to consolidate systems and / or develop more robust health information exchange engines between the systems so users have a primary CIS through which they can access an integrated picture of their patients. Both of these options were being considered by IM/IT. These solutions, however, would be a number of years away and so were not considered feasible in this study. Instead, IM/IT participants recommended the temporary, focused improvements as described and these were supported in the discussion groups.

2. Develop an Advance Directives Repository

Advance Directives are care plans specifically targeted at future declines in health. They describe limits to care in certain situations, such as describing a patient's preferred treatment when their heart might stop. Advance Directives were highlighted many times by participants as an issue in end of life care in both communities. Perhaps this was highlighted more than other information, such as allergies or medical problem lists, because this was an end of life study and participants were predisposed to think about issues related to end of life. Or perhaps it was related to the Mr. Hart scenario, which highlighted a patient who may require CPR⁴⁶ (having had several heart attacks). Nonetheless, many participants raised lack of access to current Advance Directives as an issue in this study.

Several positions, including family physicians, ER physicians, other specialists, and nurses, included discussing and documenting advance directives as part of their job. They documented Advance Directives in many different places. Advance Directives (e.g. No CPR orders) were captured in different forms in multiple paper charts and could be found embedded in transcribed documents in PowerChart. Despite all these places and people who captured Advance Directives, they were often not available when needed. The ER Physicians highlighted this during their interviews:

“The thing that is most important and is often missing is the [Advance Directives] ... we often don't get that or it's nebulous.” (V12)

The gap was also raised by long-term care nurses and further supported by participants in the discussion groups.

“Advanced Directives...how many times do I have to go and peel through the damn chart to find out what the person wants to have done...they have to be a little be more clear...I have to read through a document - which is handwritten to boot! - and find out what they did or what did they not want to have done. It's unclear. When in doubt, I'm sending them to hospital, I have not a choice” (V05)

⁴⁶ Cardio-Pulmonary Resuscitation.

Family physicians noted this problem as well and stated that electronic systems could help support this level of continuity. One family physician (who previously covered the ER) thought that there would be benefit to having a repository for Advanced Directives, particularly when the family physician offices are closed:

“Landing in Emergency on the weekend after hours and having that ability to know what those important end of life – the advance directives – in an electronic form.”
(D01)

Providing a standardized and central electronic repository for Advance Directives was felt to improve care delivery by supporting patient’s wishes at the end of life. Instead of building a separate repository, this could be part of Cerner. This recommendation was suggested and supported by IM/IT as a feasible activity to design and implement within 12 months.

“It should be doable at all levels...at all levels...YES! There is somewhere somehow we could do it in PowerChart... it should be there along with all the other pertinent information you might want at your fingertips very quickly.” (IMIT02)

“Ideally Cerner would be it [the place for code status].” (IMIT04)

Cerner was thought to be a good place to house Advance Directives, especially when the strategic directions for VIHA included expanding the use of Cerner to include clinical documentation for acute care, long-term care and some ambulatory clinics. Further, if Advance Directives were placed in Cerner, many of the appropriate acute care providers would already have access to information. ER Physicians, long-term care providers, and other hospital providers all had access to PowerChart at the time this recommendation was endorsed. Providers would need targeted training where to find a patient’s directives and how to document them. Advance Directives were felt to be important enough by participants that they could be implemented prior to the rest of the electronic clinical documentation for VIHA. That is, these suggested improvements could be implemented within the next year.

The large part of the activity for this recommendation would be to develop and standardize the electronic form of directive and the clinical processes for Advance Directives. While there was general consensus that Cerner would be the preferred place within the region for Advance Directives, what was debated was how to implement them best within Cerner, as there are several potential options for how to build them into the CIS.

*“What is the best place for it [within Cerner] is what everyone struggles with”
(IMIT02)*

These details would need to be examined during the design phase of a project.

Related to the access model, Emergency Medical Services (e.g. Ambulance) could be granted access to this information as well, as, according to the ER physician participants, they often needed to find this information in crisis situations. This could be done through PowerChart with the enhanced access model development.

3. Enhance Pt-Provider Relationship Tables

Providers in this study were not always aware who were the other members of the Circle of Care. Although most were aware of some of the key roles (i.e. the Continuity Providers), they relied heavily on patients and their families to discover whom, specifically, might be involved in a patient’s care. When a patient cannot remember, or they do not have family, it became quite challenging for providers to know who are the patient’s key providers. This was felt to be worse in intense situations with new providers, such as the Emergency Department. As one ER physician said,

“Crisis brings out amnesia.” (V13)

An accessible list of key providers, such as the Continuity Providers highlighted in the conceptual models, would help to address this gap. A relationship table that tracks long-term relationships for each patient would allow the various providers to be able to not only see who is involved, but to keep them involved appropriately in the patient’s care.

In VIHA, Cerner included a fairly robust patient-provider relationship system. The Health Authority was able to configure a set of “lifetime relationship”⁴⁷ categories that could be used for the region. Lifetime relationships were patient-specific lists of providers that persist until they are updated. Each relationship category can be assigned a specific provider for each patient, or left empty if not appropriate. As Cerner also had an active provider registry (with contact information), the relationship tables were already linked to provider contact information. Ten lifetime relationships can be defined within Cerner for the region (Cerner, personal communication).

At the time of this study, VIHA used only a single lifetime relationship. VIHA was not fully utilizing their existing tools to support Continuity of Care. The single lifetime relationship in VIHA was the patient’s family physician. This information was valuable and was used in multiple places, including automated printing on all ID bracelets and cards and papers while patients were in hospital. It was also used for results distribution for outpatient laboratory results.

There are two pieces of design / development work that would be required as part of this Suggested Improvement. First, the specific relationships would need to be defined. Table 19 provides some examples that were developed by the participants in the two discussion groups. Next, the processes to assign and maintain these lifetime relationships would need to be adopted.

Table 19: A list of possible lifetime relationships, as supported by the research participants.

Family Physician / Primary Care Provider
Home and Community Care Case Manager or Home and Community Care Unit
Long-term Specialist(s) (e.g. Oncologist)
Mental Health Case Manager
BCCA Service
Hospice Service
Surgeon

⁴⁷ Lifetime relationships is the term used by Cerner, these are relationships defined at a patient level, rather than linked specifically to an encounter / visit, a nursing shift, or an order. The lifetime relationship is meant to be long standing. They do not have to last a lifetime and can be changed when the providers change (e.g. patient changes family physician’s).

The work from this study could be taken as the first iteration of the enhanced patient-provider relationship tables and the lists can be further developed.

To be useful, a list of providers would need to be kept up to date. Participants in the discussion group raised this as a concern with this suggestion. There were two ways considered to address the increased maintenance: first, designing the list of relationships so they are more static. For example, instead of listing a single provider name, a group or unit could be used. In the case of Home and Community Care, this might be more effective as there are several providers who may take a management role for a patient at any given time, but as the units were geographically arranged, patients were less likely to change units. The second way to reduce maintenance would be to embed corrections into regular practice and provide end users (patients and providers) with benefits if they maintained these relationships. The next suggestion builds on this idea and the relationship tables, making it more valuable to the providers who would want to maintain the accuracy of these relationships (also note in the mock up notification Figure 61 how the correction process could be embedded in the notification).

This suggestion would address the need discovered in the interviews to know which providers and services are involved in a particular patient's care. It would do this through better utilizing existing functionality in the primary regional CIS. As more people have access to the Cerner suite of tools (both through the IM/IT strategic directions and through the improved access recommendation above), this feature becomes more valuable.

4. Notify Providers of Transitions

Providers who had an ongoing relationship with a patient typically wanted to know when that patient's condition changes. Transitions (e.g. admissions, discharges from acute care) were good indications of changed conditions. Transitions were also times when patient care is often transferred from one set of providers to another, as was seen in the cases of Mrs.

Cann and Mr. Hart. Some of these transfers occurred without providers knowing the need for follow up.

Providers, such as ER physicians, tried to notify providers of these transitions, such as patient's family physicians:

"If they are admitted, on the standard admission form, there is a line 'ER clerk to notify GP' I don't know if it's done. We tick it every time." (V12)

But, from the family physician perspective, this was not working well:

"It's a real regional issue, I think, for Continuity of Care with VIHA... here, sometimes I receive reports, often I don't, and when I do receive them they are often weeks or months later... it also goes on to discharge summaries which are often delayed for months...it's a major issue. Often people come to the office saying, 'I'm here for follow up from my hospitalization' and it's like 'what hospitalization?' as I haven't received anything to indicate the person was in hospital even though it's weeks that have gone by." (V03)

Providers in this study were concerned enough about these gaps to put in significant manual processes in place. Hospice, for example, phoned the Cancer Centre for every patient admitted with cancer. The Hospital Liaison Nurses printed out a hospital census daily and had each admission and discharge manually cross-referenced with their Home and Community Care census, looking for overlapping patients. These manual processes were considerable and were not always effective, as Hospice and the oncologists discovered in during the discussion groups. Hospice was surprised that the oncologists rarely were notified individually, despite regular phone calls during admissions to the cancer centre. Clearly there was a process issue with some of these manual activities.

A more targeted and automated process was considered by IM/IT. By connecting three existing pieces of VIHA's IM/IT infrastructure, the regional Admitting Discharge and Transfer system (ADT system), the regional results distribution systems, and the lifetime provider relationship tables (as they existed at the time of the study or enhanced as described above), a regional notification system could be built. This would require some fairly simple

report writing and VIHA would have a regional notification system. This system would, when a patient was admitted or discharged, automatically route simple clinical notifications to specific providers or services that are named in the patient's enhanced patient-provider relationship list.

The process, illustrated in Figure 60, would rely on existing activities related to the delivery of care. Once the reports were developed, it would require minimal additional manual intervention. All admissions, transfers, and discharges were being recorded in the Cerner ADT systems for census and billing purposes. Current practice had this completed in near real-time. Providers involved in the admission were also always recorded (e.g. admitting physician, most responsible physician). Cerner had the capability to automatically run reports based on specific triggers. Those triggers included admission or discharge actions in the ADT system.⁴⁸ An automated report could pull information already contained in the ADT system, such as patient information, location, most responsible physician and reason for admission (see Figure 61 for a report mock up based on some of the information available in the ADT system). Participants in the discussion groups agreed that this level of detail was useful in a notification.

⁴⁸ Those triggers can also be specific to the type of admission or discharge (e.g. include acute admission and discharge, ER admission and discharge, but exclude ambulatory admissions). Thus reports could be quite targeted. Reports could be customized to notify only certain types of providers for certain types of triggers (e.g. only the family physician gets notified when the patient is "admitted" to the Home and Community Care service, but multiple providers are notified of an admission to hospice or Emergency Department).

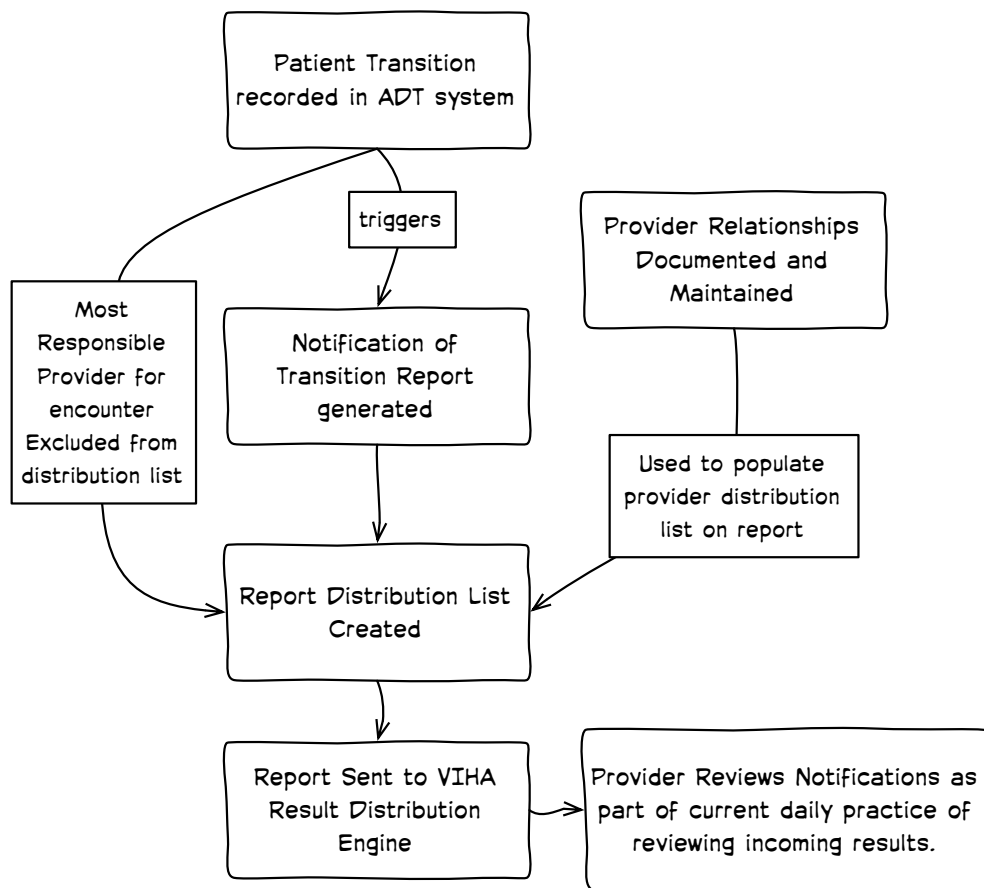


Figure 60: Description of the notification of transition process, leveraging existing VIHA infrastructure.

Name: Mr. Hart	VIHA
Age: 71 Sex: M	
Date of Birth: 13-Aug-1939	
PHN: 9354872392 BC	
Home Phone: 250-555-5555	Sent: 18-Sep-2009
	1915
Family Physician: Dr. Jones	

Your patient was Discharged from Royal Jubilee Hospital.

Admitted under: Dr. Smith (Cardiology)

Consulting Physicians:

Admitted: 12-Sep-2009 0500

Discharged: 18-Sep-2009 at 1905

Discharge Disposition: Home

This notification has been sent to you as you are registered as this patient's family doctor. If you are not this patient's current family physician, please call 1-800-NOT-MEEE.

You can review more information by logging into PowerChart.

Figure 61: Mock up of a notification sent to Mr. Hart's registered family physician after an admission under Dr. Smith, the cardiologist. Although limited in clinical details, the information contained in the report – and its timeliness – was thought to be quite beneficial by participants.

The report would be automatically sent through VIHA's regional result distribution channel, which already supports both paper and electronic messaging. The lifetime provider list would be used to populate the distribution list for these notifications.⁴⁹

Using the existing results delivery system reduces the need for additional infrastructure, only the addition of a new report type. It also limits the amount of change management as providers across the region are used to review incoming laboratory results and other reports from VIHA on a regular basis. The main additional overhead would be to ensure that the

⁴⁹ It was proposed that the admitting physician and most responsible physician would be excluded as to not overly clutter those providers' inboxes, as they already are aware of the admissions / discharges. However, this would need to be confirmed during design sessions.

list of provider relationships was up to date. A contact number in the report could be used to trigger recipients to correct errors (see Figure 61).

By leveraging these existing components, it was felt that it would be possible to create this type of notification within one year with minimal investment by the region. The report would need to be developed, a new message type would need to be defined, testing and communication to providers would need to be completed. This is a relatively small investment, with several potential benefits to the healthcare system.

This automated notification tool would allow for several of the manual notification activities to stop, reducing errors and freeing up time of existing clinical staff. Manual phone calls on admissions would be reduced, such as the calls made by the hospice Palliative Care Coordinator, freeing time to help with management of patients. The Hospice nurse, in particular, was pleased to consider that she might have more capacity.

The Home and Community Care daily review of the hospital censuses (once for each hospital) could be stopped across the region. This would improve efficiency for Home and Community Care, freeing up both nurse and clerk time each day. It was remarked by participants that this would also provide a more timely notification for Home and Community Care, as the manual review occurred only once a day based on the census printed in the morning - any discharges that occurred after the printing were not caught until the next day with the manual approach. With this automated system, the notifications would be in near real time, throughout the day. This would allow for Home and Community Care to see patients sooner after discharges.

Privacy would also be improved. Currently the entire hospital lists are reviewed, cross-referencing for any Home and Community Care patients. This would not be required with this notification tool.

This solution would improve continuity for family physicians, even those without admitting privileges.⁵⁰ Physicians would be notified of admissions / discharges quickly, and may then

⁵⁰ Family physicians without privileges currently receive results and reports through the existing distribution system.

be able to better coordinate care. They could send patient summaries to hospital on unplanned admissions. They could contact patients post-discharge to ensure they have follow-up appointments and sufficient medications (at the time of the study, physicians waited weeks for the discharge summaries to be notified of an admission / discharge). Even without developing the more robust list of lifetime relationships (as proposed above), there would be benefit to patients in the region with notifications to family physicians.

The current suggested improvement uses the ADT system as the trigger for this process as it is always used to track patients. It was thought that the ADT system had enough detail to allow for specific admission types to trigger the reports and not others (e.g. inpatient admissions, not ambulatory encounters). As VIHA implements its electronic clinical documentation tools inside of Cerner, the report could pull additional data from the Cerner repository. This would create more of an automated discharge summary, thus, this approach also creates a piece of foundation that can be scaled over time to provide more value.

5. Pilot Improved Use of Case Conferences

Several of the care teams used case conferences to help ensure Continuity of Care. These were felt by providers to be effective for Victoria Hospice, the Cancer Centre, Home and Community Care, and long-term care. They supported Management Continuity as well as helped to develop and support Inter-Provider Continuity. Providers got to see each other and speak with each other. One of the limitations of these case conferences was the lack of family physician attendance. There was a consistent lack of attendance, particularly for long-term care, Hospice and Home and Community Care. This hindered planning and often required additional communication (e.g. faxes) with information about case conferences, somewhat defeating the purpose of the conferences.

"Ideally the doctors attend that [the annual review]. The doctors very often can't... or don't" [attend case conferences]" (D04)

Family physicians had logistic challenges to attending these conferences, which were typically scheduled in the middle of busy office days and were often a distance away.

The BC Medical Association has acknowledged the benefit to having family physicians attend case conferences and added new fee codes to allow for family physicians to be paid specifically to attend community or facility based case conferences with other providers and / or family members (Table 20). These can be billed for end of life patients.

Table 20: BC Provincial Fee Codes and descriptions as of 01-Apr-2009 that relate to Case Conferencing, from (BC_Government, 2009)

Facility Patient Conference Fee	
G14015 General Practice Facility Patient Conference: when requested by a facility to review ongoing management of the patient in that facility or to determine whether a patient in a facility with complex supportive care needs can safely return to the community or transition to a supportive care or long-term facility	
- per 15 minutes or greater portion thereof.....	40.00
Community Patient Conference Fee	
G14016 General Practice Community Patient Conference Fee: Creation of a coordinated clinical action plan for the care of community-based patients with more complex needs. Payable only when coordination of care and two-way collaborative conferencing with other health care providers is required (e.g. specialists, psychologists or counselors, long-term care case managers, home care or specialty care nurses, physiotherapists, occupational therapists, social workers, specialists in medicine or psychiatry) as well as with the patient and possibly family members (as required due to the severity of the patients condition)	
- per 15 minutes or greater portion thereof.....	40.00

However, even with these new fee codes, family physicians were not taking the time to travel back and forth. The coordination and travel time appeared to prohibit attendance, at least in the communities in this study. There were two ways considered to eliminate the burden of travel time, which could improve family physician attendance at case conferences, improving their effectiveness.

First, *virtual* case conferences were discussed. The fee codes did not appear to limit Case Conferencing to face-to-face meetings. An initial pilot could be established simply by using a standard teleconference line to dial into at a specific time. This would limit face-to-face contact. The participants also discussed videoconferenced Care Conferences, to provide a greater experience. This was thought to have too much overhead and infrastructure requirements, especially with budgetary constraints in VIHA. Teleconferenced case

conferences were certainly feasible and could easily be piloted. The virtual case conferences can be easily expanded to include other specialists as well (e.g. oncologists).

The other approach would be to have the nurses, the patient, and family come to the family physician's office for the case conference. This option was only relevant for ambulatory patients (i.e. this wouldn't work for long-term care). It had the benefit of more face-to-face contact, which is helpful in improving Inter-provider Continuity. However, it moves the burden of travel from the family physician to the nurse.

Although all participants in both discussion groups supported this recommendation at a high level, the two communities were divided on which option was preferred. Duncan providers were far more supportive of working on the in-person, family physician office case conferences. Indeed, the Duncan discussion group began discussing how to reorganize the home care structure so that it is *entirely family physician centric* rather than being geographically based. The Victoria group was much more interested in setting up a few teleconference lines and piloting virtual case conferencing at a few key points of care, such as the transition to palliative care and for long term care admissions. This was one of the most prominent differences in opinion between the two discussion groups in the study.

It was decided to pilot each approach, one in each community as engaging family physicians, in particular, in the case conferences, either virtually or in person, should support better care planning and improve both Management Continuity and Inter-provider Continuity.

6. Design a Regional Clinical Communication Tool

Many participants voiced a clear need to improve communication between care teams in both communities. Often, participants requested some form of regional clinical email system⁵¹ to improve communication and to reduce the reliance on faxing and other paper

⁵¹ Email has many issues when used as a clinical communication tool, such as insufficient security (especially if communicating to non-secure addresses), lack of structure, and no

tools. The need was to better support communication beyond the borders of care teams and organizations, as one provider put it:

“Secure email would be handy for a lot of people if not all... if it’s only the physicians in there, it still doesn’t address the issues with respect to how you communicate with home care nurses and other people.” (D06)

Stead (Stead, 2007) has discussed how to stage an implementation of CISs in a way that keeps the clinical benefits exceeding baseline performance. In this view, performance should not ever dip below baseline, even when there drop in performance due to changes and learning new tools. A staged implementation, in a specific order, can help this (Figure 62). VIHA was generally at the first stage: Record Access, in Stead’s implementation model. Thus, it is fitting that the major IM/IT developmental suggestion from this study would be to design a regional clinical communication tool. This suggestion corresponds to Stead’s second stage.

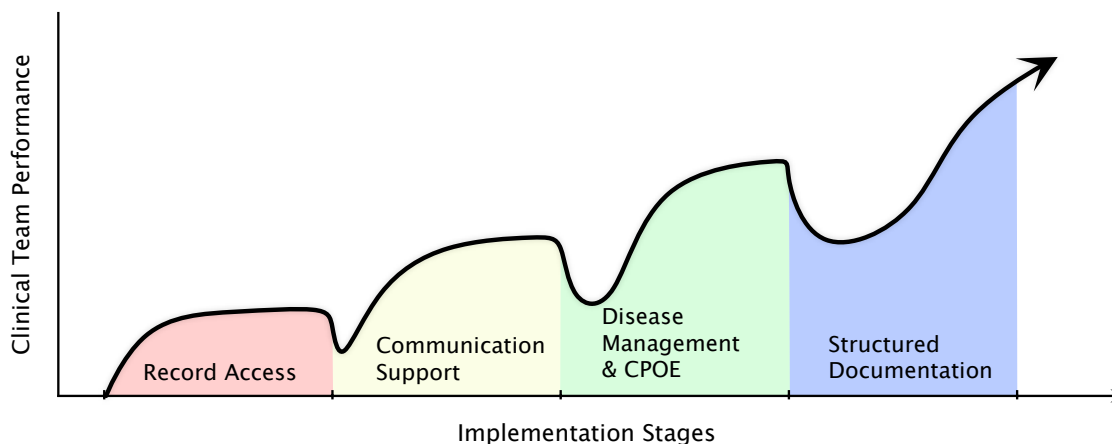


Figure 62: Clinical team performance changes related to staged implementation of features of a clinical information system. By sequencing the stages, one can attempt to ensure that the decrease in performance due to change never dips below the original baseline performance. Based on (Stead, 2007).

connection to existing electronic repositories. Still, the need for better electronic communication tools was clearly noted.

VIHA's IM/IT Strategy included the configuration and deployment of a Cerner component called *Message Centre* within acute care during 2009-2010 (VIHA, 2009c). This tool was being deployed to support results reporting within hospitals and some clinics. It contained an inbox where providers could see their new and unsigned results. The Message Centre component also included a clinical communication tool (see Figure 63 for a sample test screen capture) that could be turned on.

Participants in this study recommended and supported exploring Message Centre as a broadly available clinical communication tool for the region as part of the suggestion for an improved communication tool.

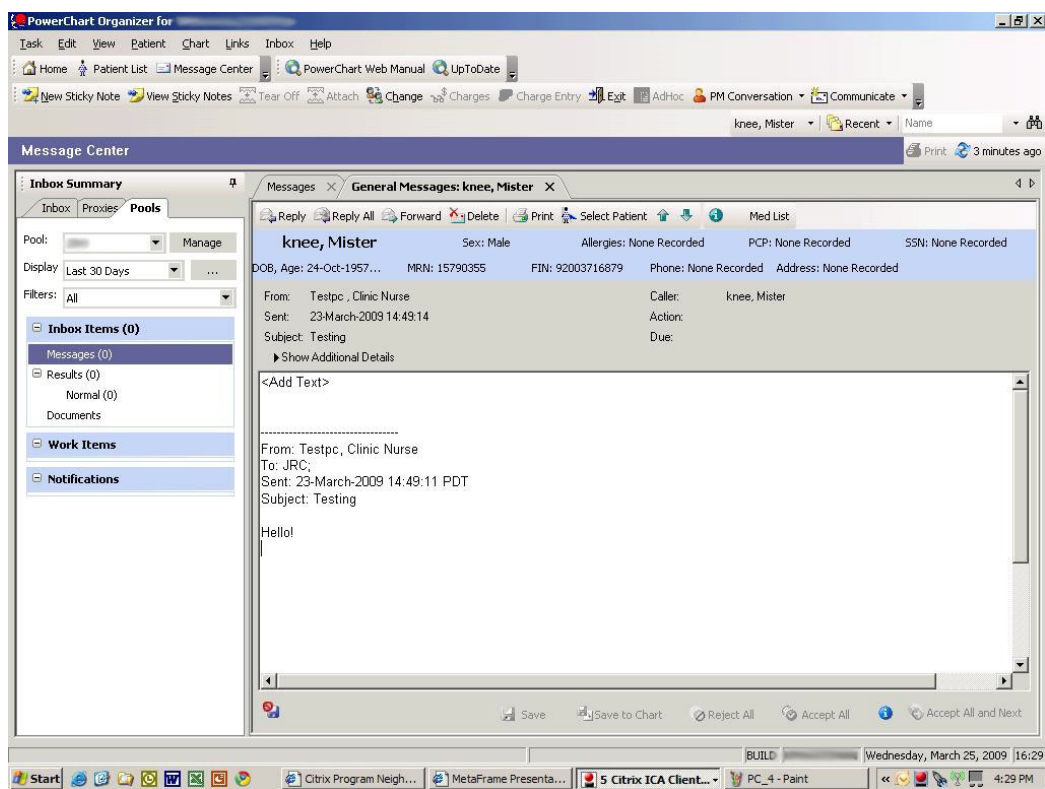


Figure 63: Screen capture from a test build of VIHA's Cerner Message Centre component.

Message Centre was able to leverage all user management and access features of the existing Cerner installation (and recommendation 1 on improving access). Unlike email, messages can be assigned to specific patients and stored in their Cerner record. This would provide two benefits over email: other members of the team can access those messages to review discussions and decisions; and messages would become part of the patient's ongoing record. Given that VIHA was embarking on developing Message Centre to help better manage results, it was considered a good time to ensure that the scope of the design effort includes a broader messaging component that could be used across the various major Care Teams in VIHA (such as home and Community Care, primary care, long-term care, hospital, and Hospice).

Despite several advantages, Message Centre was not an ideal solution. The main limitation was that there would be a significant change in workflow required for many providers. Many providers today do not use PowerChart routinely, or even daily. For providers who would use another system as their primary CIS (e.g. private offices with an EMR, Home and Community Care, private long-term care facilities, BCCA), PowerChart becomes another place that need to be reviewed consistently in order for this solution to be effective. This would be challenging change management and would likely limit the usefulness of Message Centre across the entire care system unless done well.

Further, due to the technical infrastructure that Cerner was built upon, remote printing (e.g. in the physician's office) would not be supported.⁵² Thus, a level of parallel documentation would still be required for providers outside of VIHA. Finally, another challenge was that not all care providers would have access to VIHA's Cerner PowerChart (and thus Message Centre). Private facilities and private organizations would still, likely, need to use faxes to communicate between each other instead of using the VIHA system, so this solution would not retire that form of communication.

⁵² Printers need to be individually mapped to a central master list of printers that can be printed to. The workload required to support individual printers throughout all private offices in the region was considered prohibitive for IM/IT.

Even with these challenges, the use of Cerner's Message Centre was thought to be the best – and most feasible – option to address the need for a regional clinical communication tool. The use of Message Centre could retire the use of VIHA email for clinical work, which would be an improvement over today's practices.

The recommendation here was focused, explicitly, on the design of the solution, not a full implementation. It was not felt that this recommendation could be fully realized within the next twelve months, given other priorities in the region, but that the design could be completed and, perhaps, a limited pilot would be considered in a smaller community, such as Duncan. As the implementation of Message Centre was being configured for acute care as part of an existing project in the IM/IT strategy, it was felt that timing was good to include design requirements from this recommendation into that VIHA project.

Improvements Not Recommended

There were several areas where VIHA could better support Continuity of Care that were not captured in the suggested improvements from this study. Some of these were “infeasible”, that is, they were considered by the participants to not be implementable within the timeline of one year. Other improvements were only locally relevant and did not have potential for regional improvements.

Computerized Provider Order Entry (CPOE), for example, could better support several of the Abstract Genres (Request Assessment / Treatment, Orders, and Transfer Care). CPOE was not recommended as an improvement because it was not felt that it could be incorporated into the current strategy within the timelines. The current three-year VIHA IM/IT strategy was focused on clinical documentation, with CPOE being the next large implementation, i.e. will be the focus of the next three years. Thus, improvements that would support developments of shared care plans and order sets were excluded, even though participants raised these issues.

There were also many local issues that were not addressed in the suggested improvements. These often related to local processes that could be changed or a need for specific education

on services that were currently available but not being utilized. Examples included: access challenges to Victoria Hospice outpatient dictations, and the lack of a congestive heart failure coordinator nurse position in Duncan. These were not necessarily relevant to the region, but had value to the local communities. These findings were to be brought back to the local communities through presentations upon completion of this study.

Suggested Improvements Summary

The six suggested improvements were developed from feedback from the research participants and were designed to build on the existing infrastructures in the region. They were designed to address gaps observed in Continuity of Care. Table 21 provides a mapping between the suggested improvements and each of the four types of continuity.

Table 21: Mapping of the six recommendations from this study to the four components of continuity in the Extended Continuity of Care Model.

Recommendation	Information Continuity	Management Continuity	Relationship Continuity	Inter-Provider Continuity
Improve Access to appropriate CISs	X			
Develop an Advance Directives Repository for the Region		X		
Enhance Pt-Provider Relationship Tables			X	
Notify Providers of Transitions		X	X	
Improved Use of Case Conferences		X		X
Design a Regional Clinical Communication Tool		X		X

Together, these suggestions would support improvements to each type of continuity. This was felt to be important because many clinical information systems today are being designed and implemented with a focus on Information Continuity being the main aspect of Continuity of Care (see 0). They can miss other aspects of Continuity of Care.

DISCUSSION SECTION

Chapter 16 Discussion Outline

The discussion section is organized by the four potential contributions that this study has made. These were initially based on the four objectives of the study, although there has been evolution of these aspects as the study progressed. The four areas are:

1. **The Six Suggestions for Improvement** – This chapter reviews the six regional recommendations and explores their broader application, outside of Vancouver Island.
2. **The Extended Continuity of Care Model** – Describes a new model for Continuity of Care that includes key findings from this study. This model is discussed in the context of how it might support future work on describing and measuring Continuity of Care.
3. **Abstract Genres as Communication Patterns** – examines the broader applicability of the Abstract Genres that were developed in this study. First, they are compared to Genres developed in pediatric nephrology. This is followed by an exploration into how the Infoway pan-Canadian Electronic Health Record supports the Abstract Genres.
4. **The Circle of Care Modeling Approach** – This chapter summarizes the modeling approach developed in this study. It also discusses how it could be used to support strategic thinking as well as provide useful context for more detailed requirements development.

The discussion section ends with a review of the study's research question and the original four objectives.

Chapter 17 Further Application of the Suggestions for Improvement

This chapter reviews this study's suggested improvements and explores their applicability to other jurisdictions by relating these recommendations to the Canada Health Infoway EHR design.

The Six Suggested Improvements

Six suggested improvements were developed based on the challenges highlighted by the research participants and the gaps discovered in the Rich Picture and Conceptual Model analysis (see Chapter 15). The six recommendations were interconnected and intentionally built on each other. The suggested improvements were developed to solve regional issues and were based on findings in two local communities.

The issues they addressed were likely not unique to Vancouver Island and these suggestions could have application in other regions and jurisdictions.

To confirm this, the six suggested improvements were compared to the current Canada Health Infoway blueprint for the pan-Canadian EHR (Infoway, 2006) to see if these recommendations were met by the current EHR design.

Six Suggested Improvements

- 1. Improve Access to appropriate CISs*
- 2. Develop an Advance Directives Repository for the Region*
- 3. Enhance Pt-Provider Relationship Tables*
- 4. Notify Providers of Transitions*
- 5. Improved Use of Case Conferences*
- 6. Design a Regional Clinical Communication Tool*

1. Improve Access to Appropriate CISs

The pan-Canadian EHR was designed to improve access to patient information that was previously inaccessible. The EHR improves access to patient information not by providing direct access to existing clinical information systems, but by allowing those systems to interface with the EHR and upload and/or view content housed within the EHR. This option was not considered feasible for this study, due to timing. It was not clear when the EHR would be available for providers in the region populated with the content that was needed from the regional CISs.

Provided the EHR contained the content, the EHR would have addressed the need to improve Information Continuity, but in a different manner. Further, the EHR approach may be more scalable when there are many disparate systems. With a jurisdictional EHR with sufficient patient information, a provider may only need access to their primary CIS and the EHR repositories. This assumes that the EHR would contain the data that the provider needs.

2. Develop an Advance Directives Repository

Advance Directives were seen to be an important piece of patient information that should be shared across the Circle of Care. Gaps in continuity of Advanced Directives have been noted by other studies; for example, there are gaps in communicating Advance Directives between hospital and nursing homes (Ghusn, Teasdale, & Jordan, 1997). Advance Directives were not part of the pan-Canadian EHR content standards at the time of this study. Future work could include promoting the inclusion of Advance Directives into the EHR. Having the directives in a provincial level EHR repository better supports access to this important patient care plan across a province or the country, as per the Infoway EHR design.

3. Enhance Patient-Provider Relationships Tables

The Infoway EHR design had both a patient registry and a provider registry. However, it did not include a mapping of patient-provider relationships. Providing a list of ongoing relationships for patients in the EHR would be a significant benefit to Relationship Continuity, but it was not supported in the current Infoway design. Admittedly, there would be significant business processes that would have to be developed to support maintaining

this at a provincial level, which may have been a reason why this was excluded from the current design.

4. Notify Providers of Transitions

The Infoway EHR design did not support results distribution or sending of specific messages to providers. Thus, work would need to be undertaken in the future to include this feature in the EHR. The Infoway blueprint did have the concept of encounters and it maintained a repository of providers, so it could trigger messages based on when various encounters are added to the repository. Patient-provider relationship tables would be a dependency to this work. Notifications of this kind would improve communication between providers during times of transitions for patients, which is one of the position statements described by the American Geriatrics Society as a way of improving quality of transitions (Coleman & Boulton, 2003). Discharge notifications to patients' family physicians (as the primary care provider) on the day of discharge would be considered the simplest, effective notification type (Kripalani, Jackson, Schnipper, & Coleman, 2007).

5. Improved Use of Case Conferences

The EHR itself did not support improved case conferences. Infoway did also have a mandate is to support telehealth activities, and Infoway has invested nearly \$100CDN million in telehealth projects to date (Infoway, 2009). Telehealth supported virtual case conferences were discussed by participants in this study. Case conferences were one of the more difficult aspects of care to coordinate, particularly for home care, where the various providers were not in the same location (Warner, RNC, & MLSP, 1996). Telehealth could be effectively used to support the virtual case conferencing (S. Wilson, Marks, Collins, Warner, & Frick, 2004). Infoway's telehealth program could consider exploring the use of the telehealth infrastructure to trial video-based virtual case conferences.

6. Design a Regional Clinical Communication Tool

With its cross-organizational focus, the EHR would be the preferred system to house a clinical communication hub. Indeed, the overall messaging approach of the EHR could support this very well. An ER physician in VIHA could use Cerner, a family physician could use their own EMR, and Home and Community Care could use their application. Each

would create, receive and respond to messages within their own system, integrating with their existing workflow. Messages would be sent through the EHR to their intended recipients.

At the time of this study, the scope of Infoway's EHR was focused on the jurisdictional / pan-Canadian repositories. However, if Stead's (Stead, 2007) recommended implementation approach were supported (Figure 62), then communication tools (which could include notifications of transitions as well) would be the next step in Infoway's design for the EHR.

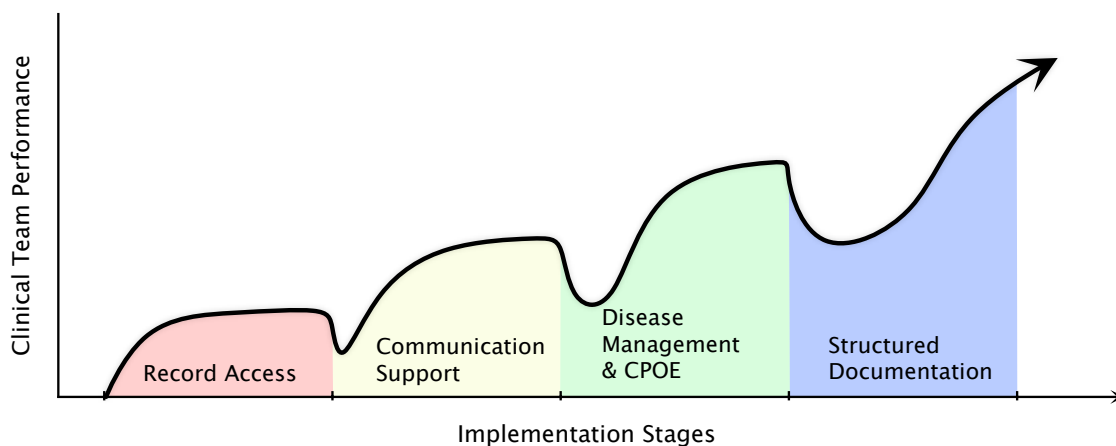


Figure 64: Clinical team performance changes related to staged implementation of features of a clinical information system. By sequencing the stages, one can attempt to ensure that the decrease in performance due to change never dips below the original baseline performance. Based on (Stead, 2007).

In summary, the six suggested improvements discovered in this study, potentially, have a level of application outside Vancouver Island. In some ways, Canada Health Infoway's pan-Canadian Electronic Health Record was at a similar point of design to the regional clinical information systems seen in this study – both are primarily focused on providing access to records (using Stead's model above). Therefore, it was not surprising that the findings in this study may have some application in Infoway's future work. Therefore, the suggested improvements from this study could provide support and direction to expand the Infoway EHR's design for content and functionality.

Chapter 18 An Extended Model of Continuity of Care

This chapter describes the development of Extended Continuity of Care Model, which occurred over the course of the study. It also compares the extended Continuity of Care Model to other models of Continuity of Care from the literature and describes why this model is an improvement over previous descriptions of Continuity of Care.

The Haggerty and Reid model of Continuity of Care was used as a foundation for this study (Figure 3 and described in the background chapter on Continuity of Care). It was based on a multidisciplinary literature review and had been adopted nationally in Canada and consists of three levels of Continuity of Care.

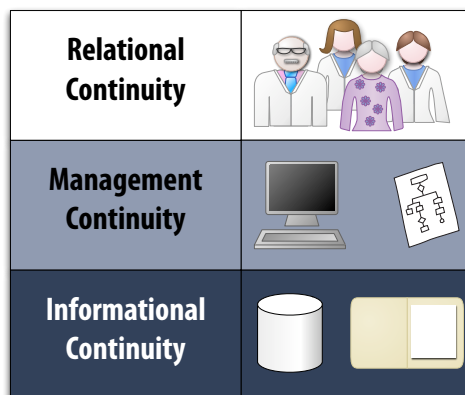


Figure 65: Three levels of Continuity, based on (Haggerty, et al., 2003).

There were findings from this research that supported each of the three levels of continuity in the Haggerty and Reid model. Also, through the course of the study additional aspects to Continuity of Care were highlighted (see Chapter 12). To address these additional aspects, the Extended Continuity of Care Model was developed (Figure 66).

This new model is derived from the patient-centric, systems approach taken in this study. The model, therefore, has made the patient explicit and central to Continuity of Care.

In this study the family also played a significant role in care. Perhaps this was because of the focus on end of life care, where families have a larger role. Nonetheless, they were found to be an important component of the care system, acting as family, providers, and surrogates for the patient when they were not able to make decisions. Communication with family members has been cited as one of the key issues in end of life care (Hanson, Danis, & Garrett, 1997). Family members were included with the patient as part of the core of the model to signify that they may also act as surrogates for the patient.

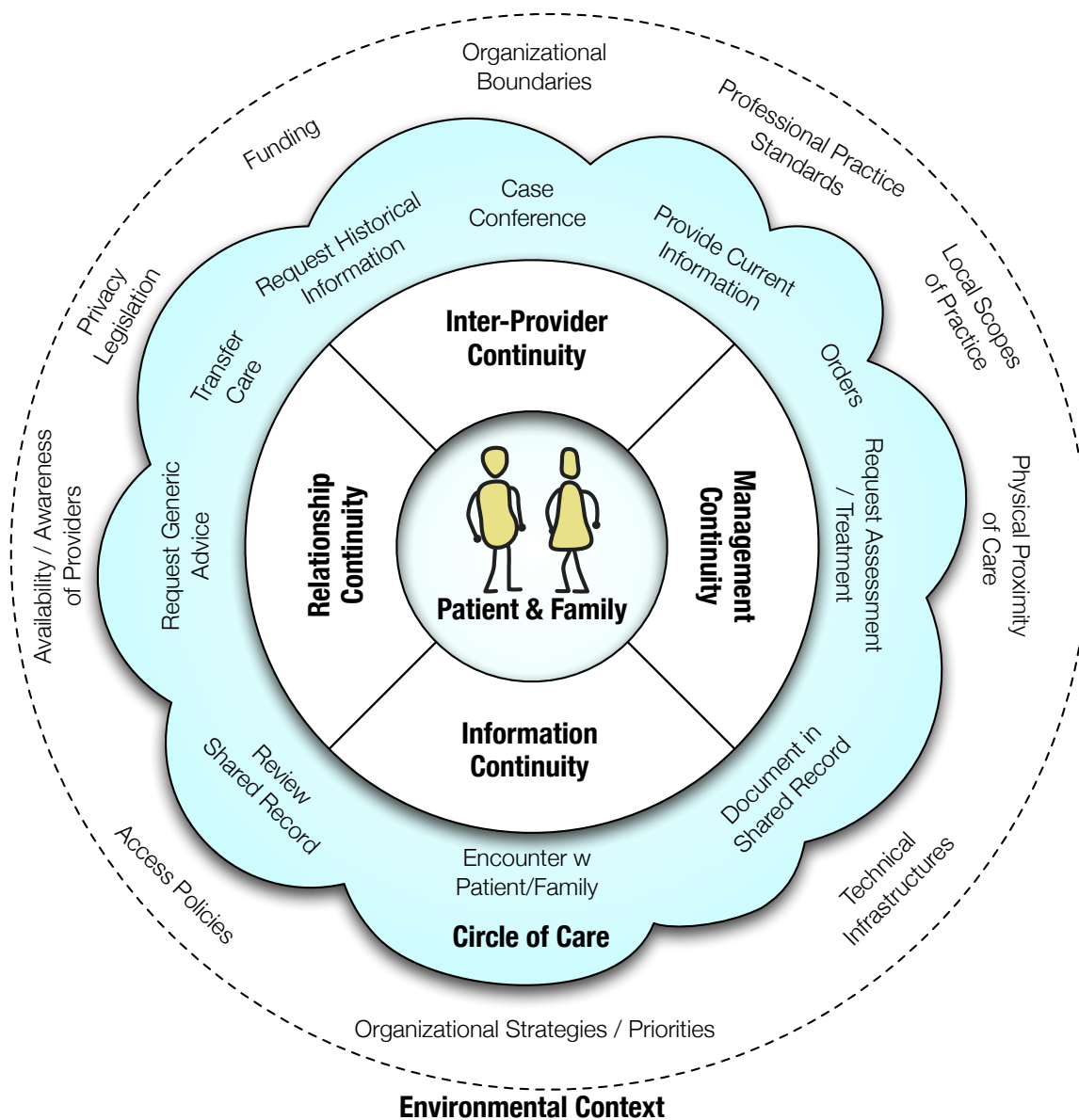


Figure 66: *The Extended Continuity of Care Model.*

The four types of Continuity of Care were captured in the model. This included three types of continuity from Haggerty and Reid as well as Inter-Provider Continuity. These were illustrated in a circle around the patient and family as there was a balance that occurred between these that should be considered when making changes. There were examples from the study where one type of continuity was traded for the other, such as: transferring care from a patient's family physician to a dedicated long-term care physician during an admission

to a residential facility, or transferring patients to other providers in another community to receive hospice services. In both of these examples, Relationship Continuity was sacrificed to improve Inter-Provider Continuity and Management Continuity. It was important to note that these types of continuity were not equal. One cannot simply increase access to information (increasing Information Continuity) to fully compensate for a reduction in Relationship Continuity (GK Freeman, Olesen, & Hjortdahl, 2003). Consideration of the trade offs is required to ensure high quality care is delivered.

Next, the Circle of Care was explicitly highlighted. The Circle of Care describes the boundaries of the system in which Continuity of Care was maintained. The Circle of Care contains all the providers involved in the patient's care as well as the information repositories and communication activities between providers. The Circle of Care may not be homogeneous, but could be made up of embedded Care Teams, which have different members, repositories, and communication patterns. The irregular shape of the circle highlights this irregularity seen within the Circle of Care. The Abstract Genres describe the types of communication patterns; they captured the ways in which members within the circle communicate to maintain Continuity of Care. The Abstract Genres were highlighted as they described the type of work needed to support the levels of Continuity of Care (see Table 22).

The Environmental Context was the background to the system (i.e. the Circle of Care) that maintains Continuity of Care. As in SSM, the environment can influence activities within systems, but the system does not have control over the environment. The examples within the Environmental Context were captured from the SSM modeling of the Abstract Genres (See Appendix J). As an example from this study of how the environment factors could impact Continuity of Care: during this study, between the interviews and the discussion groups, VIHA announced a significant budget shortfall. The media highlighted this in the local paper, *"The health authority is scrambling to avoid a budget shortfall of \$45 million - about 3.1 per cent of its budget"* (Shaw, 2009). This required a clear limiting of the scope of the recommendations so they remained "feasible" and it was out of control of members of the Circle of Care. Funding was one environmental constraint that particularly impacted this study's recommendation development.

Table 22: Mapping between the four levels of Continuity of Care and the Abstract Genres.

	Information Continuity	Management Continuity	Relationship Continuity	Inter-Provider Continuity
Communicate with Patient / Family	X	X	X	
Request Historical Information (PMHx) ⁵³	X	X		
Provide Information	X	X	X	X
Document in Shared Record(s)	X	X		
Review Shared Record	X	X		
Request Advice				X
Request Assessment / Treatment	X		X	X
Order		X	X	
Transfer Care		X		X
Coordinate as Care Team		X	X	X

Comparison to other models of Continuity of Care

Haggerty and Reid’s model of Continuity of Care was chosen as the initial Continuity of Care model for this study. There were other models that were also considered. The reader may recall that these were described earlier in the Background Section. These were mapped to the extended Continuity of Care Model (see Table 23).

⁵³ PMHx = Past Medical History

Table 23: Mapping of three other models of Continuity of Care to the Extended Continuity of Care Model.

Source	Type of Continuity	Mapping to the Extended Continuity of Care Model
Hennen (B. Hennen, 1981)	Chronologic	Management Continuity, but Hennen's description has a distinct focus on care being provided by a single provider over time rather than across multiple providers.
	Geographic	Captured within the Environmental Contexts "physical proximity of care" and "availability of providers"
	Interdisciplinary	No direct mapping, this refers specifically to the family physician being able to provide to care for a patient at multiple stages of their life, i.e. that a family physician is a generalist.
	Interpersonal	Relationship Continuity
Wall (Wall, 1981)	Chronologic	As in Hennen
	Geographic	As in Hennen
	Interdisciplinary	As in Hennen
	Interpersonal	As in Hennen
	Informational	Information Continuity
Saultz (Saultz, 2003)	Informational	Information Continuity
	Longitudinal	Some overlap with Management and Relationship Continuity, however, also has the concept that a patient has a 'medical home' where the majority of care is delivered.
	Interpersonal	Similar to Relationship Continuity
	Geographic	Some overlap with Management Continuity in that care delivery is consistent across settings.
	Interdisciplinary	Overlap with Informational and Management Continuity, does not appear to address the concept of Inter-provider Continuity.
	Familial	Captures the concept of the social aspects of family impacting care, does not capture the role of the family in supporting care.
Sparbel (Sparbel & Anderson, 2000b)	Communication Issues	Captured in several areas including patient and family central to the model, Inter-provider Continuity, and Organizational Boundaries
	System Issues	Captured in the Environmental Contexts

Many of the concepts in these models were similar and there was overlap between the types of continuity listed in the various models. The majority of concepts from the different models map back to the new extended model. The one potential gap was the concept of Familial Continuity in (Saultz, 2003), which captured the genetic aspects of Familial

Continuity. Familial Continuity was not explicitly part of the Extended Continuity of Care Model; however, it would be contained within Information Continuity.

Several of these models were similar in that they list continuity types. Sparbel's Continuity of Care model (Sparbel & Anderson, 2000b) was the only model that explicitly described system issues and so a deeper comparison was performed between this model and the Extended Continuity of Care Model. The Sparbel description of continuity (in a two part series (Sparbel & Anderson, 2000b) and (Sparbel & Anderson, 2000a)) includes communication and system issues. This model was developed based on a review of the nursing literature. Papers that were reviewed included focus on different care settings (acute, community) as well as transitions of care between these settings. Communication was found to be a factor influencing Continuity of Care in nearly two thirds of the studies in their review (see Table 24 to review the specific communication issues). System issues impacted continuity in over 80% of studies they reviewed. Table 24 also lists the specific system issues described. In reviewing the list of system issues in the table, one can see that these issues are related to the greater healthcare system. Thus, Sparbel's system issues describe many of the other aspects that would be captured in the Extended Continuity of Care Model's Environmental Context. Unlike this study, Sparbel did not define the system within which Continuity of Care is maintained.

No model defined the system within which Continuity of Care was maintained. In SSM and other systems thinking, it was considered important to understand and describe the system in order to appreciate its wholeness (P. Checkland, 1981). Indeed, it is a requirement of using SSM. By taking a systems approach, and defining the Circle of Care as the system, I was able to describe the nature of Continuity of Care in a different manner than other previous studies. The Extended Continuity of Care Model captures many aspects of the other models, but it also defines additional aspects of continuity not contemplated. There were several implications the Extended Continuity of Care Model. These are discussed next.

Table 24: Detailed list of factors related to continuity from (Sparbel & Anderson, 2000b).

Sparbel's Continuity Model
Sparbel Communication Issues
Between Organizations
Between provider and family/patient
Between providers within same organization
Sparbel's System Issues
Coordination/networking process
Organizational commitment
Financial/length of patient stay
Staff support or availability
Professional role
Consistent personnel
Lack of or incorrect resources or knowledge
Patient needs or assessment

Implications of Extended Model of Continuity of Care

In this study, I took a patient-centric and systemic approach to Continuity of Care. Combining the approach with the specific study findings, I was able to capture several components in a new and more robust model of Continuity of Care. The other models individually captured several of the elements of the Extended Continuity of Care Model, but none explicitly defined the boundaries of the system or captured the specific communication patterns required to maintain continuity. The Extended Continuity of Care Model has specific benefits for those wanting to apply this model in practice.

Unlike other models of Continuity of Care, analysts can apply the extended model more readily, as it contains more explicit content. First, the model helps analysts understand that continuity occurs within a system, the Circle of Care. By describing the patients' care system, challenges can be highlighted and improvements sought at community or regional levels as were done in this study. Analysts could adopt a similar improvement process to the method described in this study, or they can take the model and explore Continuity of Care using other methods.

The Extended Continuity of Care Model can be used by IT practitioners who are considering implementations and changes to CISs. The Abstract Genres defined in the extended model provide a set of communication patterns. These could be used to explore

ways to better support flow of communication within an organization or between organizations.

At a higher level, health system planners (e.g. government) could consider how large system / organizational changes impact the aspects of the Environmental Context. Planners could reason about how changes would support / disrupt activities within Circles of Care for various types of patients. The Extended Continuity of Care Model, with its defined system and more explicit content, makes the somewhat vague concept of continuity more concrete to analysts and planners seeking to improve quality of care.

Analysts and planners can use the four types of continuity to reason about trade offs required for activities like creating specialized services or the regional consolidation of services. Through consolidation, for example, Management Continuity may be improved locally, but at a trade off of Relationship Continuity and Inter-Provider Continuity. Further, consolidation or increased specialized services will require increased communication to ensure Information Continuity is maintained across the larger Circle of Care. Trade off analysis (Johnson, 1974) or conjoint analysis (Green, Krieger, & Wind, 2001) can be used to reason about proposed changes and compensate for expected gaps while planning changes in processes. For example, in this study, the Palliative Response Team actively increased communication with family physicians and home care nurses when they were involved so that Relationship Continuity would not be as impacted when they came in to deal with a pain crisis. The four types of continuity can be used, then, as comparators in analyses of changes to care delivery. If an option improves Management Continuity, while decreasing Relationship Continuity, is this acceptable? What activities can be changed or enhanced to improve communication to mitigate the impacts to Relationship Continuity? Trade off analysis can determine from stakeholders what are the preferred improvements.

Evaluators and researchers may also benefit from the Extended Continuity of Care Model. Today, the available continuity indices are based primarily on visit patterns or subjective ratings (Jee & Cabana, 2006). This new model highlighted several components of continuity that could lead to new continuity indices and measurements. For example, the size and composition of the providers within the Circle of Care was an important aspect of the care system, which was not well described in the indices. The Abstract Genres capture the types

of communication between providers in the Circle of Care. This study described these forms of communication, but it did not quantify them. Future work might include understanding how to apply these various forms of communication as well as how to quantify them into useful indices.

This model is still very young and needs further application and refinement. Still, one can see how practitioners and researchers might be able to adopt it in the future. Chapter 20 describes the methodological approach developed in this study specifically and suggests how others could use it. Even without the approach, the Extended Continuity of Care Model could be applied in the future to further enhance and concretize our understanding of Continuity of Care.

Chapter 19 Abstract Genres as Communication Patterns

This chapter revisits the set of Abstract Genres and looks at their application as reusable communication patterns that can be applied in other settings. The chapter ends with a reflection on the role of Abstract Genres within Genre Theory.

I initially developed a set of Abstract Genres to streamline and standardize the communications shown in the communication views for the Circle of Care modeling. As the Abstract Genres were developed, it became clear that these might have broader applications than simply the models within this study. The Abstract Genres were redefined to describe the current communication practices that support Continuity of Care. Specific participants, situations, and forms were abstracted away. The focus of the Abstract Genres became their *purposeful activity* or intent. Purposeful activity was a concept from SSM used to focus discussions on systems. This level of abstraction allowed me to effectively capture all the described communication activities related to Continuity of Care in ten categories.

In this chapter I explore how the Abstract Genres could be used to describe two other detailed healthcare Genre Ecologies. I predicted that each specific Genre should map to the Abstract Genres, if the Genre is involved in supporting continuity. If the Abstract Genres have sufficient coverage, this suggests that they do have wider applicability and reasonable coverage to describe communication outside of my study's setting and patient population. They could be considered *communication patterns*, which describe repeatable communicative activities with broader application outside of this study.

I also reviewed the Canada Health Infoway EHR design to explore how the EHR supported the set of Abstract Genres. With this comparison, the purpose was reversed. Here I compare the Abstract Genres to see if the EHR appropriately covers the communication needs to support Continuity of Care. Predicting here that Communication Patterns that were not supported in the EHR at this time could be areas for future improvement in functionality, to better support Continuity of Care.

I end this chapter with a discussion on how the concept of Abstract Genres extends Genre Theory.

Mapping to the Varpio Genre Ecologies

Before looking for applications for the set of Abstract Genres, it was important to see if this set provided sufficient coverage of communication forms to be used in other settings. That is, could the Abstracted Genres be applied to another set of established healthcare Genres? If they had wider applicability, they could then serve a basis to describe a set of communication patterns in healthcare that can be applied to the design of systems in the future. Instead of completing a second study, I reviewed the literature and selected a previously published Genre study from a different healthcare setting.

The reader may recall from Chapter 4 that there have been several Genre studies in healthcare. Dr. Lara Varpio developed two Genre Ecology maps to describe the communication Genres found in a pediatric nephrology ward (L. Varpio, 2006). The Varpio study examined provider communication on a single inpatient ward that treats a sub-specialty population of inpatient children in a children's hospital. This is a domain that was decidedly different to adult end of life patients in the community. The Varpio study was interested in local communication patterns, that is within one care team on one ward, compared to my study's cross setting, community level analysis. It was also not a study exploring Continuity of Care, but rather describing communication amongst a team. The mappings between the Abstract Genre and the two Varpio Genre Ecologies are described in Table 25 and Table 26. The mappings were completed after reviewing the published descriptions of each Genre in the two ecologies.

Table 25: A mapping of Varpio's physician Genre Ecology to the Abstract Genres (L. Varpio, 2006)

Physician Genre Ecology (Varpio 2006)	Abstract Genres
EPR ⁵⁴ Medical Summary	Review Shared Record
Medical Summary	Review Shared Record
Transformations	GAP
Progress Notes	Document in Shared Record
Patient Flow sheet	Document in Shared Record
Electronic Laboratory Results	Review Shared Record
EPR Laboratory Results	Review Shared Record
EPR Order Entry	Order
Medication Order	Order
Conversation with Nurses	Request Assessment / Treatment, Order
Conversation with Other Nephrologists	Coordinate as Care Team, Request Advice Request Assessment / Treatment Transfer Care

Table 26: A mapping of Varpio's physician Genre Ecology to the Abstract Genres (L. Varpio, 2006)

Nursing Genre Ecology (Varpio 2006)	Abstract Genres
Nurse Handover	Transfer Care
EPR Patient Care Summary	Review Shared Record
Transformation	GAP
Nurse Report Sheet	Provide Current Information
Conversation with other Nurses	Request Advice Transfer Care
Conversation with Nephrologists	Provide Information Request Assessment / Treatment
Medication Order	Order
Patient Flow sheet	Document in Shared Record
EPR Laboratory Results	Review Shared Record
Electronic Laboratory Results	Review Shared Record
Progress Notes	Document in Shared Record
EPR Information Entry	Document in Shared Record

Only one Genre from the Varpio Genre Ecologies did not clearly map to an Abstract Genre. All others corresponded to at least one Abstract Genres. Where there was more than one mapping, it was clear that the Genre might be used for more than one purposeful activity. For example the physician may have a *Conversation with the Nurse* to ask for an assessment or may have a *Conversation with the Nurse* to deliver and order. Nephrologists might have a

⁵⁴ EPR – Electronic Patient Record, Varpio's term to describe the clinical information system in use in the study setting.

Conversation with Other Nephrologists to Request Advice or to Transfer Care on call, as examples.

The one Genre that did not map was that of “*Transformations*”. In the Varpio study, this Genre describes where a provider (either physician or nurse) was seen converting shared information (e.g. from the electronic chart) into a personal format that was then used by that person in the process of care delivery. This is an important activity, and one that would likely have also been seen in my own study. Transformations, however, are not directly related to the communication of Continuity of Care. Transformations were not used for inter-provider interactions. I would have expected that any Genre that was described that was not directly related to Continuity of Care would have no mapping. This was the case.

The Abstract Genres appeared to have relevant coverage outside of this study’s setting from this analysis.

Communication Patterns and the Infoway EHR

The reader may recall the description of Canada Health Infoway’s Electronic Health Record, from the background section. The Infoway EHR design was meant to provide a repository that links local point of service systems (such as an office electronic medical record). The systems would be connected through a set of electronic messages. Infoway had developed the EHR, in part, to improve Continuity of Care (Infoway, 2006). As part of this review, the Infoway EHR design was compared to the Abstract Genres to see how the information system supported Continuity of Care. See Table 27 for a description of how the Infoway EHR design supported each Abstract Genre. The Infoway EHR was focused on providing a longitudinal health record for patients across Canada. As such they have focused on two of the ten Abstract Genres: Document in Shared Record(s) and Review Shared Records. Also, the EHR provides workflow to support electronic prescribing, which would be an Order.

This review showed that there were several areas where Infoway could, in future iterations, better support the communication needs of Continuity of Care, which was one of Infoway's stated goals.

A semi-structured electronic communication system, for example, could be added to the EHR, as described in Chapter 17. This would support several of the Genres, including: Request Historical Advice, Provide Information, Request Advice, and for some, Transfer Care. This would follow the recommendations from (Stead, 2007) on a staged implementation of clinical information system functionality. The Infoway EHR is currently at the stage of providing a repository. The next step would be to support communication. This would be changing the media of the Genres and there may be a subsequent evolution of the Genre itself brought about by that change (JA Yates & Orlikowski, 1992).

With the available repositories, there would be less need to support the distribution of information between providers, but there would still be a need to be able to be notified when new information was available and relevant to a specific provider. This kind of notification service would support the Provide Information Genre. A more robust set of order entry messages that included referrals would support both Request for Assessment / Treatment and other Orders.

Finally, if patients (and delegates, such as family) had access to their own Personal Health Record, they could also use their communication tool to interact virtually with their providers (although this would certainly not replace all other forms of patient communication / assessment). Although personal health records have been seen as another form of repository of data that can be shared between patients and their providers, (PC Tang, Ash, Bates, Overhage, & Sands, 2006) a personal health record can also empower patients and enhance communication between patients and providers (Ueckert, Goerz, Ataian, Tessmann, & Prokosch, 2003).

Table 27: A description of how the Infoway EHR Design supports the set of Abstract Genres.

Abstracted Genre	Support in Infoway’s EHR Design
Communicate with Patient / Family	GAP - Currently no communication tools in the EHR design. Telehealth activities with Infoway may include projects related to provider – patient communication.
Request Historical Information (PMHx) ⁵⁵	GAP - No ability to communicate directly with other providers through the EHR. However, with the availability of the EHR, the need for this Genre may be reduced (and replaced by Review Shared Record).
Provide Information	GAP – The Infoway EHR design does not include an ability to proactively distribute information to specific providers through the EHR.
Document in Shared Record(s) ⁵⁶	Ability to document information in the EHR repository. There are several profiles that support the documentation of multiple types of information, including: medications, laboratory results, medical imaging reports, several document types, problems / diagnoses, and multiple observations (e.g. blood pressure, weight). Not all documents are supported.
Review Shared Record	Several ways, in the design, to review the information in the EHR. A standalone EHR Viewer is available as are HL7 v3 messages to allow viewing from within a provider’s own CIS.
Request Advice	GAP - No ability to communicate directly with other providers through the EHR.
Request Assessment / Treatment	GAP - No ability to communicate directly with other providers through the EHR.
Order	Partial GAP - Only electronic prescribing is in scope, no other forms of order, such as lab orders or delegation of tasks to other providers.
Transfer Care	GAP - Not possible in the EHR. No concept of patient – provider relationships. This would likely be considered the domain of the Point of Services systems, such as the hospital information systems.
Coordinate as Care Team	Not through the EHR. Supported through Telehealth activities.

⁵⁵ PMHx = Past Medical History

⁵⁶ The EHR design used to have a specific repository called the “Shared Health Record”, this Abstract Genre does not refer to that repository, but to any shared records, which would include all the EHR.

Abstract Genres and Genre Theory

The Abstract Genres, from this analysis, appeared to have broader applicability and could be seen as a starting point for the development of a set of communication patterns that describe the activities related to Continuity of Care. They could be reused in multiple care settings.

These Abstract Genres were derived from Genres discovered in the field and they were collected together based on common *purposeful activities* (See Figure 67). By extracting a common goal and activity, these Abstract Genres have the potential for broader application in other areas in healthcare than they would have otherwise. Indeed, with the meso-level of analysis in this study (i.e. multiple communities, multiple care settings), it was necessary to have this level of abstraction to model and compare communications even within this study. I have highlighted that these Abstract Genres can be applied to care settings outside end of life care and the region where this study was conducted.⁵⁷ I have shown that they can also be used to seek gaps in Continuity of Care for clinical information systems. The Abstract Genres, then, have a level of both descriptive and predictive potential when looking at CIS functionality.

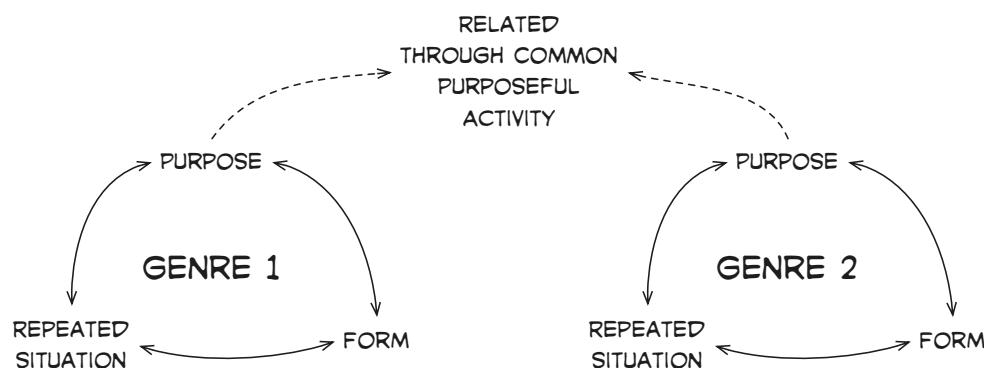


Figure 67: Similar Genres are related together through common purposeful activity as Abstract Genres

These Abstract Genres may also be more resilient to change than the specific Genres from which they were derived. That is, the intent of the Abstract Genres should persist as the details of the specific Genres change over time. Genres are derived from their socio-

⁵⁷ Varpio's work was completed in Ontario, Canada.

historical context. That is, they have evolved through use within an organization (JA Yates & Orlikowski, 1992). The focus on the purposeful activity provides a level of consistency while the media of the Genres may change over time. When changes are introduced, particularly technology (e.g. Clinical Information Systems), the form and situations may change, but the purposeful activity, or intent may not (See Figure 68).

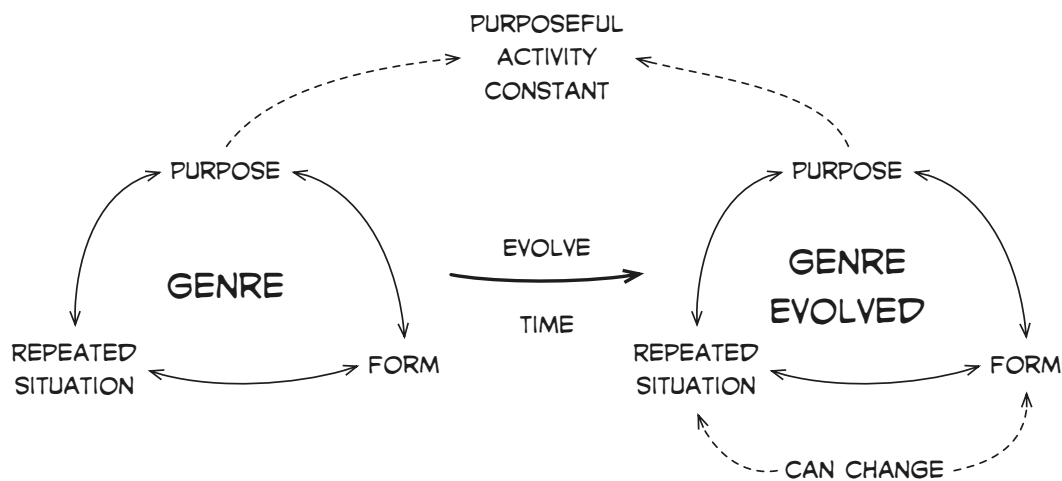


Figure 68: Genres evolve over time; the purposeful actions are more likely to remain constant, while form and situations may change. This was found to be a useful construct while seeking feasible improvements.

Genre Theory has explored several assemblages of Genres, such as sets, collections, series and ecologies (Spinuzzi, 2004). Genre Ecologies have been developed to explore the mediating relationships between Genres (Spinuzzi, 2002). Unlike other visualizations of Genre, such as Genre Ecologies, I have explicitly included the actors in the conceptual models with the Abstract Genres in the form of a UML Communication Diagram. UML has been used with Genre Theory before, as part of a research or design process (e.g. Haraldsen, Stray, Paivarinta, & Sein) or to describe the characteristics of Genre Theory (e.g. (Latapy, Lopisteguy, & Dagorret, 2004) and (Honkaranta & Tyrvaïnen)). I was not able to find examples where Genres, such as the Abstract Genres from my study, were embedded into UML Communication Diagrams. Genre Theory was developed to look at communication as iteratively evolving through use and change by the actors using them (W.

J. Orlikowski, 1992). By linking Genres with UML, I have perhaps provided a framework of improving the traceability of requirements through the early design phases of requirements generation. This was an important aspect in addressing the issue of requirements traceability (Gotel & Finkelstein, 1994), requirements traceability is an important problem in software design.

Abstract Genre Summary

Genre Theory was a helpful theoretical foundation for this study, anchoring the exploration of communication within the Circle of Care on a strong socio-historical base (JA Yates & Orlikowski, 1992). Abstracting Genres through purposeful activity, a concept taken from Soft Systems Methodology (P. Checkland, 2000), allowed for comparison of communication patterns between settings in this study and between domains of end of life care and pediatric nephrology. This has suggested that the ten Abstract Genres have application outside of this study. Comparison of the Abstract Genres to the pan-Canadian EHR suggested that there were additional Genres that could be supported by the EHR in the future. Finally, application of UML Communication Diagrams provided an additional way of visualizing Genre assemblages. Communication Diagrams included the actors involved in the communicative acts, providing a more complete view of the system in which Genres were enacted.

Chapter 20 The Circle of Care Modeling Approach

This chapter highlights the contribution to health information system modeling, describing the three-level Circle of Care Modeling Approach and how it complements both organizational strategic planning and more detailed analysis work. Also highlighted is the need for an extension to the UML 2.0 Communication Diagram modeling standard.

Exploring Continuity of Care should require exploration within the system in which care is delivered. Without an appreciation for the care system, gaps in continuity may not be properly highlighted. For this study, I developed a modeling approach as part of my methods that was both patient centric and systems oriented, it was built upon the elements described previously. This modeling approach, the Circle of Care Modeling Approach, was complementary to both higher-level organizational strategic level thinking and more detailed process level analyses.

Defining the Patient's Care System

In this research, the Circle of Care was used to define the system for analysis of Continuity of Care for end of life patients. The definition of the system was, as per SSM, an *intentional* decision. That is, the system was defined in a manner that helped with reasoning about issues. The Circle of Care system was useful in exploring Continuity of Care for a number of reasons. First, patients were central to the definitions of quality of care, Continuity of Care, and to the delivery of care. Second, the scope provided by being patient-centric was at a meso-level, situated between traditional business process modeling and strategic directions.

Third, the patient centric view crossed boundaries, both organizational and professional, and this allowed for a new way of thinking as well as spurred debate to occur that was less focused on ownership of functions and more on the needs of the patients.

Information about the patient's Circle of Care could be collected in several ways; the modeling approach does not dictate a specific approach. In this study, provider interviews were used. Equally, patient or family interviews could be used. Prospective studies or retrospective chart reviews could also be used to discover sources of information. Preferably a multi-method approach would be used to enhance understanding of the complexities of a patient population's Circle of Care (B. Kaplan, 2001).

Selection and development of specific models can be and, perhaps, should be done iteratively as one learns about the realities of care and the models that were generated. Findings about the system will drive future exploration, as is the nature with investing complex systems, where it is not possible to know everything about the system (Cilliers, 2002).

Modeling Three Views of Circle of Care

An approach to modeling the patients Circle of Care was developed as part of this research. It was used to describe a patient's Circle of Care from three views: care providers, communications, and information / repositories. Here we describe the benefits to modeling these specific views.

The Provider View described the members of the Circle of Care. By first modeling the Circle of Care from each role's perspective, differences in viewpoints were highlighted (see Appendix K to see the specific models). These can then be used during discussions and planning. If a provider group was not aware of another provider or service, this can be clearly demonstrated. Further, by comparing the individual models, the key providers involved in coordinating care can be highlighted. These were termed Continuity Providers and were the focus of the communication models.

The Communication View highlighted the flow of patient specific information between, in this study, Continuity Providers. Providers found it easy to describe their communication activities during the interviews and their descriptions provided useful information about reliance on CISs. Communication activities were described by using the Abstract Genres.⁵⁸ This study used an extended version of the UML Communication Diagram (see below) for the notation of the communication views.

The Information / Repository View complemented the previous two models by highlighting the longer-term stores of patient information (both paper and electronic). This view was useful in understanding the potential silos of patient information within the system. This diagram was intentionally simple in notation in order to be equally accessible to designers and providers. The repository view provides a visual representation of the repositories – again in a patient specific manner - to reason against how the major systems might need to interface to better share information or be consolidated to decrease complexity. This view could be used to highlight how new systems either increase or decrease the complexity of the repository view, either in their numbers or their functions. Simplified UML class diagrams were used to highlight the types of patient information that were stored in the repositories, although these were not used with providers in this study.

Together these three views provided a unique way of visualizing a patient's care system, the Circle of Care Modeling (CCM) Approach.

The Circle of Care Modeling Approach Complements Strategic Planning and Detailed Analysis

The Circle of Care Modeling Approach is a contribution to our body of analysis methods. It fits between high-level strategic planning and the more detailed level process modeling. It can be used to support either level (Figure 69).

⁵⁸ In this study, the Abstract Genres were modeled in more detail using SSM notation. This would not be necessary in future studies that might take this set of Abstract Genres as part of the methodology.

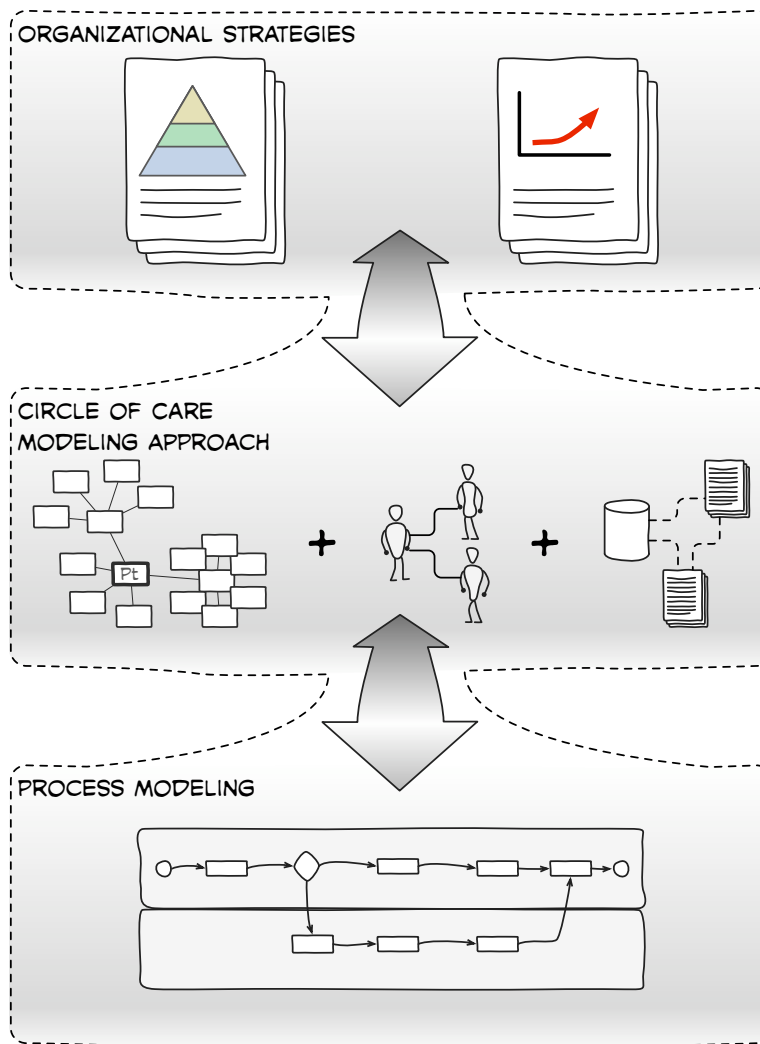


Figure 69: Circle of Care Modeling Approach is a meso-level analysis, bridging the gap between higher-level organizational strategies (super-system) and detailed information systems requirements and process modeling (sub-system).

The Circle of Care Modeling Approach could be used to inform strategic directions in a number of ways. First, this type of analysis could be used to help better define the scope of strategic goals and align them across organizations. Although CCM is more detailed than the strategic level direction, it crosses organization boundaries, providing a different perspective than typical organizationally centric strategies. This could inform and change strategies. For example, VIHA’s strategic priority of “Improving Seniors Health” (VIHA, 2008) could be explored with some early Circle of Care modeling of typical seniors in various communities across the region. This would help improve broader understanding of the likely challenges to care delivery for seniors across the region, and not just for existing VIHA programs. This

view could be used to help groups align their strategic planning to better support patients in a coordinated manner.

Second, CCM highlights complexities in the system of care providers, communications, and information systems. In this way, CCM can inform strategy with areas targeting specific initiatives that might not have been visible from a program specific view. The list of suggested improvements in this study are examples of how CCM can inform strategy development. CCM can highlight unexpected elements of the system of care, such as the relative size and complexity of the Circle of Care. Flows of patients between communities need to be considered, for example, and these have been highlighted through the use of CCM. Assuming that the complexity of care delivery increases with the size of a community and the resources available is not always a valid assumption, for example, as was discovered in this study with the case of Mrs. Cann. The Circle of Care shows hallmarks of complex adaptive systems: the Circle of Care is dynamic, entangled, emergent and robust (Begun, et al., 2003). It adapts to clinical needs of the patient, expanding beyond organizations and geographic boundaries as needed.

Further, CCM supports traditional detail level requirements analysis work. It provides a broader context than typical business process modeling. It could be considered a super-system to the traditional business process modeling (or the process models could be considered sub-systems). CCM gives context for the more detailed work. For example, the challenges of coordination between organizations that were found in this study might not be realized by only mapping out processes for one location or one role.

Finally, local recommendations and changes can be explored at a systems level using the models to see how changes might impact the system. For example, implementation of a tailored, standalone electronic medical record for a specific clinic might make sense to that clinic; however, when considering the patient's Circle of Care, it might be apparent that the isolation of information in that system could have a unforeseen negative consequences across the Circle of Care. Indeed, when looking at the models of the existing repositories, it would be difficult to recommend adding another, standalone clinical system, without at least consolidating some of the others in the process. Thus, the context afforded by the Circle of

Care Modeling Approach can highlight potential broader unintended consequences that might not be seen.

These models were not meant to be exhaustive representations. In complex systems, such as a patient's Circle of Care, this would not be possible (Plsek & Greenhalgh, 2001). Instead, as in Soft Systems, the approach is to develop a sufficient representation to reason with, comparing the models against the real world challenges in order to seek improvements (P. Checkland, 2000).

Extension to UML 2.0 Communication Diagrams

During the development of the Communication Views, the UML 2.0 Communication Diagram notation was used (as described in the methods section). However, it was found to be lacking in one key feature that required extending the diagram notation. Specifically, the notation requires that the individual communications be described in numbered sequences (Figure 70) (OMG, 2009).

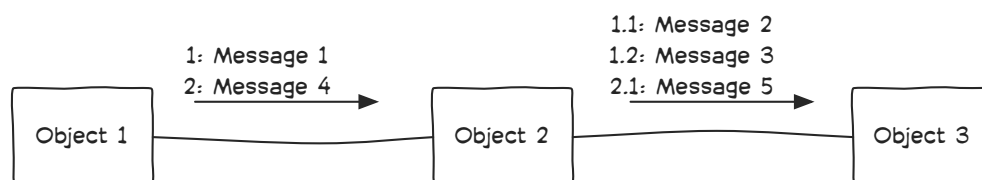


Figure 70: Example of a UML 2.0 Communication Diagram. Note the message ordering.

In this study it was not possible to determine an explicit order of communication. The order of communications, even using the higher level Abstract Genres, was highly dependent on individual variation in the scenarios and many types of communication could occur in any sequence. Therefore, no sequencing was used in this study, as it was not possible to describe defined sequences.⁵⁹

⁵⁹ Some sequencing was embedded in the Abstracted Genres, such as responding back to a request. However, this detail was intentionally abstracted out and not included in the communication diagram.

The UML Communication Diagram notation could not handle this level of ambiguity, as it required messages be ordered. The Communication Diagram notation could be extended, formally allowing a level of ambiguity to the sequencing of communications. This could be achieved through the use of letters to symbolize variable sequencing. The other approach might be to denote dependencies in the communication diagram. SSM models explicitly denote dependencies between actions, not sequences, as there was felt to be more value, from an SSM perspective, of understanding what activities depend on precursor activities instead of the specific sequence of those activities. There could be multiple dependencies and, thus, a form of gating could be illustrated in the Communication Diagram notation that is not possible today.

I chose the simplest extension to the models for this study. I removed the sequencing from the communication diagrams as it added very little to the conceptual models for this particular analysis. For other work, variable sequencing and dependencies may be quite important.

Circle of Care Modeling Approach Summary

The Circle of Care Modeling Approach provided a new way of visualizing the patient-centric healthcare system, using three views to describe the patient centric health care system: a Provider View, a Communication View, and an Information / Repository View. CCM complements other levels of planning and analysis, providing a cross-organizational, meso-level view of care from a patient's (or patient type) perspective. Based on SSM, CCM is suited to exploration of the complex systems of healthcare. The CCM Approach is not an approach that provides an exhaustive list of resources, Genres, or providers in a region or community. It can, however, provide a representative view of the care system that can be used to explore challenges and seek improvements in a way that is consistent with a Soft Systems Methodology approach. It was designed to seek improvements to Wicked Problems in complex systems. It is an approach that could be adopted by others.

Chapter 21 Study Objectives Revisited

This chapter reviews the study's initial question and the four objectives. It describes if and how they were met in the study.

In this study, I sought an answer to the following question:

What feasible changes can be made to care processes and clinical information systems to improve Continuity of Care for end of life patients?

I found an answer to that question through my iterative process of interviews, analysis and discussions with the research participants, both clinical and IT. The answer took the shape of the six suggested improvements for Vancouver Island. Supporting the primary question, there were also four specific objectives for this study:

- 1. To develop and apply a method that combines Genre Theory with Soft Systems Methodology to generate recommendations for improvements in practice and the requirements for an EHR that better support Continuity of Care.*
- 2. To describe the Genres used by providers caring for patients who are at the end of their life, focusing on the Genres used to provide and coordinate the transitions of care.*
- 3. To compare the Genres and needs of Continuity of Care at the end of life with the current design for the Vancouver Island Health Authority's (VIHA) Electronic Health Record (EHR) to see where specific improvements to content and functionality can be made.*

4. *To seek improvements in Continuity of Care within two communities in British Columbia, making recommendations that would ensure the right providers are aware of key care decisions for community-based patients at the end of life.*

See Chapter 8 for the specific success criteria for each objective.

Objective 1: Method Development

This study's Circle of Care Modeling Approach developed on foundations from Genre Theory (J. Yates & Orlikowski, 1997) and Soft Systems Methodology (P. Checkland, 2000) met each of the three criteria for success. The methods and specifically the modeling approach proved to be quite valuable in highlighting challenges to Continuity of Care. The methods proved to be manageable for a small research group of one. Suggestions for six regional improvements were endorsed by the study participants, which included IM/IT leadership.

Objective 2: Genre Collection to support Transitions of Care

This objective was not met in this study, at least not in its original intent. The Genre Collection was to be a catalogue of the specific Genres in use by participants. During this study, it became clear that this catalogue would be large and unwieldy. The collection would have also contained redundancies that were caused by small uniqueness in the local circumstances. Instead of compiling a large list, I attempted to create a short set of Abstract Genres related to Continuity of Care. The specific Genres were collected, based on their similar purposeful activities. What evolved during the analysis was a set of ten Abstract Genres or common Communication Patterns. These Abstract Genres appeared to have some utility outside of this study, beyond the scope of end of life care. These Abstract Genres were used in this study to describe types of Communication Patterns in the Extended Continuity of Care Model and this model will be made available to other researchers.

Objective 3: Comparison of Existing Genres with EHR Functionality

The Abstract Genres were mapped to Vancouver Island Health Authority's (VIHA) current clinical information system (CIS) infrastructure. Also included in the mapping was the current use of the telehealth program, as there were examples where some Genres were being supported through Telehealth. The primary purpose of the regional CIS, at the point when this study was completed, was as a regional repository. As such, it did not support many of the Genres directly. VIHA's future strategic direction included components such as electronic clinical documentation and computerized provider order entry, which could map to the Abstract Genres. These Abstract Genres, therefore, could help provide some of the framework needed when considering the types of documentation and orders needed in VIHA in the future.

Objective 4: Suggested Improvements to Continuity of Care for End of Life Patients

The final objective of this study was to generate a set of recommendations to improve Continuity of Care for End of Life patients. The list of suggested improvements was generated collaboratively with the IM/IT participants and supported by the research participants (primarily provider participants) in the discussion groups.

1. Improve provider access to appropriate CISs
2. Develop an advance directives repository within the regional CIS
3. Enhance patient-provider relationships in the regional CIS
4. Develop automatic notifications to Continuity Providers of key patient transitions
5. Improve use of case conferences
6. Design a regional clinical communication tool to support cross team communication and coordination

The recommendations have been shared with research participants, but – at the time of this writing – had not been shared with broader leadership. Several presentations and discussions were in the process of being planned, including presenting at various clinical rounds and leadership meetings within Vancouver Island Health Authority, the BC Cancer Agency, and the BC Ministry of Health Services, but these have yet to happen.

CONCLUSION SECTION

Chapter 22 Conclusion

This chapter summarizes the study, highlighting the contributions to our knowledge, the study's limitations, and potential future work.

Contributions to Knowledge

This study sought improvements to Continuity of Care for end of life patients. Through the research grounded in two communities on Vancouver Island, the study has added to our knowledge in several areas including: methodological, theoretical, and practical contributions. There were four key contributions from this study: the Circle of Care Modeling Approach that is both patient-centric and systems based; a set of Communication Patterns (Abstracted Genres) related to Continuity of Care; an Extended Continuity of Care Model; and specific recommendations for improvement of Continuity of Care for the region and the two communities that participated in the study.

First, I developed a method and modeling approach that was built on Soft Systems Methodology that allowed for the exploration of care processes in a way that is both patient-centric and systemic, the *Circle of Care Modeling Approach*. By using Patient Personas as the focus of the data collection, multiple perspectives on care processes were captured from those who would be involved in the patient's care. The Circle of Care was the boundary of the system. The analysis, based on Soft Systems Methodology, permitted exploration into the providers, communication patterns, and the repositories in the patient's care system, using a three-view modeling approach. CCM was designed to generate new understandings in Continuity of Care, which is itself interested in the system of care provided to a patient over time. CCM could be used to approach and understand complex

or wicked problems in healthcare, such as improving management of chronic diseases. It was designed to complement both higher-order planning activities as well as provide additional context to more detailed analysis work. CCM Approach may well have more broad applications when exploring the needs of patients. The approach has flexibility to allow adaption to other clinical areas.

Second, the application of Genre Theory within this study supported understanding the communication activities related to maintaining Continuity of Care, particularly the communication view in the CCM Approach. This work took the granular Genres and abstracted them based on common purposeful activity. This resulted in a much smaller, more generalized set of Abstracted Genre related to maintaining Continuity of Care. Comparison to other settings suggests that these may have application to other healthcare organizations and settings. With further development and testing, they may provide a framework to discuss more broad types of communication patterns in healthcare. Other research in Genre Theory has extended Genres into sets, collections, and ecologies. This work shifted the analysis approach to finding groupings and isolating common patterns based on purposeful activity, or intent of the individual Genres. The use of UML Communication Diagrams and concept of Abstract Genres may have application in other domains where Genre Theory may be applied.

Third, the Extended Continuity of Care Model was developed from the findings in this study. This model included several elements, including: the patient and family, the Circle of Care, Inter-Provider Continuity, the Abstracted Genres, and other environmental contextual elements that impact Continuity of Care. These extensions provided a more robust, systems-based model of continuity that could be used by analysts and researchers in the future when exploring Continuity of Care. This model may also help when developing more robust indices for Continuity of Care, including measuring aspects of the Circle of Care and the communication patterns between provides, not just measuring visit patterns.

Finally, this study has provided a set of practical improvements for improving Continuity of Care within the region of Vancouver Island, where this study was performed. These suggested improvements were developed with members of the IM/IT staff at VIHA and PHSA, addressing issues raised by providers in two communities on the island. The

suggested improvements were confirmed and supported by the participants. These suggested improvements might also resonate with other regions and jurisdictions that are facing similar challenges with Continuity of Care.

Study Limitations

Despite the rigor of the study design, there were constraints on this research and there were several limitations. Described here, the limitations were organized from methodological / conceptualization issues through to limitations of the final suggested improvements.

First, there were several limitations to the study method. The method was scenario based, focusing on describing care for Patient Personas. Not all examples of patients and care pathways could be captured within a scenario based analysis. This was partially remediated for by having two personas that were carefully developed to cover as many nuances of care (as was felt to be believable) and applying those two personas to two communities.

Participants were also encouraged to not only talk around the cases (i.e. highlight challenges if the scenarios were slightly different), but also to raise other issues not directly related to the scenarios. An example of a gap would be: the method assumed that each of the Patient Personas had family physicians. This is the most common case, but not all people in Canada have family physicians. One in seven Canadians does not have a regular medical doctor (Talbot, Fuller-Thomson, Tudiver, Habib, & McIsaac, 2001). Further, the method relied on participant interviews as the primary data collection method, which introduced significant selection or recall bias. Different participants may have led to the discussion of different gaps and suggested improvements. The study design did compensate for this through triangulation in the study: between the different perspectives of the providers both within and between roles, between the two Patient Personas, and between the two communities. Also documentation (e.g. clinical forms, strategy documentation, literature) was reviewed to complement the interview findings. The suggested improvements were confirmed with providers who were involved in the study; they were not validated externally with another group of providers.

Second, while this study explored Continuity of Care in two communities that were different in size and available resources, both communities were within the same health region. This was intentional, as then the recommendations could be applied to the region. However, other regions or jurisdictions may well have different constraints or issues related to Continuity of Care. It is possible that the conceptual models and the Abstract Genres that have been generated within this study would be different if the study were applied to a Health Maintenance Organization in the United States, or to a community in Denmark, for example. A mapping of the Genres to pediatric nephrology and to the pan-Canadian EHR blueprint provided some additional support to the generalizability of the findings.

Third, participant recruitment proved to be challenging. Ultimately, there were gaps in the participants who were recruited. Although there were 34 participants, this did not include all roles named in the Circle of Care in either community. This was noted early on as an issue, and several educational presentations were made at meetings and rounds to increase provider awareness to the study. This helped considerably, but there were still some gaps. Community providers with little connection to the health authority were underrepresented. Some roles in each community were not interviewed as no participants came forth. In Duncan, it was not possible to recruit ER physicians. In Victoria, it was not possible to recruit cardiologists or Hospital Liaison Nurses (outside of Hospice). Community pharmacists in private practice could not be recruited in either community. Some extrapolation had to occur in the analysis to fill these gaps. Feedback from other participants was used, for example, hospital pharmacists provided some context about the community pharmacists as they had worked in private practice previously.

Forth, a single researcher completed all interviews, developed the rich pictures and the conceptual models, co-developed the recommendations with IM/IT, and facilitated the discussion groups. This did provide for excellent research continuity, but a more robust design would have included a parallel modeling effort with comparisons between the models and recommendations. To mitigate this limitation in the study, the analysis methods were clearly described as to be replicable. The iterative design process ensured that there was time for multiple reviews with feedback on the conceptual models from the IT participants and from participants in the discussion groups. Also, work in progress was shared with members of the researcher's supervisory committee and was presented for feedback in a seminar at the

Department of Medical Informatics and Clinical Epidemiology, School of Medicine, Oregon Health & Science University (OHSU), Portland, OR.

Fifth, the findings in the study led to suggested improvements only. These recommendations were reviewed and supported by participants, several of whom were also regional leaders in their fields. The recommendations were not taken to a pilot or implementation phase. Due to constraints in the study, it was decided at the outset of this study to stop at the recommendation phase. Implementation and assessment of impact would strengthen the findings in this study.

Finally, this is a single study. The CCM Approach needs to be further refined through application in other settings, as do the Communication Patterns derived through the abstraction of the Genres in this study. Further application of the approach and findings will lead to a hardened methodology with a greater empirical base of evidence.

Future Work

This study was theory generating, as opposed to hypothesis testing. As such, it has opened up several activities that could be pursued in future research. These are summarized below, based on the four key contributions from this study. As each element has been developed from this single study, a reasonable starting point would be to suggest that each aspect is further validated through a complementary study in a different setting. This would serve to further confirm the specific models and refine and enhance the analysis methods.

Circle of Care Modeling

The Circle of Care Modeling approach is just in its infancy, but shows considerable promise as a concept to approaching and making improvements to care systems. There is opportunity to expand on its application to other settings, refine the modeling techniques, and adapt the Circle of Care to support additional theoretical foundations.

A similar study could be undertaken for end of life patients in different communities or regions. A study could be undertaken with different patient populations that have similar needs for improvements in continuity. Patients with chronic conditions in general have a

need for increased continuity. Specifically, people with chronic addictions and mental health issues in the inner city are an example of a population who often “fall through the cracks”. Without an understanding of their Circle of Care, it is difficult to specify improvements in care for these patients as they can have considerable unplanned care. Thus, a similar study in this population could prove fruitful. This future study should include enhancements to the data collection methods. For example, the triangulation of findings can be improved by: interviewing patients, informal care givers, and family members; reviewing actual patient charts retrospectively to confirm actual circles of care; or including a prospective component to observe the challenges in communication. Each of these were considered in the study design, but were not included in this initial study.

The modeling techniques and notations should also be refined. For example, knowledge from Social Network Theory may prove to be fruitful in describing the Circle of Care and highlighting why different communities function differently. Social Network Analysis explores how networks are organized, with particular focus on the connections between actors. The structure of the systems defined in my current modeling approach support the concepts needed for social network analysis. There are several concepts that could further support analysis of the Circle of Care. Exploring the nature of the circle, through measurements such as “betweenness”, “centrality”, and “closeness”, may provide more quantitative descriptions on the nature of the relationships within a patient’s Circle of Care and could further highlight gaps. A simple comparison of the centrality or closeness of family physicians within the circle, depending on whether or not they have hospital admitting privileges, could be quite telling in measuring the continuity challenges, for example. This kind of work would require capturing additional information, such estimates on frequency of communication, for example.

The concept of the Circle of Care was used to explore Continuity of Care, but other aspects of care delivery could also be explored within the Circle of Care system. For example, one could explore how diagnoses are typically developed, or how specific care plans are developed, modified, and executed. Traditionally, these are viewed as single events (such as writing an order); however, diagnoses often begin as tentative or working diagnoses, plans are often initial, have contingencies, or are adapted over time depending on patient needs and responses. This is particularly true for chronic conditions. Understanding how these

plans evolve across the system is something that could be explored. Structuring chronic disease management as an act of distributed cognition across a patient's Circle of Care could prove fruitful. Through placing the lens of Distributed Cognition onto the Circle of Care, where both people (patients, families and providers) and other agents of the network (e.g. clinical information systems) play roles in supporting the processes, the Circle of Care models could be used as reasoning tools for changes to the overall system. For example, a future study could include modeling the circle of care for a patient with congestive heart failure (such as Mr. Hart), but instead of generally describing gaps in Continuity of Care, models could highlight how congestive heart failure plans are developed and managed over time. Then, these models could be adjusted to highlight expected management changes when heart failure nurses are added to the circle or when a patient has access to a personal health record with specific decision support algorithms embedded to support them managing their own condition.

Other modeling notations may be helpful in structuring the conceptual modeling phase of this work, depending on the issues being explored. Agent-oriented modeling tools, for example, could also be useful to re-visualize the provider (or person) level models and should be explored. Deeper understanding of dependencies between people may highlight need for better sharing of records. Most of the modeling work for this study was completed by hand. Additional work could include adapting or creating specific tools to capture, visualize, and analyze the findings during the conceptual modeling phase. This could allow for more rapid development and provide analysts the ability to look at how patterns might change with the implementation of specific recommendations. For example, with automated tools, it would be feasible to visually highlight provider access to records for each provider. This was not feasible using the current tools. A balance must be struck with modeling notations; however, as the models need to be consumable by all participants as they reason about improvements. One of the strengths of Soft Systems is that the approach is accessible to a wide range of participants and this should not be lost in future design work.

Abstract Genres

The process of abstracting Genres through “purposeful activity” proved useful for this study. A set of ten communication patterns emerged related to maintaining Continuity of

Care. These specific Abstract Genres need further application and testing to determine if they have broader applicability within healthcare. The intent of these Abstract Genres was to find common patterns of communication related to Continuity of Care across multiple settings in the study. If these Abstract Genres have wider application within healthcare, as suggested in Chapter 19, they could be used in other care settings to review Continuity of Care communication. They could be used predicatively to highlight potential gaps in communication and to recommend local improvements for practitioners. Potential re-use would be in the Circle of Care modeling studies described above, but also these Abstract Genres could be used prospectively to help catalogue and guide selection of communication tools as a community or organization implements CISs. For example, the physicians in Duncan are considering how to implement a community-wide Electronic Medical Record. The ten Abstract Genres from this study could be used to help define and analyze their communication and information access needs as part of their requirements analysis.

Extended Continuity of Care Model

This study was qualitative in nature, but the model may well have application in supporting the development of more robust quantitative measures of continuity. Many of the current quantitative Continuity of Care indices look at patient visit patterns (e.g. visit frequency, visit sequence). The Extended Continuity of Care Model suggests that there are other aspects to the system in which Continuity of Care exists that would be worthwhile describing. Correlating the sizes of Circles of Care (number of providers and / or geographic spread of members), for example, with unplanned hospital admissions or with lengths of stay may provide an interesting view into the challenges of continuity. These comparisons could be completed using existing regional or jurisdictional (i.e. provincial) level administrative databases.

Further, understanding the nature of connections between providers, and the specific provider communication patterns may suggest other mechanisms that could maintain continuity across care teams. As communication becomes increasingly electronic, these patterns will be easier to measure quantitatively through the review of audit logs, for example.

Evaluation of the Suggested Improvements

If the six suggested improvements that were developed in this study move from recommendations into design and implementation, their impact on clinical behaviours and outcomes should be evaluated. Evaluation plans that include pre- and post- implementation metrics could be conducted at the regional level. For example, prior to implementing an electronic Advance Directive Repository, a small study could look at baseline gaps in access to code status in the Emergency Departments within VIHA as well as numbers of unnecessary intubations / resuscitations performed. This could be compared to post-implementation rates to see if there was a change in rates and would be achievable as part of the project implementation, without requiring grant funding.

This research was designed as a qualitative, model generating study that explored a systemic approach to Continuity of Care for end of life patients. As such, it provided both the first sketches of a new methodology and ideas for subsequent research into measuring, evaluating and improving Continuity of Care. Any of these aspects could be further developed over the coming years.

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APPENDICES

Appendix A. Patient Personas

Purpose

The participant interviews were structured around two Patient Personas, who were introduced to participants through the Genre of a Clinical Case Presentations. The full details of each Patient Persona are in this appendix, Table 28. The narrative of the Clinical Case presentation is captured in Table 29 (Mrs. Cann) and Table 30 (Mr. Hart). These Patient Personas and the Clinical Case Presentations provided consistency in the interviews. These two cases each have two “scenarios”, showing progression of the patients over time. These two patients were used as the organizing structure when building our Circle of Care models and were central to the Structured Discussions.

Development of Patient Personas

The Patient Personas were designed as a pair, providing as much coverage of end of life issues as possible. Based on the CIHI review of End of Life care in BC (CIHI, 2008), several decisions were made about the Patient Personas. First, I decided to use two patients to provide breadth of coverage, while still trying to maintain the 1-hour long interview duration. Two patients also allowed comparison between the responses. The two primary diagnoses represent the top two causes of death in BC, cardiac and cancer. Breast Cancer was one of the most prevalent cancers in women. CHF was a more protracted form of cardiac disease, causing a loss of functionality over time. The multiple scenarios in each case provided the opportunity to explore the trajectory of illness and different care settings over time without having to orient the participants to new Patient Personas. This provided greater coverage of typical end of life situations. The cases were further aligned to levels in the Palliative Performance Scale (PPS). The scores chosen corresponded to where we would expect clinical engagement by specific palliative care providers. These cases were drafted by Dr. Price and then reviewed by the Research Director of the Victoria Hospice to ensure the goals were met and the patients were realistic.

Table 28: Detailed Description of the Patient Personas Mrs. Cann and Mr. Hart used for this study.

	Patient Persona 1: Mrs. Cann	Patient Persona 2: Mr. Hart
Purpose of this Case	Cancer patient Good family support Living at home Slow decline Pain control issues	Cardiac Patient Poor Social Supports Residential Care Emergency Admission to ER
Name:	Mrs. Megan Cann	Mr. Bill Hart
Age	64 yo F	71 yo M
DOB	1944 Nov 01	1937 Oct 31
Active Problems	Metastatic Breast Cancer OA L Hip Dyslipidemia	2005 Dec CHF 2004 April Stable Angina 2003 May 13 – Dyslipidemia 1999 Mar 05 – Hypertension 1998 Diabetes Obesity Mild COPD
Past Med History	Fibroids	2005 Dec – MI 2004 April 01 – MI 2003 May 13 – MI
Past Surgical History	2005 Mastectomy 1982 Hysterectomy 1952 Tonsillectomy	1955 Appendectomy 2004 Angioplasty
Medications	Advil PRN Tylenol XS MS-Contin 30mg bid Atorvastatin Anastrozole	Hydrochlorothiazide Atenolol Glyburide Ramipril Atorvastatin Nitro Spray Ventolin and Flovent
Allergies	No known drug allergies	No known drug allergies
Immunizations	Flu vaccine	Annual Flu vaccine
Social History	Lives alone in family home. Husband died in 2002 after a protracted decline. 3 daughters close by with their own families. One younger brother on the mainland	Smoker - 110 pack years Alcohol - 2-3 drinks / day No Drugs any more. Divorced; He lives alone; no close family. One son overseas, no contact 10+ yrs Previously in construction; no savings, on pension
Family History	Breast CA in 2 aunts.	Diabetes - parents Depression – Father
Code Status	No Code (not mentioned in presentation)	No Code

Table 29: Clinical Case Presentation for Mr. Hart. This narrative was read to participants as part of the interviews.

Patient Persona 1: Mr. Hart	
Scenario 1	Mr. Hart is a 71 year-old man with Stage III CHF. This developed after several heart attacks, the last in 2006. He also has diabetes, high blood pressure, high cholesterol, and had mild COPD. He drinks 2-4 daily, smokes and is overweight. He lives alone in an apartment, his only supports are a “buddy” he goes to the pub with (when he can afford to go) and the manager of his building who checks in every once and a while. He is divorced and has no close family – his one son is overseas and they have not spoken in 10 years. He takes care of his apartment on his own fairly well, but has trouble with laundry, as the 3 flights of stairs are a challenge in his building. He has difficulty getting his weekly groceries as he finds the walk very tiring and has to stop every 1 or 2 blocks. He is on several medications and two inhalers, but not oxygen. He has a DNR.
PPS Score	~70%
Scenario 1 Worsening Sign	When you see Mr. Hart, you notice he is not as lucid as he usually is. He is having difficulty getting words out and slurring his words. He is leaning to the right and has difficulty walking, as he is weak.
Scenario 2	Over the intervening months since the first scenario, Mr. Hart has not fared well. After an admission to hospital with a stroke, he is now at The Sunset Lodge, a residential care facility. He spends most of his time in bed in his room in a chair watching TV after the staff helps him get up. He is able to shuffle down to the dining room for most meals. He has a moderate vascular dementia from the stroke.
PPS Score	~40%
Scenario 2 Worsening Sign	Mr. Hart experiences chest pain, not relieved by Nitro, and his O2 saturation is declining, he is requiring O2. The covering night staff at the Lodge was not able to handle his acute decline and despite a no hospital order, he ended up in the ER at 4am. You find out at 8am of his admission.

Table 30: Clinical Case Presentation for Mrs. Cann. This narrative was read to participants as part of the interviews.

Patient Persona 2: Mrs. Cann	
Scenario 1	Mrs. Megan Cann is a 64-year-old widow with breast cancer, osteoarthritis of her left hip and high cholesterol. Her breast CA was treated with mastectomy and hormone suppression in 2005. Despite what appeared to be successful surgery for her breast cancer, Mrs. Cann now has confirmed metastases to her bones. She is receiving treatment (chemotherapy and radiation) and is now quite weak after the treatments. She is able to care for herself, for the most part, but has some difficulty getting up in the morning, which is quite unlike her, even 4 months ago. She is living at home and wants to stay there until she dies, but is having trouble maintaining the house. She has three daughters all who live close by in the city and are very supportive. Her family has developed a rotating schedule to ensure at least one of them brings dinner and provides Megan some company every night. They are not able to be there during the day. Her pain is well controlled on MS-Contin.
PPS Score	~60%
Scenario 1 Worsening Sign	When you see her today, she is looking worse. Normally well kept, she does not have make up on today and she is a bit disheveled. She developed new pain in her back where she has not had pain before. The pain control is not working and Mrs. Cann has been in bed for the better part of the past 3 days.
Scenario 2	Over the past several months, Mrs. Cann's situation has deteriorated. She has extensive metastases, including to the brain. She moved into her eldest daughter's home, staying in the spare room on the main floor. The family and Mrs. Cann agree that they want her to stay at home as long as possible. Mrs. Cann is mostly in bed, requiring two people to help her into her chair. She is weak and her pain is variably controlled.
PPS Score	~30% → 20%
Scenario 2 Worsening Sign	You discover that Mrs. Cann's intake has declined and she has barely been eating over the past two weeks. Both Mrs. Cann and her family are quite anxious. Mrs. Cann confides in you that she does not want to burden family any more. She does not want any life prolonging treatment, she asks about facilities and options.

Appendix B. Provider Participant Interview

Purpose

This appendix describes the interview questions used in the semi-structured provider participant interviews. The questions are presented here in a nested format as many of the questions are repeated for each patient case and each provider. There are two patient cases that have two specific scenarios that capture points in time (described in the previous appendix). Each participant could have been involved in one to four of these scenarios (for example, a GP would likely be involved in all four case scenarios. A residential care nurse would only be involved in one scenario). In each scenario, a participant may name multiple provider roles. Thus, nesting the questions for this appendix is an efficient way of capturing all the questions with no redundancy. Figure 71 highlights the process for the interview.

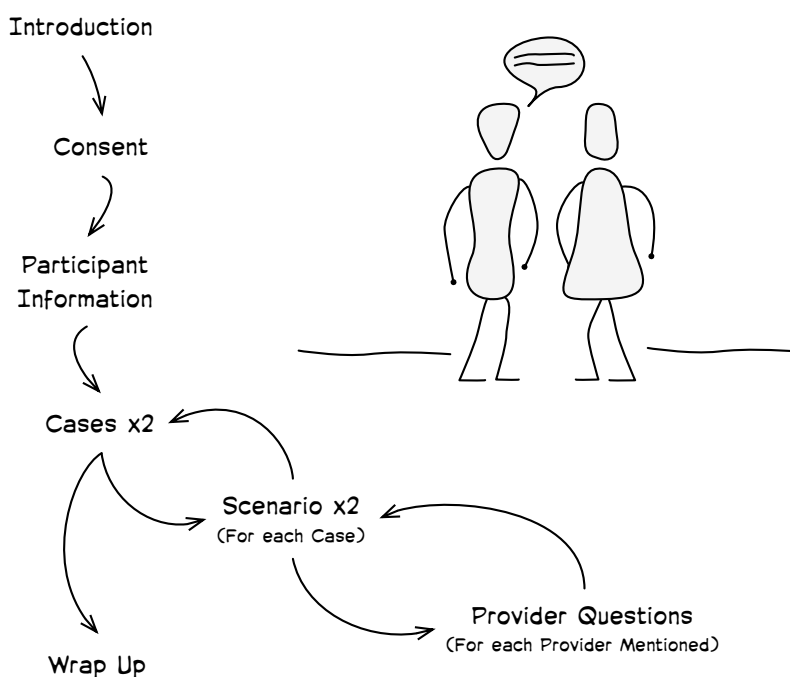


Figure 71: The stages of the provider participant interview. The illustration highlights the nesting of multiple cases, with scenarios and the recursive nature of questioning about each provider.

Introduction and Purpose of the Interviews

Suggested dialogue, provided as an example, is in quotes. Actions are described within angle brackets, such as <participant signs consent>. The interviews were semi-structured and performed by one researcher for consistency. The interviews were allowed to take their course to capture details.

“Thank you for agreeing to participate ‘Care Continuity’ a study on Continuity of Care for patients at the end of life. This study consists of two parts – first, a series of interviews with providers, such as you, to explore how Continuity of Care is maintained for patients at end of life. Two discussion groups will be held after the interviews are complete to review the findings and make recommendations for improving continuity of care for end of life patients. Continuity of Care is defined as the care provided to an individual patient over time, it includes continuity of information, management and relationships over time. Patients who are at the End of Life are patients in their final 12 months of life.

“This interview is structured around two fictional patients. These are used to help me elicit your clinical practice for patients at various stages of end of life and are used to standardize our findings.

“The Purpose of this interview is to understand your practice, particularly how it pertains to communicating to other providers to maintain Continuity of Care for your patients. I am interested in discovering how you communicate as well as with whom you communicate. This interview will also help me to define the other providers involved in end of life care.

“All information will be stored consistent with UVic and VIHA ethics policies and any information shared will be shared anonymously.

“Do you have any questions?”

“I will give you a consent form to sign before we begin.

Consent

“Please read through this consent form... Do you have any questions?” <Signs Consent>

“Thank you, we can begin”

Participant Information

1. What is your Profession or role in supporting end of life care?
2. How many years have you been in practice? (or NA)
3. Gender: M/F
4. Please briefly describe your practice...

Cases

“Now we will get into the clinical cases. I will describe the scenario to you in the form of a typical short clinical case. I am going to follow up with some questions. You are welcome to ask clarifying questions about the case.”

“Let us begin with case #1: Mr. Bill Hart

<READ SCENARIO> <ASK SCENARIO QUESTIONS BELOW>

<READ SCENARIO WORSENING SIGN> <ASK QUESTIONS BELOW>

<REPEAT FOR SCENARIO 2>

“Let us move on to case #2: Mrs. Megan Cann

<READ SCENARIO> <ASK SCENARIO QUESTIONS>

<READ SCENARIO WORSENING SIGN> <ASK QUESTIONS>

<REPEAT FOR SCENARIO 2>

Wrap Up

“That concludes the two cases. Before we wrap up, I have one last question:

“Could you describe how you think the current Electronic clinical systems (e.g. Cerner) are helping you provide care and maintain continuity? How could this be improved?”

“Thank you for participating in this study.”

“Do you have any additional questions / comments / thoughts?”

“Would you be interested in participating in the two group discussions to review findings and to develop recommendations for improvements?”

<Provide participant with reimbursement form>

Example Scenario Questions

1. Would you be engaged in this patient's care at this point?
 - a. If No:
 - i. Why not?
 - ii. Should you be involved with this patient's care at this point?
 - iii. In SCENARIO 2 ONLY:
 1. If you were involved with this patient prior to this, whom would you have handed over to?
 2. What would trigger the handover?
 3. How would you handover responsibility? (e.g. discharge form, etc)
 - b. If Yes:
 - i. How would you have become involved in their care? (if not previously)
 - ii. Who would have engaged you in this patient's care (e.g. another provider, patient themselves, etc)
 - iii. How would they have communicated to you the need for your involvement?

- iv. Describe the care you would be providing for this patient at this stage? (e.g. assessment, home care, pain management, etc)
- v. Where else would you gather information about this patient? (e.g. do you have a referral letter, chart, patient themselves, etc)
- vi. What information do you often need that is missing for patients like this?
- vii. Would you access information from their Cerner PowerChart record?
- viii. Would you access information from another electronic record / electronic system?
- ix. From your experience, who else would be engaged in <PT NAME>'s care at this point? (Please describe the various provider roles you would expect to be involved)
- x. *<GO THROUGH PROVIDER QUESTIONS FOR EACH PROVIDER MENTIONED>*

2. *<READ WORSENING SIGN FOR SCENARIO X>*

- a. Who would you communicate this change with?
- b. How would you communicate this change?
- c. *<GO THROUGH PROVIDER QUESTIONS FOR EACH NEW PROVIDER MENTIONED>*

PROVIDER QUESTIONS:

For each provider mentioned by the participant, ask the following: For provider XXXXX:

1. What role are they playing in the Care of our patient at this point?
2. Do you communicate directly with this provider?
 - a. If Yes:
 - i. How do you communicate with them? (Describe what you communicate)
 - ii. When does this happen?
 - iii. How do they communicate with you? (Describe what they communicate)
 - iv. Which methods of communication are most important to you to ensure Continuity of Care?
 - v. If there are any forms that you use, would it be possible to have a copy of the blank form?
 - b. If No:
 - i. Should you communicate with them?
 1. If yes, please tell me why it would be important?
 2. If No, please tell me why would it not be important?
 - ii. How can you improve Continuity of Care with this provider?
 - iii. How could the provider improve Continuity of Care with you?

Appendix C. IM/IT Participant Interview

Purpose

This section describes the interview for the IM/IT participant interviews in the Care Continuity study. The purpose of these interviews was to engage VIHA IM/IT participants in the study prior to the group discussion. The interview allowed IM/IT staff to review the findings, providing the participants with context of the clinical situation. IM/IT were then able to provide feedback on existing features of the CISs that may benefit Continuity of Care in the scenarios but had not been described by our provider participants (due to lack of knowledge, etc). IM/IT participants were asked to suggest and explore possible improvements to the gaps raised by the provider participants.

The questions presented here are in a nested format as many of the questions were repeated. Each draft Rich Picture and Conceptual Model was reviewed during the interview.

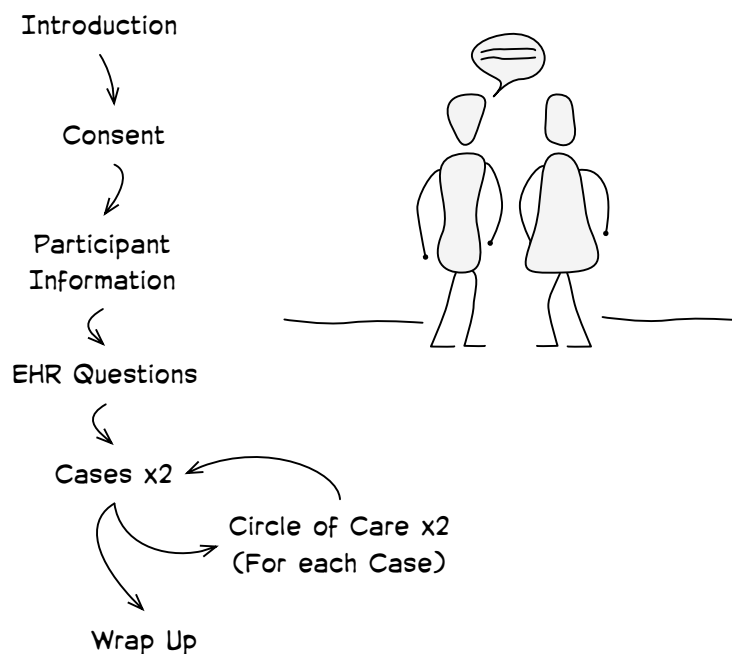


Figure 72: The stages of the provider participant interview. The illustration highlights the nesting of multiple cases, with scenarios and the recursive nature of questioning about each provider.

What follows is a sample script for the interview, including questions that the participant answered. The conceptual models being presented were draft models based on the analysis of the provider interviews please see the Results Section of this paper.

Introduction and Purpose of the IM/IT Interviews

“Thank you for agreeing to participate “Care Continuity” a study on Continuity of Care for patients at the end of life. This study consists of two parts – first, a series of interviews, which is what we are doing now to explore how Continuity of Care is maintained for patients at end of life. A key aspect of this is to understand how VIHA’s clinical systems support Continuity of Care.

“The interviews will be followed by two discussion groups to review the findings and make recommendations for improving continuity of care for end of life patients. You are also invited to attend the focus groups if you would like.

“**Continuity of Care** is defined as the care provided to an individual patient over time, it includes continuity of information, management and relationships over time. Patients who are at the End of Life are patients in their final 12 months of life.”

“This study and this interview are structured around two fictional patients. The providers who would care for these patients have been determined through a series of interviews with care providers in Duncan and in Victoria. I have modeled how these providers communicate to support Continuity of Care.

“The Purpose of this interview is to review my findings with you and understand how VIHA’s clinical information systems, specifically the regional EHR, support the communication activities described by the providers.

“All information will be stored consistent with UVic and VIHA ethics policies and any information shared outside of the study participants will be shared anonymously.

“Do you have any questions?”

“I will give you a consent form to sign before we begin.

Consent

“Please read through this consent form... Do you have any questions?”

<Signs Consent>

“Thank you. Let’s begin with the interview.”

Participant Information

5. What is your role in IM/IT?
6. Do you have a clinical background?
 - a. If Yes:
 - i. What profession?
 - ii. How many years?
 - iii. Do you have any experience with palliative care or end of life care?
7. Describe what you do and are responsible for in IM/IT: _____
8. What activities in your job relate to designing clinical content and clinical workflow design?

Clinical Information System Questions

1. Please describe what clinical information systems are available to care providers:
 - a. In Victoria.
 - b. In Duncan.
2. Continuity of Care is described at three levels, how do each of these systems support:
 - a. INFORMATIONAL CONTINUITY? (Providing access to relevant information)
 - b. MANAGEMENT CONTINUITY? (Sharing and ensuring consistent management plans for patients)
 - c. RELATIONSHIP CONTINUITY? (Sharing and supporting defined relationships, such as family physician)

Clinical Scenario: Circle of Care Questions

“Now we will get into the clinical cases. I want to show you some pictures that describe our two simulated patients and care system that was modeled based on the interviews with the participants. I will describe some of the gaps that were found and I would like your opinions on how we can improve those. You are welcome to ask clarifying questions about the case as we go along.”

“Let us begin with case #1: Mr. Hart

<INTRODUCE SCENARIO AND REVIEW RICH PICTURE>

“How can we address the gaps discovered?”

<DISCUSS GAPS AND POSSIBLE SOLUTIONS>

“Let’s review the models based on my findings”

<SHOW THREE MODELS, ASK MODEL QUESTIONS BELOW FOR EACH MODEL>

“Let us move on to case #2: Mrs. Megan Cann“

<REPEAT ABOVE FOR CASE 2>

Model Questions

“This model describes the members of Mr. Hart’s Circle of Care for Mr. Hart...”

<HAND PAPER COPY OF MODEL TO PARTICIPANT TO REVIEW>

<Describe structure of the model and the Continuity Providers>

1. Where can I clarify the model for you? <Re-describe as needed>
2. Is this a helpful format to describe communication between providers?
3. What could be done to improve the clarity of this model for you?
4. Is there anywhere that the existing clinical information systems could be improved to support Continuity of Care for this patient?
5. How difficult would it be to build and implement a change like that?

Appendix D. Recruitment Letters

Recruitment Invitation Letter to Professional Care Providers v1.1

Palliative Care Research Opportunity

Care Continuity: Communication Genres at the End of Life.

Dear _____

I am sending you this letter to tell you of a very interesting research study that is seeking improvements to Continuity of Care for patients at end of life in VIHA. This highly interactive study is looking to engage healthcare providers in Duncan and Victoria along with IM/IT staff to co-discover ways to improve Continuity of Care for our patients. Depending on how much you choose to participate, it will only take from one hour to a maximum of five hours of your time over the next few months. Your time will be compensated. The study is currently looking to interview <INSERT ROLE HERE> who are involved in providing care to end of life patients in <INSERT DUNCAN OR VICTORIA>.

Dr. Morgan Price, a family physician who works in Victoria, is running this study as part of his PhD at UVic in the School of Health Information Science. He has developed this study to discover with us what feasible improvements we can make in VIHA to improve Continuity of Care for our end of life patients. There are two aspects to this study:

First, Dr. Price will be interviewing members of the VIHA healthcare team. First, he will interview key healthcare providers in Duncan and Victoria who are involved in end of life care to discover current care and communication practices. Next he will interview VIHA health IT staff to discover how the current IT systems support continuity and the practices discovered. Each interview will take about an hour with Dr. Price and he will meet you when and where it is convenient for you.

Second, Dr. Price will facilitate a set of two group discussions to review the findings with study participants. The focus of the group sessions will be to co-develop recommendations for *feasible* improvements to processes and to technology use to better support Continuity of Care. Providers and health IT staff will be participating in the review of findings in two highly interactive sessions. This pair of two sessions will take two hours each and will be videoconferenced so that people in Victoria and Duncan can equally participate in the discussions.

I have attached a letter from Dr. Morgan Price, along with his contact information. Please contact Morgan if you are interested in participating or pass this along to any of your staff who are <INSERT ROLE HERE> that would be interested and are involved in providing care to end of life patients in <DUNCAN OR VICTORIA>. Participation in this research is entirely voluntary; there are no negative implications for not participating.

Sincerely,

Dr. G. Michael Downing, MD
 Director of Research & Development, Victoria Hospice Society;
 Clinical Associate Professor, UBC Division of Palliative Care;
 Adjunct Assistant Professor, UVic School of Health Information Science;

Recruitment Letter to VIHA IM/IT v1.1

Palliative Care Research Opportunity Care Continuity: Communication Genres at the End of Life.

Dear _____

I am sending you this letter to tell you of a very interesting research study that is seeking improvements to Continuity of Care for patients at end of life in VIHA. This highly interactive study is looking to engage IM/IT staff along with healthcare providers to co-discover ways to improve Continuity of Care for our patients. Depending on how much you choose to participate, it will only take from one hour to a maximum of five hours of your time over the next few months.

Dr. Morgan Price, a family physician who works in Victoria, is running this study as part of his PhD at UVic in the School of Health Information Science. He has developed this study to discover what feasible improvements we can make in VIHA to improve Continuity of Care for our end of life patients. There are two aspects to this study:

First, Dr. Price will be interviewing members of the VIHA healthcare team. First, he will interview key healthcare providers in Duncan and Victoria who are involved in end of life care to discover current care and communication practices. Next he will interview VIHA health IT staff to discover how the current IT systems support continuity and the practices discovered. Each interview will take about an hour with Dr. Price and he will meet you when and where it is convenient for you.

Second, Dr. Price will facilitate a set of two group discussions to review the findings with study participants. The focus of the group sessions will be to co-develop recommendations for *feasible* improvements to processes and to technology use to better support Continuity of Care. Providers and health IT staff will be participating in the review of findings in two highly interactive sessions. This pair of two sessions will take two hours each and will be videoconferenced so that people in Victoria and Duncan can equally participate in the discussions.

I have attached a letter from Dr. Morgan Price, along with his contact information. Please contact Morgan if you are interested in participating or pass this along to any of your staff that would be interested and are involved with the design and use of VIHA's Clinical Information Systems. Participation in this research is entirely voluntary; there are no negative implications for not participating.

Sincerely,

Dr. G. Michael Downing, MD
Director of Research & Development, Victoria Hospice Society;
Clinical Associate Professor, UBC Division of Palliative Care;
Adjunct Assistant Professor, UVic School of Health Information Science;

Care Continuity: Communication Genres at the End of Life. Opportunity to Participate in Research Study

Version 1.1 Recipient ID: _____

Principal Investigator:

Dr. Morgan Price, MD, CCFP.
PhD Candidate, University of Victoria, Health Information Science.
Phone: 250-216-7709 email: morgan@virtuallypriceless.org

About the Study:

This study seeks to explore how to improve Continuity of Care for patients at the end of life. It is a study designed to engage healthcare providers and IM/IT staff to answer the question:

What feasible recommendations can be made to care processes and to clinical information systems to improve Continuity of Care for End of Life patients?

The study is being conducted in Duncan and Victoria and seeks to engage providers in each community as well as VIHA IM/IT staff to help describe current practices and to seek feasible recommendations for improving Continuity of Care.

If you are interested in participating in this study, there are two phases to the study:

- A single 1-hour interview, where current practices are discussed, and
- two, 2-hour discussion groups where findings will be shared and recommendations will be sought.

You can participate in just the interview or can participate in all three sessions. Interviews will be arranged at a convenient location for you. Discussion Groups will be held at Royal Jubilee Hospital and Cowichan Regional Hospital, connected via Video Conferencing. Participation is voluntary; there are no negative implications of not participating.

You will be compensated for your time (1-5 hours, depending on level of participation). Physicians will receive sessional reimbursement, other providers will be compensated at their current salary rates, and VIHA IM/IT staff has permission to record participation as part of their normal work hours. If you are receiving compensation for participating, you cannot engage in this study during your regular work hours, I am happy to meet you when you are not working.

Research of this type is important because it will make contributions both to the improvement in quality of care for end of life patients on Vancouver Island, and will also expand our understanding of communication patterns between providers and how we can improve that communication with technology. Recommendations and findings from this study will be shared with VIHA and more widely in order to support the development of better electronic systems in the future.

To participate in this study or if you have any questions, please contact Dr. Price via email (morgan@virtuallypriceless.org) or phone (250-216-7709).

Thank you for your time and interest,

Morgan Price MD, CCFP, PhD Candidate.

Appendix E. Consent Forms

Care Continuity: Communication Genres at the End of Life.

Consent to Participate in Interviews - Version 1.1 - Participant ID: _____

You have been invited to participate in a study entitled *Care Continuity: Communication Genres at the End of Life* that is being conducted by Dr. Morgan Price. Dr. Price is a practicing family physician and also a PhD Candidate in the department of Health Information Science at the University of Victoria and you may contact him if you have questions at morgan@virtuallypriceless.org or 250-216-7709.

This study is part of Dr. Price's requirements for his PhD degree in Health Information Science. It is being conducted under the supervision of Dr. Francis Lau, whom you may contact at 250-472-5131. This research is being funded through Dr. Lau's CIHR e-health chair research fund.

The purpose of this research project is to discover what feasible recommendations can be made to care processes and the clinical information systems to improve Continuity of Care for End of Life patients. The study is being conducted in the communities of Duncan and Victoria.

Research of this type is important because it will make contributions both to the improvement in quality of care for end of life patients on Vancouver Island, and it will expand our understanding of communication patterns between providers and how we can improve that communication.

You are being asked to participate in this study because you have been identified as a provider who has a role in providing care to patients who are at the end of their life⁶⁰.

If you agree to voluntarily participate in the interview portion of this qualitative research, your participation will include a single, one-hour interview to explore what your clinical involvement would be in the care of two *simulated*, end of life patient cases. You would be one of approximately 40 interviewees. The interviews will occur at an agreed to, convenient location for you (such as your local hospital, your office, or clinic). Interviews will be audio-recorded so that the researcher can confirm what was discussed during the analysis phase.

After the interviews you will have to opportunity to follow up the interview by participating in two, 2-hour discussion groups to review findings and to help co-develop recommendations to improve Continuity of Care for end of life patients. These sessions will be held in Victoria at the Royal Jubilee Hospital with videoconferencing available for out of town participants.

There are no known or anticipated risks to you by participating in this research.

The potential benefits of your participation in this research include developing recommendations for improving communication practices and Continuity of Care for patients in your community. These recommendations will be designed to be feasible so that they can be adopted in your community.

As a way to compensate you for any inconvenience related to your participation, you will be paid for one hour of your time to participate in this portion of the study (physicians will be compensated based on BC sessional rates, other providers will be compensated based on their current hourly rates, IM/IT staff given release time from VIHA as part of regular work). It is important for you to know that it is unethical to provide undue compensation or inducements to research participants and, if you agree to be a participant in this study, this form of compensation to you must not be coercive. If you would not otherwise choose to participate if the compensation was not offered, then you should decline.

⁶⁰ End of Life patients are defined as patients who have less than 12 months to live.

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you decide to withdraw from the study after completing the interview, your data will be removed from the study analysis. It will not be possible to remove your input completely from the study if you request to have your data be removed from the study after analysis has begun (one week after the interview), every effort will be made to remove any sensitive data that you declare. You will be compensated for your time in the study, even if you withdraw. If you are receiving compensation for participating, you agree that you are not engaging in this study during your regular work hours.

The researcher may have a relationship with some study participants as he is a family doctor in Victoria and also provides consultation to VIHA. To help prevent this relationship from influencing your decision to participate, the following steps to prevent coercion have been taken: recruitment is through the Victoria Hospice Research Office and your participation is voluntary. Further, Dr. Price will not disclose any individualized information or comments to anyone outside of the study, including IM/IT leadership. **No data will be shared that can be identifiable either in the discussion groups or as part of sharing the research findings.**

If you wish to participate in the future discussion groups, and to make sure that you continue to consent to participate in this research, I will provide similar consent forms at each session for you to sign.

Your participation will not be shared back to VIHA or to those who recruited you for this study. Removing names from all data and transcriptions will protect your confidentiality. Descriptions of practice will reflect aggregate findings, not individual practice. A sufficient sample size of interviews will ensure anonymity. Data will be protected: all data will be stored electronically on an encrypted drive under lock and key in Dr. Price's office and at a secure back up site. All paper materials will be scanned electronically and stored on that drive. Any paper will then be shredded. Electronic materials will be erased after 5 years.

It is anticipated that the results of this study will be shared with others in the following ways: recommendations from the study to improve Continuity of Care will be shared with your local Palliative Care team and with VIHA leadership; academic presentations and publications will also be sought to share findings of the study; Dr. Price will also complete his PhD Dissertation based, in part, on the findings from this study. Each participant will receive a copy of the recommendations.

You may contact Dr. Morgan Price and Dr. Francis Lau with any questions. Contact information above. In addition to being able to contact the researcher and/or supervisor at the above phone numbers, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria at 250-472-4545 or ethics@uvic.ca and the VIHA Research Ethics office at 250-370-8620.

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers.

Name of Participant

Signature

Date

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Care Continuity: Communication Genres at the End of Life.
Consent to Participate in Discussion Group - Version 1.1 - Participant ID: _____

You are being invited to participate in a study entitled *Care Continuity: Communication Genres at the End of Life* that is being conducted by Dr. Morgan Price. Dr. Morgan Price is a family physician and a PhD Candidate in Health Information Science at the University of Victoria and you may contact him if you have questions at morgan@virtuallypriceless.org or 250-216-7709.

This study is part of Dr. Price's requirements for his PhD degree in Health Information Science. It is being conducted under the supervision of Dr. Francis Lau, whom you may contact at 250-472-5131. This research is being funded through Dr. Lau's CIHR e-health chair research fund.

The purpose of this research project is to discover what feasible recommendations can be made to care processes and the clinical information systems to improve Continuity of Care for End of Life patients. The study is being conducted in the communities of Duncan and Victoria.

Research of this type is important because it will make contributions both to the improvement in quality of care for end of life patients on Vancouver Island, but it will also expand our understanding of communication patterns between providers and how we can improve that communication.

You are being asked to participate in this study because you have been identified as a provider who has a role in providing care to patients who are at the end of their life⁶¹.

If you agree to voluntarily participate in the discussion group portion of this qualitative research, your participation will include two, 2-hour discussion groups co-develop recommendations to improve Continuity of Care for end of life patients. These sessions will be held in Victoria at the Royal Jubilee Hospital with videoconferencing available for out of town participants. In these sessions you will review anonymized findings of a series of interviews and help to develop feasible recommendations to improve communication patterns, care practices, and potentially functionality of IM/IT tools to better support care delivery in VIHA.

There are no known or anticipated risks to you by participating in this research.

The potential benefits of your participation in this research include developing recommendations for improving communication practices and Continuity of Care for patients in your community. These recommendations will be designed to be feasible so that they can be adopted in your community.

As a way to compensate you for any inconvenience related to your participation, you will be paid for two hours of your time for each of the two discussion groups (4 hours total compensation) (physicians will be compensated based on BC sessional rates, other providers will be compensated based on their current hourly rates, IM/IT staff given release time from VIHA as part of regular work). IM/IT staff are expected to bill VIHA for their time as part of regular work. It is important for you to know that it is unethical to provide undue compensation or inducements to research participants and, if you agree to be a participant in this study, this form of compensation to you must not be coercive. If you would not otherwise choose to participate if the compensation was not offered, then you should decline.

⁶¹ End of Life patients are defined as patients who have less than 12 months to live.

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study during the discussion group, every attempt will be made to remove your input from the discussion; however, it would not be possible to truly remove your influence as comments may influence the future discussions. Where possible, your data will be removed from the study analysis. You will still be compensated for your time. If you are receiving compensation for participating, you agree that you are not engaging in this study during your regular work hours.

The researcher may have a relationship with some study participants as he is a family doctor in Victoria and also provides some consultation to VIHA. To help prevent this relationship from influencing your decision to participate, the following steps to prevent coercion have been taken: recruitment is through the Victoria Hospice Research Office, your participation is voluntary, further Dr. Price will not disclose any individualized information or comments to anyone outside of the study, including IM/IT leadership. **No data will be shared that can be identifiable.**

Your confidentiality will be protected. Your participation will not be shared back to VIHA or to those who recruited you for this study. All names will be removed from all data and transcriptions. Models will be developed that describe care processes not individual practice. Data will be protected: all data will be stored electronically on an encrypted drive kept under lock and key in Dr. Price's office and at a secure back up site. All paper materials will be scanned electronically and stored on that drive. Any paper will then be shredded. Electronic materials will be erased after 5 years. Study participants in the group discussion may recognize each other. **As a participant in this study, you agree to maintain the confidentiality of other participants by not sharing the discussions outside of the study and not naming participants to non-participants in the study.**

It is anticipated that the results of this study will be shared with others in the following ways: recommendations from the study to improve Continuity of Care will be shared with your local Palliative Care team and with VIHA's End of Life program; academic presentations and publications will also be sought to share findings of the study; Dr. Price will also complete his PhD Dissertation based, in part, on the findings from these sessions. Each participant will receive a copy of the recommendations at the end of the study.

You may contact Dr. Morgan Price and Dr. Francis Lau with any questions. Contact information above. In addition to being able to contact the researcher and/or supervisor at the above phone numbers, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria at 250-472-4545 or ethics@uvic.ca and the VIHA Research Ethics office at 250-370-8620.

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers. This consent form will be presented at the beginning of both sessions for you to review and sign.

Name of Participant

Signature

Date

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Appendix F. Study Budget

		Units	Cost / Unit	Total Cost
Interviews				
	Provider Participant Fees*	34	90	\$3,060.00
	IM/IT Participant Fees	6	80	\$480.00
	Transcription Fees	36	120	\$4,320.00
	Presentation Material (Printing)			\$30.00
	Travel Costs	14	20	\$280.00
Discussion Groups				
	Provider Participant Fees	7	360	\$2,520.00
	IM/IT Participant Fees	3	320	\$960.00
	Support Staff (hours)	6	50	\$300.00
	Transcription Fees (hrs)	4	120	\$480.00
	Presentation Material (Printing)	2	30	\$60.00
	Video Conferencing Fees	2	0	\$0.00
	Coffee and Snacks	2	50	\$100.00
Totals				
	TOTAL Estimated Cost			\$12,590.00
	From CIHR eHealth Chair			\$11,150.00
	From VIHA IM/IT Operational Cost			\$1,440.00

* Provider Participant Fees are estimated as provider rates will vary based on role.

Funding Sources:

CIHR eHealth Chair Research Fund. Held by Dr. Francis Lau (Supervisor).

eDrug Observatory Research Account will provide Support Staff for Discussion Groups.

IM/IT Operational Budget to cover IM/IT staff time for interviews.

Appendix G. Ethics Approval Certificate



University
of Victoria

UVic/VIHA Joint Research Ethics Sub-Committee
Human Research Ethics, University of Victoria
PO Box 1700, Stn CSC, Victoria BC, V8W 2Y2
Tel (250) 472-4545 Fax (250) 721-8960 Web www.research.uvic.ca



Vancouver Island Health Authority, Memorial Pavilion, Kenning Wing
1952 Bay Street, Victoria BC, V8R 1J8
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UVic/VIHA Joint Research Ethics Sub-Committee Certificate of Approval

<u>Principal Investigator</u> Morgan Price Ph.D. Student	<u>Department/School</u> HEIS	<u>Supervisor</u> Dr. Francis Lau	
<u>Co-Investigator(s):</u> Dr. Michael Downing, Research Director, Victoria Hospice			
<u>Project Title:</u> Care Continuity: Communication Genres at the End of Life.			
<u>Protocol No.</u> 2009-13	<u>Approval Date</u> 23-Mar-09	<u>Start Date</u> 23-Mar-09	<u>End Date</u> 22-Mar-10

Certification

This certifies that the UVic/VIHA Joint Research Ethics Sub-Committee has examined this research protocol and concludes that, in all respects, the proposed research meets appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Subjects and the Vancouver Island Health Authority Research and Evaluation administration.

This Certificate of Approval is valid for the above term provided there is no change in the procedures. Extensions or minor amendments may be granted upon receipt of "Request for Continuing Review or Amendment of an Approved Project" form.

2009-13 Price, Morgan

Appendix H. Visual Thinking

This appendix reviews some relevant aspects of Visual Thinking as well as a discussion on Conceptual Modeling notations as they relate to the choice of models used in this study.

Introduction

Diagrammatic representations are central to the work of SSM and they are used in other work, such as Genre Ecologies. The types of representation can impact reasoning with those diagrams. Diagrams were an important part of the description of findings in this study and were used when seeking improvements in Continuity of Care. Thus, a short description of Visual Thinking and a review of the some of the selected forms of Conceptual Modeling were warranted and were placed here in this appendix for reference.

Cognitive Fit and Visual Thinking

The theory of *cognitive fit* was developed by Iris Vessey to explain the connection between task performance and presentation of information. It predicted that the closer the mental representation of a problem is to the problem-solving task, the better the observable problem solving ability (Vessey, 1991). Shaft and Vessey extended Cognitive Fit after a review of its application after 15 years (Figure 73). The extension incorporated concepts related to Distributed Cognition (Hutchins & Klausen, 1996) and the importance of both internal and external representations in solving problems (Shaft & Vessey, 2006). The types of external representations also impacted problem-solving performance. Those external representations with high level of cognitive fit to the task at hand were better at supporting discovery of solutions. Thus, diagrammatic representations that make certain aspects of a system explicit and easy to comprehend are more likely to support problem solving around those specific aspects.

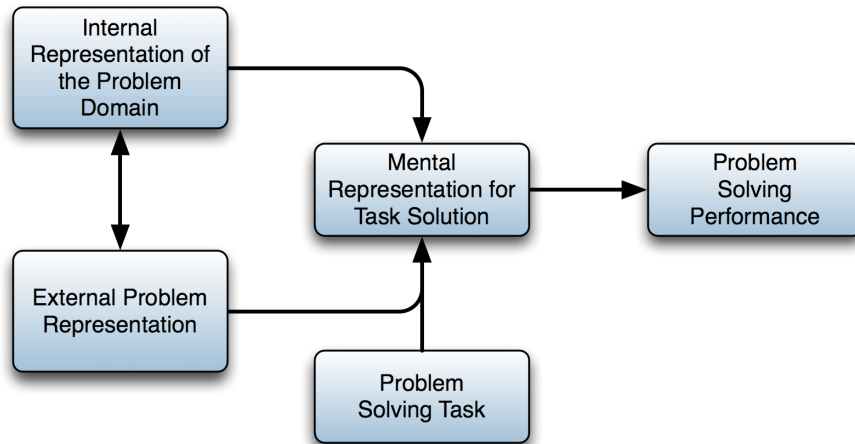


Figure 73: The extended Cognitive Fit model, incorporating external representations. Based on (Shaft & Vessey, 2006)

Larkin and Simon, in their landmark paper, explored diagrammatic reasoning. They studied two problems: a physics pulley problem and a geometry problem. These two examples were used in their study to explore types of reasoning using two distinct types of external representations: text and diagrammatic representations (Larkin & Simon, 1987). These two domains both have a long history of use of diagrams to support problem solving. Larkin and Simon compared performance in problem solving with two different representations, one textual and one diagrammatic, that were informationally equivalent (i.e. they contained the same information). They found that performance (e.g. speed / accuracy) was improved with diagrams. The diagrams provided some context within the system to data elements that text representations could not. Thus, the *fit* of the diagram to the specific problem changed performance.

Scaife and Rogers have reviewed how visual representations support decision-making. They have considered external cognition arguments for supporting the use of diagrams to offload some of the cognitive processing to the visual representation (Scaife & Rogers, 1996). This work was consistent with Hutchins's distributed cognition theories (Hutchins, 1995a) (Hutchins, 1995b) (Hutchins & Klausen, 1996). They concluded that users should easily understand the diagram(s) structure and notation in order to utilize it. Overly complex diagrams may degrade cognition ability, as too much attention would be focused on learning the syntax of the diagram type instead of the content of the specific diagram.

Conceptual Modeling in Information Systems Design

Conceptual models are primarily graphical representations of domain phenomena and are used, in Information System (IS) development, for the following four purposes:

- A. Communicating requirements between developers and users
- B. Improving analysts understanding of the domain being studied
- C. Providing an input tool for information system design
- D. Documenting requirements for future reference (Wand & Weber, 2002)

Conceptual modeling has been considered key to success of IS development projects (Siau, 2004). Conceptual modeling serves to facilitate interaction between users and developers and reach a common understanding of how the resulting system should perform (Berg & Toussaint, 2003). Conceptual modeling is a success factor in software projects allocating significant resources to the requirements process (15-30% of the budget), independent of end user involvement (Hofmann, Lehner, & Motors, 2001). In practice, the most common diagram types that are used in practice include Entity Relationship diagrams, data flow diagrams, systems flowcharting, workflow modeling, UML diagrams, and structured charts (Davies, Green, Rosemann, Indulska, & Gallo, 2006).

SSM provides modeling tools and has been used successfully with the development of Information Systems (P. Checkland & Holwell, 1998), but the SSM modeling has not yet taken advantage of some of the advances in conceptual modeling for Information Systems.

One of the challenges of the use of Genres with Information Systems work is their descriptions may not lend themselves to translation to standardized requirements for the information system. Although there has been work in modeling Genre Ecologies (Spinuzzi & Zachry, 2000), Genre modeling has also not yet taken advantage of developments in conceptual modeling.

Jurisica, Mylopoulos and Yu provide a framework for ontologies for knowledge management (Jurisica, Mylopoulos, & Yu, 2004). They surveyed knowledge representations used in computer science and found they were able to classify concepts into four broad categories: structural, dynamic, intentional, and social (Table 31). This was a useful breakdown of the primary types and uses of conceptual models and was helpful to this study to provide a sense of the major types of conceptual models that could be applied, the current state of conceptual models in SSM and Genre Ecologies,

and provided some additional guidance to the selection of specific conceptual model languages for this study. What follows is a review of some of the modeling languages in each of the four categories: static, dynamic, intentional, and social. NOTE: This breakdown was meant to show *primary* intent of the modeling languages, as many have overlap with the four categories.

Table 31: Framework of ontologies that is useful to categorize types of conceptual models. Based on (Jurisica, et al., 2004)

Ontology Type	Description	Examples
Static Ontology	Describe things that exist in the world, their qualities, and the relationships between those things. Key concepts: entities, attributes, and relationships.	Unified Modeling Language Class Diagram
Dynamic Ontology	Capture the changes of states of objects and the associated processes involved to make those changes. Dynamic models / process models allow people to focus on different changes to the steps involved in completing activities.	Flow Chart; Activity Diagram; Business Process Modeling Notation
Intentional Ontology	Intentional models describe goals, beliefs and intentions. They allow for various perspectives to be expressed and reviewed to describe and reason about conflicting goals. Soft Goals can capture non-functional requirements, such as security, usability, etc.	Goal-oriented Requirements Language (GRL)
Social Ontology	Social Models capture organizational structures and dependencies between participants. They describe agents/actors and their relative positions and responsibilities.	Organizational Charts; i* (pronounced “I star”).

Selection of an effective visual language that was accessible to participants and that described the issues related to Continuity of Care was important to this research so that participants could reason about the findings and challenges.

Current Modeling in Genre Ecology and SSM

Spinuzzi (Spinuzzi, 2002) described the formalization of Genre Ecology modeling. These models have been primarily static models that highlight the different Genres observed in the ecology. Figure 74 shows a partial example of a Genre Ecology Model, illustrating Genre’s in use in a family physician’s office. The lines describe mediatory relationships between Genres. Spinuzzi has defined

the types of mediatory relationships. This modeling notation is primarily focused on the Genres. It does not capture actors in the models.

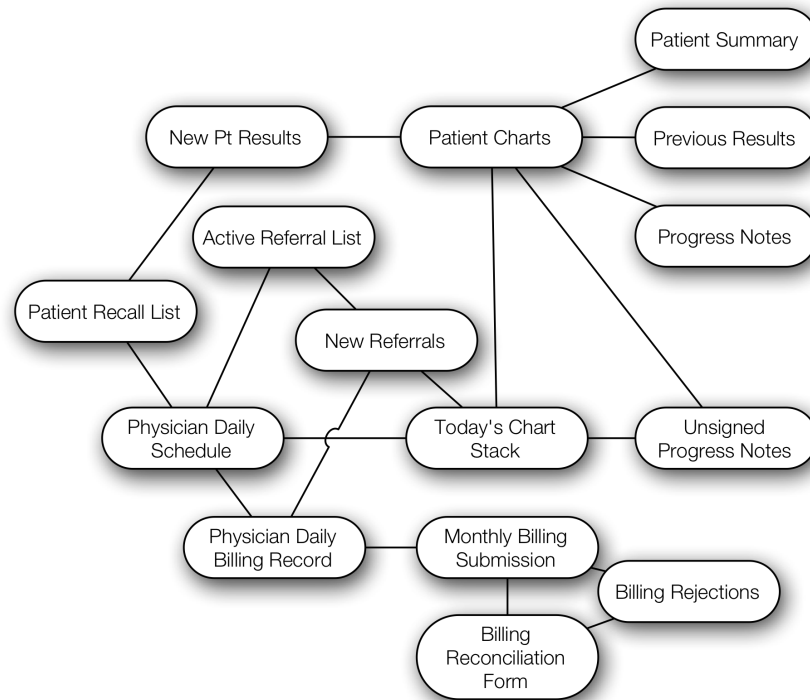


Figure 74: A sample informal Genre Ecology Diagram of the partial ecology of Genres in use in a family physician's office.

SSM uses two major types of diagrams, as previously described, the Rich Picture and the Conceptual Models. The Rich Picture is an informal diagram without specific notation, allowing the potential focus on any of the four levels. The purpose of the Rich Picture is to illustrate the Real World, including structures, processes, relationships, goals and issues. The practitioner will decide what aspects to highlight. The SSM Conceptual Models have more structure. The diagrams are process focused. However, the complete model, including CATWOE and Root Definition, can describe a system at all four levels.

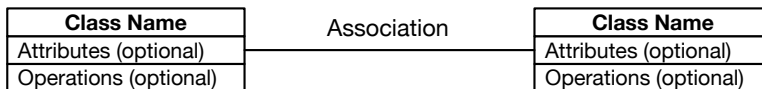
Unified Modeling Language (UML) 2

Unified Modeling Language has emerged in software engineering as a dominant notation to describe software systems. It has been used extensively, particularly for object-oriented systems. UML 2.2, the latest iteration of UML includes fourteen diagrams that can be used by analysts and developers when designing and developing systems (Ambler, 2005) (OMG, 2009). Briefly, we have highlighted three diagram types here: class diagrams, deployment diagrams, and communication diagrams.

The class diagram could be used to describe objects, their elements, and the relationships between them. Class diagrams are used for static ontological representations, such as information designs (Figure 75).

The deployment diagram is used to describe physical or runtime deployments of the nodes and components of a system (Figure 76). It is focused mainly on the structure of system and describes communication paths between nodes. The complexity of a deployment diagram is considered arbitrary, that is it can vary, reflecting what is needed to describe the system at that moment.

Communication diagrams focus on the communication between objects or agents in a system. They highlight the sequence and types of communication messages back and forth between actors (Figure 77).



Example

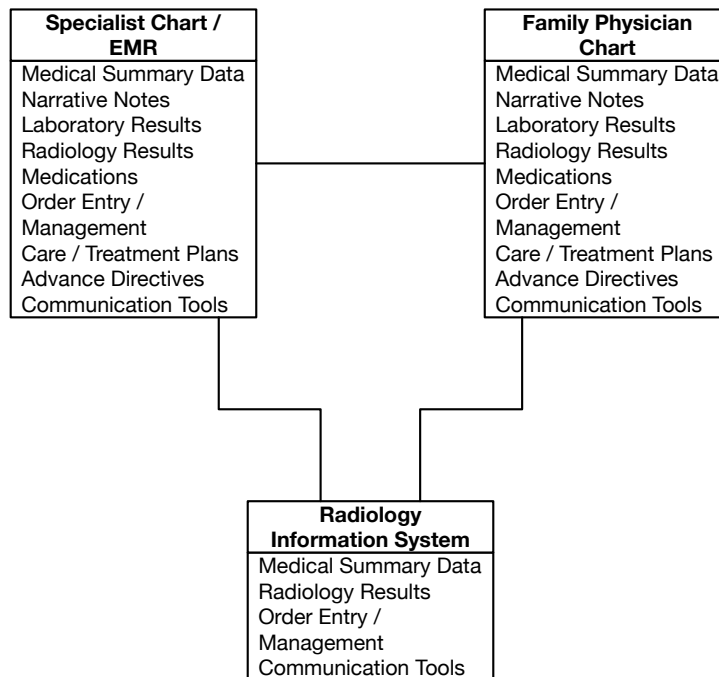
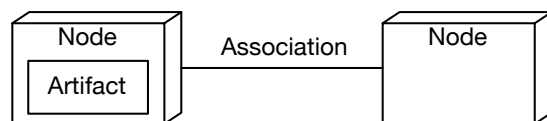


Figure 75: Simple example of a UML Class Diagram. There can be multiple kinds of associations between classes. The Attributes, in this example include content from the medical record.



Example

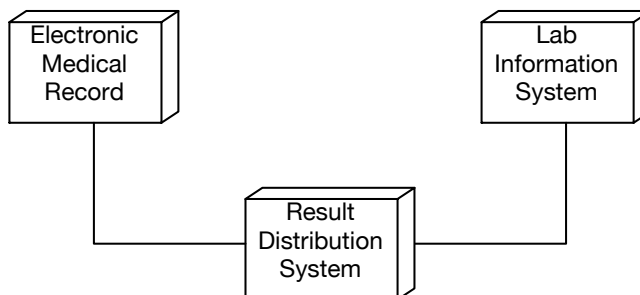
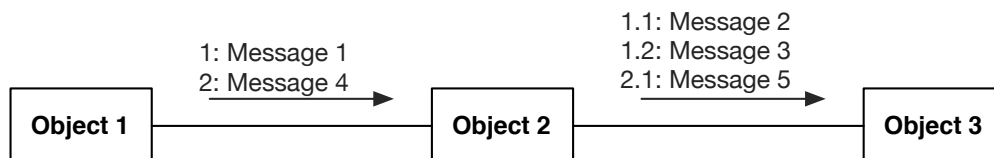


Figure 76: Simple example of a UML Deployment Diagram. The nodes represent physical aspects of deployment that allow artifacts to be deployed.



Example

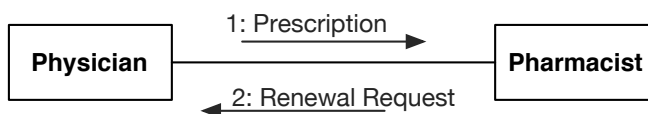


Figure 77: Simple UML Communication Diagram. Note the sequence numbers on the diagram indicating the ordering of the messages between entities.

UML was designed to support the design, development and maintenance of object oriented software systems. As such, the specifications can be very detailed. They can also be simplified and used for initial conceptualization and can be used for “soft”, early design work, such as the work in my study.

Modeling for this Study

My study sought improvements at all three levels of continuity: Relationship Continuity, Management Continuity, and Information Continuity. To be consistent with SSM, this study used a combination of Rich Pictures and Conceptual Models. The Rich Pictures described the real world more closely, while the Conceptual Models were meant to describe systems that highlight aspects of systems to support reasoning.

Taking Cognitive Fit into consideration, the diagrammatic models that were developed for this study specifically illustrated continuity at all three levels of the Haggerty Reid model of Continuity of Care. Three diagrammatic notations were selected to provide coverage of each type of continuity.

Relationship Continuity could be considered as a social ontology and thus a diagrammatic notation such as a simple organizational chart could suffice. As the Circle of Care system was patient centric, though, the typical organizational-centric chart may not be quite appropriate. Therefore, a modified organizational chart, centered on the patient was desired. It was assumed that much of the Management Continuity occurred through communications between the providers involved in the care of a patient and between providers and the patient / family. Communication can be through access to shared records or through direction communication. UML Communication Diagrams provided a notation for this and were selected for this study. Finally, Information Continuity was related to access to information, primarily information available in patient records. Diagrams that highlight where patient information was stored and how it was routed supported reasoning around Information Continuity challenges. UML Deployment Diagrams or Class Diagrams provided a useful notation to support reasoning about the current state of the information repositories. Combined, these three views provided reasonable fit to the problem of Continuity of Care.

Appendix I. Mr. Hart's Rich Pictures

This appendix describes the case of Mr. Hart, the findings and Rich Pictures in both Duncan and in Victoria.

The Clinical Case Presentation of Mr. Hart was provided earlier in the methods, and the overview was provided in the results section. This appendix describes the details of the Mr. Hart story in Duncan and in Victoria.

As described earlier, the Clinical Case Presentation provided the framework for the interviews and discussion groups in both communities. For the case of Mr. Hart, he was revisited at four key points in his last year of life. During the interviews, it became clear that there were additional important gaps that would be highlighted, if Mr. Hart's story was changed slightly. An additional step was added to the Rich Pictures to highlight the gaps if Mr. Hart was discharged from Emergency back to the community. The five points in his life were:

1. Stage III CHF, coping somewhat poorly in the community, fairly isolated.
2. Initial stroke, managed in the Emergency and **discharged home**
3. **Second stroke**, requiring longer admission to hospital.
4. Transfer to Long Term Care facility as rehabilitation not successful enough to safely discharge home.
5. Mr. Hart has an acute MI in the long-term care facility in the middle of the night and is transferred to the Emergency.

These five points are illustrated in Figure 26.

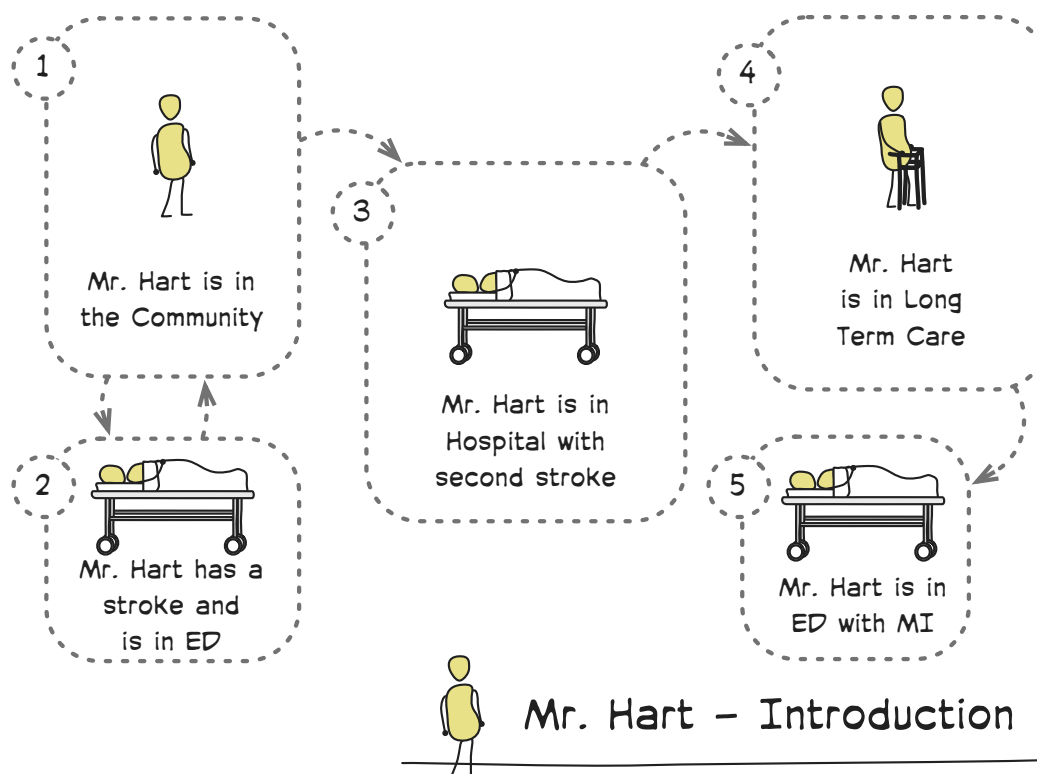


Figure 78: The skeleton framework of the case of Mr. Hart, each provider participant filled in the details through the interviews.

The framework of these stages allowed sufficient detail and focus to explore key transitions, but still allowed for each participant to create their own story and provide their perspective and availability and effectiveness of local resources, constraints, and skills. After the interviews were complete, two composite Rich Pictures were developed, as they were for Mrs. Cann. The paths were chosen from findings in the interviews. They were meant to highlight key findings / gaps for discussion. They were not the most frequent path nor were they an idealized path.

Mr. Hart's Rich Picture of Care in Duncan

This Rich Picture (Figure 79) captured the flow of care for Mr. Hart in Duncan, based on the findings from the interviews. The five stages are described in more detail below. Gaps for each stage were highlighted as these were presented to the participants in the Discussion Groups. The Rich Pictures highlight key activities and flows; they were not exhaustive in illustrating all the providers or all the potential ad hoc communications.

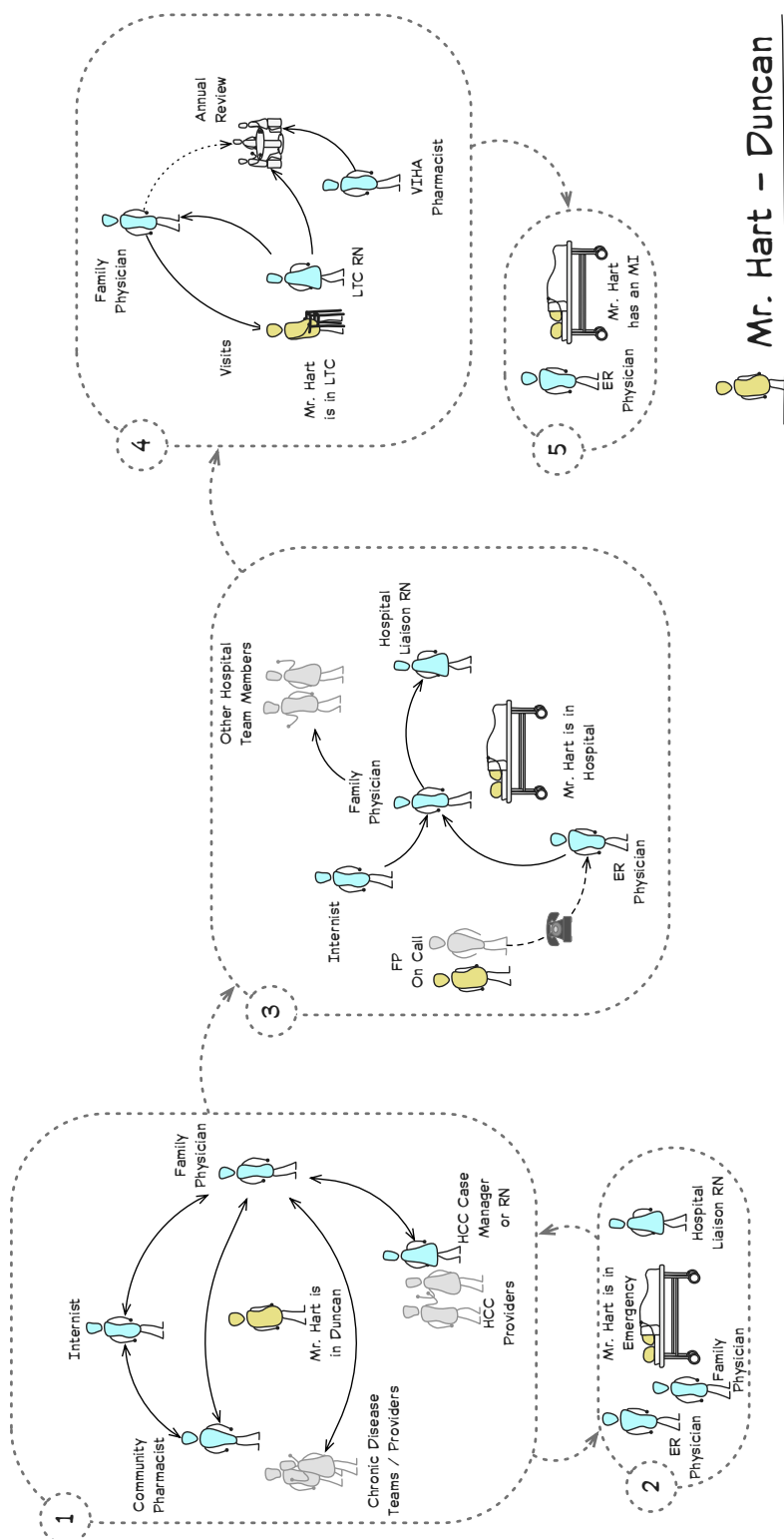


Figure 79: Rich Picture of Mr. Hart's story in Duncan. This was used to reflect back to participants, the findings from the provider interviews. Mr. Hart is highlighted in bright yellow and he has no family. Providers with significant roles in ensuring Continuity of Care ("Continuity Providers") are blue, and where there are other providers they are hinted at in grey (not all of these providers are displayed).

Stage 1 – Mr. Hart Living at Home (Figure 80):

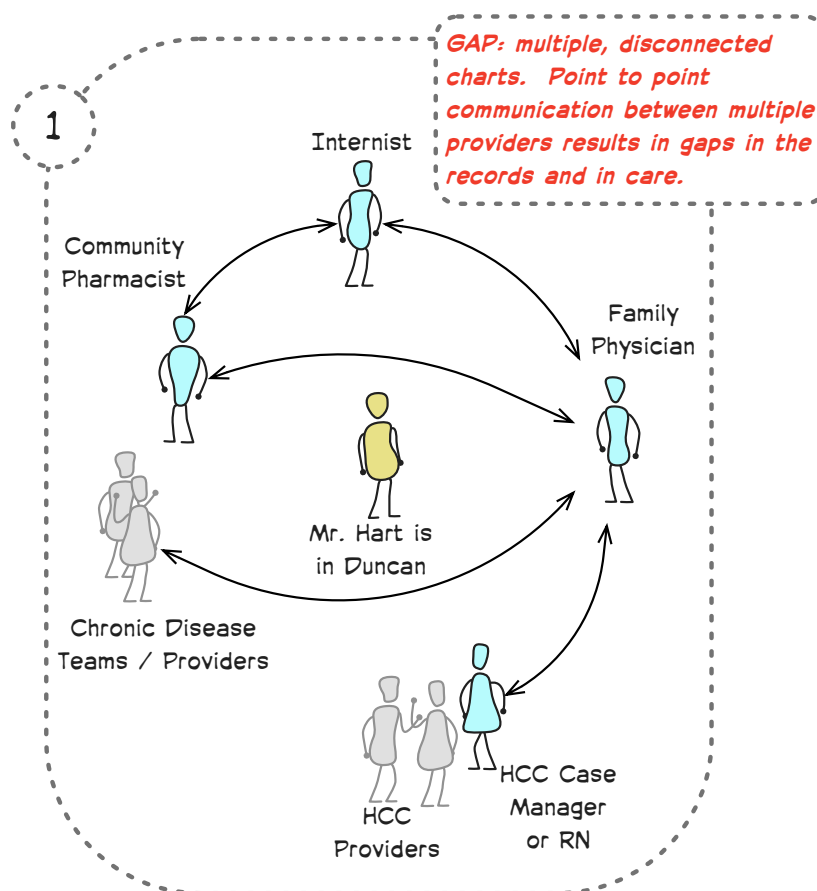


Figure 80: Mr. Hart is living in Duncan and he is ambulatory. There are several providers involved in his care, primarily coordinated by his family physician.

We first met Mr. Hart in Duncan while he was living alone in his apartment and he was beginning to have difficulty functioning at home alone. He had a complex (but not uncommon) set of medical conditions, including heart, lung, and alcohol issues. Mr. Hart had some shortness of breath when going to the grocery store and when climbing stairs in and out of his apartment or doing laundry. He was someone with few social supports and was starting to have trouble with some of his activities of daily living. At this point, his family physician was the primary coordinator and manager of his care. Mr. Hart has seen an Internist, who provides consultative assessments and recommendations on how best to manage Mr. Hart's constellation of medical issues. Mr. Hart has also attended, on occasion, the Diabetes Education Centre.

Mr. Hart had also been referred to Home and Community Care by his family physician. His coping and isolation were warning signs to Home and Community Care. He was assigned a case manager and the home and Community Care social worker came in to assess his financial situation and to ensure he had the appropriate pension. Occupational Therapy came in to make some suggestions about how he could better cope with his physical restrictions. He also had a few hours from community support worker time each week at this point. At the beginning, he did not require many Home and Community Care nursing services, so he was put on Duncan's "Keeping in Touch" program, where a nurse called him monthly to do a phone clinical assessment. Over time, as his coping declined, the Home and Community Care nurses were more involved. They were particularly involved as Mr. Hart was not that compliant with his medications and needed to be monitored more closely.

Gaps:

Not unlike Mrs. Cann's care at this stage, the key gap discovered was Information Continuity. There were multiple charts, basically one for each provider or care team. Information was shared through point-to-point communications (calls, faxes, letters) and not everyone was always informed of changes or functional status.

"It's a very ad hoc process at the moment...[the assessment] is part of their record that I don't see." (D02)

"There is not the time to meet and discuss things face to face and that's where if we had some kind of congestive heart failure clinic... we could have that kind of resource." (D06)

As Mr. Hart did not have close family. This highlighted a further dependence on family as assessors of how patients are coping:

"Without much family to get that other view on how he's functioning, I think that would be something missing." (D01)

Management Continuity would be impacted, for example, when one provider changed a medication without informing another provider. This could lead to confusion amongst the Circle of Care. This could also trigger a loss of trust and that can impact Mr. Hart's sense Relationship Continuity.

Stage 2 – Mr. Hart has his First Stroke (Figure 81):

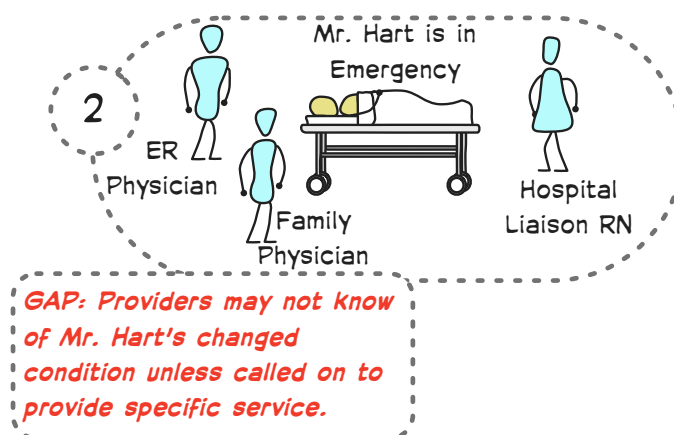


Figure 81: While in the community, Mr. Hart has a stroke and is sent to the Emergency Department. He is then sent home.

One day, Mr. Hart had a stroke. His apartment manager noticed he was not doing well and called 9-1-1. Mr. Hart was stumbling and slurring his words as he left his apartment. Mr. Hart visited the Emergency at Cowichan District Hospital. There, he was assessed and treated by the ER physician and admitted under his family physician for a brief hospital stay, although he never leaves the Emergency Department. While in the ED, the Hospital Liaison Nurse coordinated with the Home and Community Care team and notified them of the admission (she manually reviews the hospital admission and discharge lists every day at 8am and has them manually cross referenced with one of the Home and Community Care information systems).

Mr. Hart recovered enough to return home. As part of the discharge planning, the Hospital Liaison Nurse assessed Mr. Hart's need for increased Home and Community Care services and arranged another home occupational therapy assessment.

Gaps:

There was no automated mechanism to notify providers of admissions to either the ED or hospital. Unless called upon for specific service (e.g. to admit the patient), a provider might not know of the admission. For example, Mr. Hart's internist might not have been made aware of the stroke until the next scheduled visit, which could be six months or more in the future. This could impact Management Continuity and Relationship Continuity. If there was better continuity and notification,

the internist, and perhaps a specialized nurse would be able to better help get Mr. Hart back out to the community:

“If they wind up back in the hospital there is also that continuity in terms of the doctor and [CHF] nurse who can helping out and stabilizing things more quickly and get the patient out into the community again.” (D06)

Home and Community Care had addressed the gap of lack of information and notifications. They developed a labour intensive process of reviewing the hospital census lists daily and manually reconcile all admissions and discharges against their list of Home and Community Care patients that were currently registered with Home and Community Care. As one provider pointed out in the discussion groups, Home and Community Care was not aware of discharges that happen after 8am, (which were most of the discharges) and as such, there was typically a gap of at least 24 hours before Home and Community Care services were restarted.

Another gap was that the ER physician did not have access to the various records and consult letters from either the family physician’s office, Internist’s clinic, or the assessments from Home and Community Care. Although the Internist typically dictated a consult letter, these were done privately and were not available in the regional Cerner system. This was different for inpatient consults, which would have been dictated and transcribed within VIHA and would be available to the ER physician. In this scenario, as the Internist had not seen Mr. Hart in hospital, there were no consults available. The ER physician would have reviewed Mr. Hart’s PharmaNet profile and would have seen who had prescribed medications to Mr. Hart, which would help understand who was involved in the care.

Stage 3 – Mr. Hart is Admitted with his Second Stroke (Figure 82):

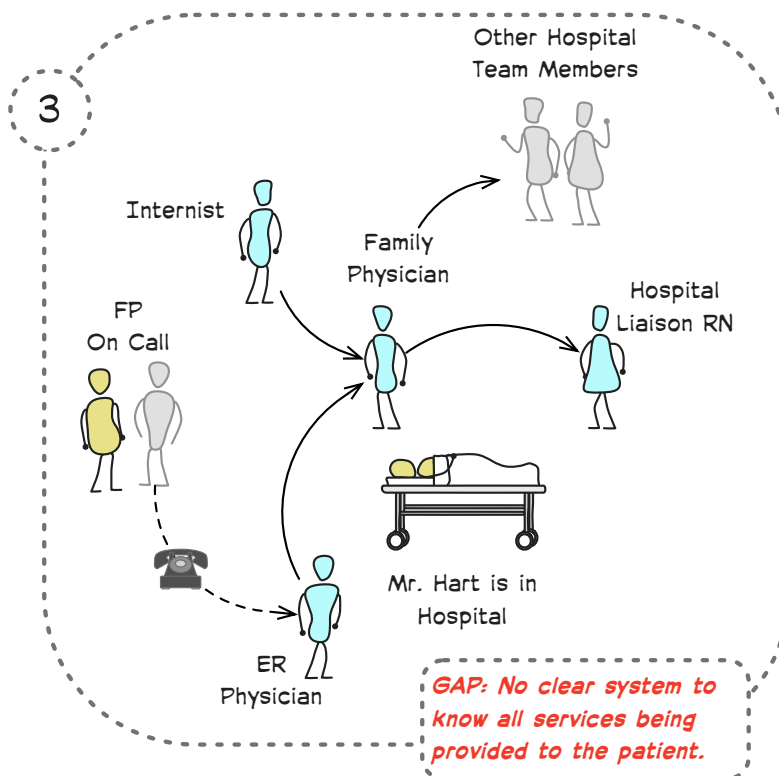


Figure 82: Mr. Hart had a second stroke. This time he is unable to return home and is in hospital. He is admitted under his family physician.

Mr. Hart had a second stroke and this time he had developed significant motor and cognitive difficulties. Since the previous stroke, Mr. Hart's family physician had educated both Mr. Hart and his building manager to call his office or the physician on call if anything happened. So this time the family physician on call was called and she notified the ER physician of the incoming Mr. Hart.

Mr. Hart was admitted to hospital under his family physician and underwent some rehabilitation. During this longer stay, the Internist was consulted to review optimizing Mr. Hart's medications and manage his blood thinners, which proved to be a bit difficult to adjust.

It became clear that Mr. Hart could not return to his apartment. The family physician placed an order to the Hospital Liaison nurse for "placement to a nursing home". She completed her assessment, using a standardized form and then used the Pathways system at VIHA to enter in information to match Mr. Hart with the appropriate facility.

Several weeks after the order was placed, a bed became available and Mr. Hart can be transferred to Sunset Lodge, a (fictional) VIHA long-term care facility in Duncan.

Gaps

At this stage the gaps were similar to Mr. Hart's previous admission to hospital. While there was better coordination, using the family physician on call, there was still no access to the family physician's records after hours.

As he stayed longer and was admitted to the wards, there was a new care team. Handover from the ER to the hospital ward occurs manually, but his chart is able to move with him to the wards, allowing the shared record to be accessed by the next Care Team.

As he was not being discharged back into the community, there was another transition of care. Mr. Hart's transition from hospital into a long-term care facility is discussed next and there are significant gaps here.

Stage 4 – Mr. Hart is in Sunset Lodge (Figure 31):

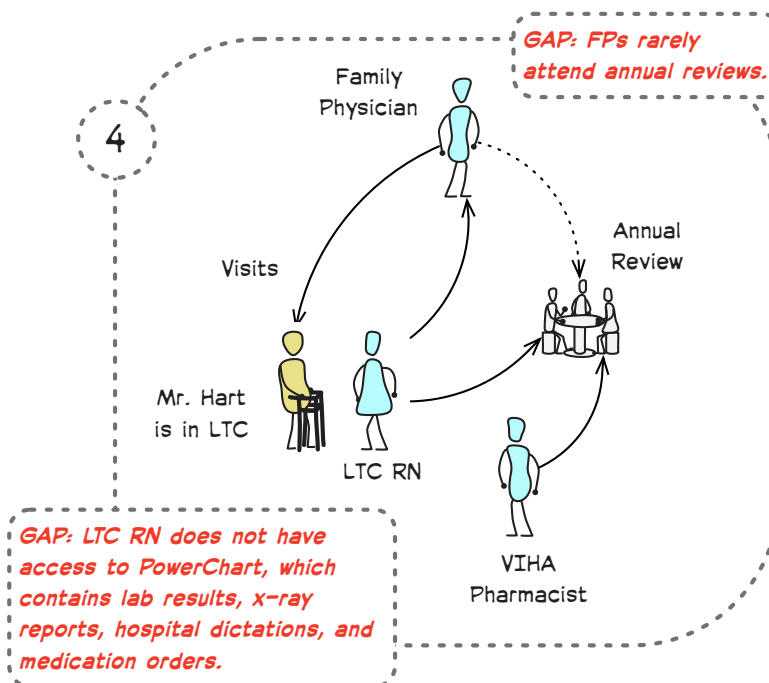


Figure 83: Mr. Hart is transferred to Sunset Lodge, a (fictional) VIHA long-term care facility in Duncan.

After staying on the ward for some weeks, a bed became available for Mr. Hart at Sunset Lodge and the Pathways system notified the hospital team of the match. It was the first available bed and Mr. Hart was the next patient who qualified for a bed, so the transfer process began.

The Duncan Hospital Liaison Nurse may have mentioned Mr. Hart at Sunset Lodge rounds, as she attends rounds at both the hospital and at Sunset Lodge to help inform providers of patients likely to be transferred. Once the transfer was confirmed, the long-term care nurse was notified and she began to review Mr. Hart's case to ensure that he was indeed a good match for her ward. However, she had none of his records and did not have access to PowerChart. The paper chart was on the ward with Mr. Hart, so the long-term care nurse needed to speak to someone on the ward to learn about Mr. Hart and then she requested some information by fax so she could complete her required review prior to him arriving in her facility. She had difficulty coordinating with a nurse who knew Mr. Hart, which was common. Once the review was completed, she accepted the transfer.

Mr. Hart arrived at Sunset Lodge with his complete VIHA hospital paper chart, which was used to begin his new long-term care paper chart. After Mr. Hart settled in and was physically assessed by the nurse, the long-term care nurse phoned Mr. Hart's family physician to notify him of the admission to Sunset Lodge. At that time she requested that the family physician come in to do an admission History and Physical so it would be documented in the chart. She also faxed a request for medication orders. The family physician signed the medication orders promptly but did not get in to Sunset Lodge for a few weeks to see Mr. Hart.

The long-term care providers (nurses, care aids, physiotherapist, occupational therapist, social worker) documented Mr. Hart's care in the facility's local CIS and then batch print out their notes for the chart, so the family physician can review them (family physicians did not have access to Sunset Lodge's CIS). The nurses had difficulty monitoring Mr. Hart's INR and other bloodwork as they did not have access to Cerner and cannot review any bloodwork. Results were available in Cerner but not on paper in VIHA facilities in Duncan; however, the long-term care staff in Duncan did not all have access to PowerChart since it went live in the hospital 8 months prior to this study.

Gaps

There were two main gaps noted here in Duncan. First, the Long-Term Care nurses did not have ready access to results that were stored in Cerner.

“Not being on PowerChart when everybody else is very difficult. I get no lab results...we have had a lot of missed labs and important things happen here” (D03)

Many of the nurses had to rely on the Unit Clerk at the facility to access results on patients:

“Our Unit Clerks [have access to PowerChart] but we don’t. If it is after 3:30 or on a weekend -- too bad” (D03)

One nurse did have access, due to another role at VIHA. She found this very helpful:

“I have access to PowerChart so I can find out what they did with him, but not everybody has that information...I find it very helpful...the admitting history...and lab work in there and it lets us know where they are” (D05)

Another gap that was raised was the communication with the family physician. The family physicians in Duncan typically admitted patients to long-term care facilities in the community, but there were communication gaps. Bluntly, one nurse said:

“We don’t see GPs...” (D03)

Getting timely responses and attendance at the lodge was challenging:

“We require a history and physical from the physician and that is really helpful...it’s a requirement, but we don’t always get it.” (D04)

Lack of physician attendance at the annual review was also an important gap raised by several providers:

“Ideally the doctors attend that [the annual review]. The doctors very often can’t... or don’t [attend case conferences]” (D04)

Family physicians were aware of this gap as well, but there were challenges for them to get to the meetings:

“They do have the annual reviews, but of course they are usually at 11:30 on Tuesday... we do now get paid for them...but it’s so hard, I mean, to get there. Usually when you go there they are really appreciative that you’re there because most people don’t go.” (D13)

Stage 5 – Mr. Hart has his Final Heart Attack (Figure 84):

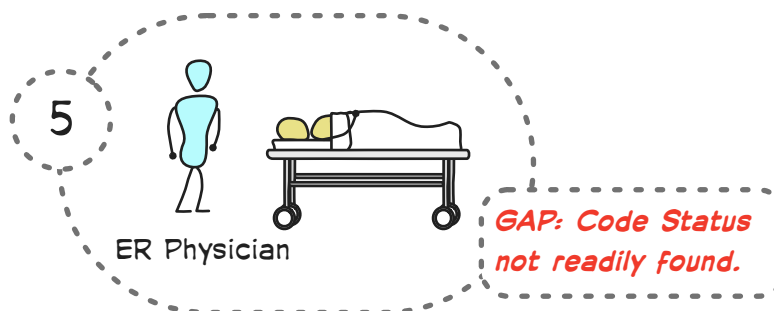


Figure 84: Mr. Hart has a heart attack and is transferred from long-term care to the Emergency in the night.

In the final stage of Mr. Hart’s story, he experienced a heart attack in the middle of the night at the facility. The nurse who was on duty, who did not know Mr. Hart, contacted the family physician on call and then sent in Mr. Hart to the Emergency Department by ambulance along with his entire paper chart.

Gaps

The main gap here was challenge with the patient’s Advance Directives or Code Status. In the patient’s story, Mr. Hart had a DNR. No participant confirmed the status of that order – each one sent the patient to the Emergency.

Also, there was a challenge with communication back and forth with emergency. For example, even though the entire paper chart goes to emergency, it might not contain all the information, due to the parallel charting system:

“That often happens, we’ll have a lot of recent notes in the Meditech⁶², but if they haven’t recently been printed off to put in the chart, it might not be there with the chart. So they can’t look back and see what were the most recent issues.” (D04)

⁶² Meditech was the local CIS used by Sunset Lodge.

Unfortunately, ER physicians in Duncan could not be recruited in this study, but the ER physicians from Victoria confirmed that it was common for patients to arrive at the ER only to eventually discover they either had a no hospital order or a no code order.

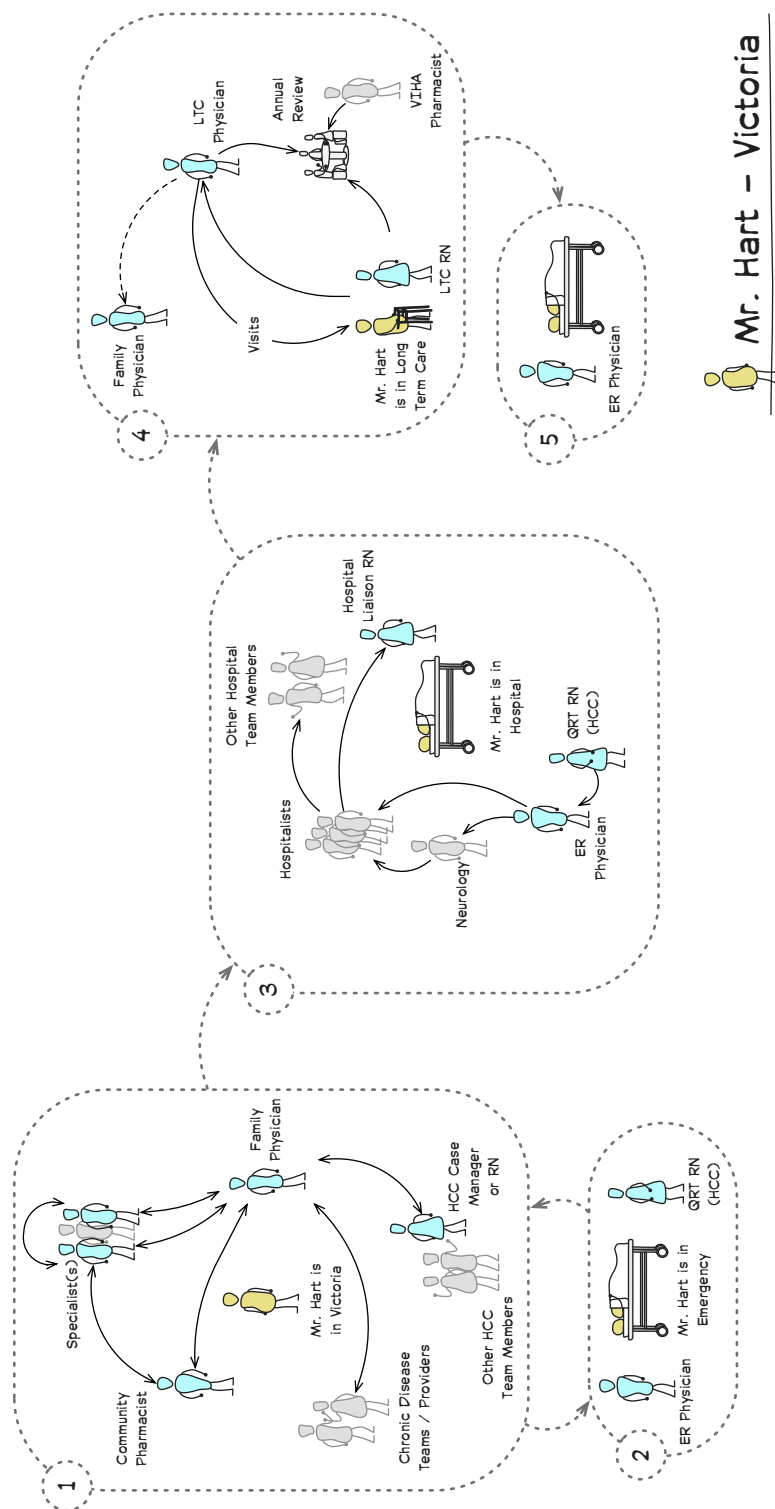
This ended the scenario of Mr. Hart in Duncan.

Mr. Hart's Rich Picture of Care in Victoria

This Rich Picture (Figure 32) captured the story of Mr. Hart in Victoria. It was developed in a consistent manner to the Duncan Rich Picture. This facilitated comparisons between the two communities. Note that Mr. Hart went through the same five stages. Instead of repeating the story in detail, this section highlights the major differences between Victoria and Duncan.

In this scenario, Mr. Hart's family physician did not have admitting privileges to VIHA facilities (both the hospital and to Sunset Lodge). This was more common in Victoria than in Duncan. It had a negative impact on Continuity of Care at several stages throughout the scenario.

The other issue that permeated the scenario was the size of Victoria. Victoria was a larger community than Duncan and there were more providers and sub-specialists. This, in general, caused an increase in providers and potential providers. Coordination work was more complex and harder to do well.



Mr. Hart – Victoria

Figure 85: Rich Picture of Mr. Hart's care in Victoria.

Stage 1 – Mr. Hart Living at Home (Figure 86):

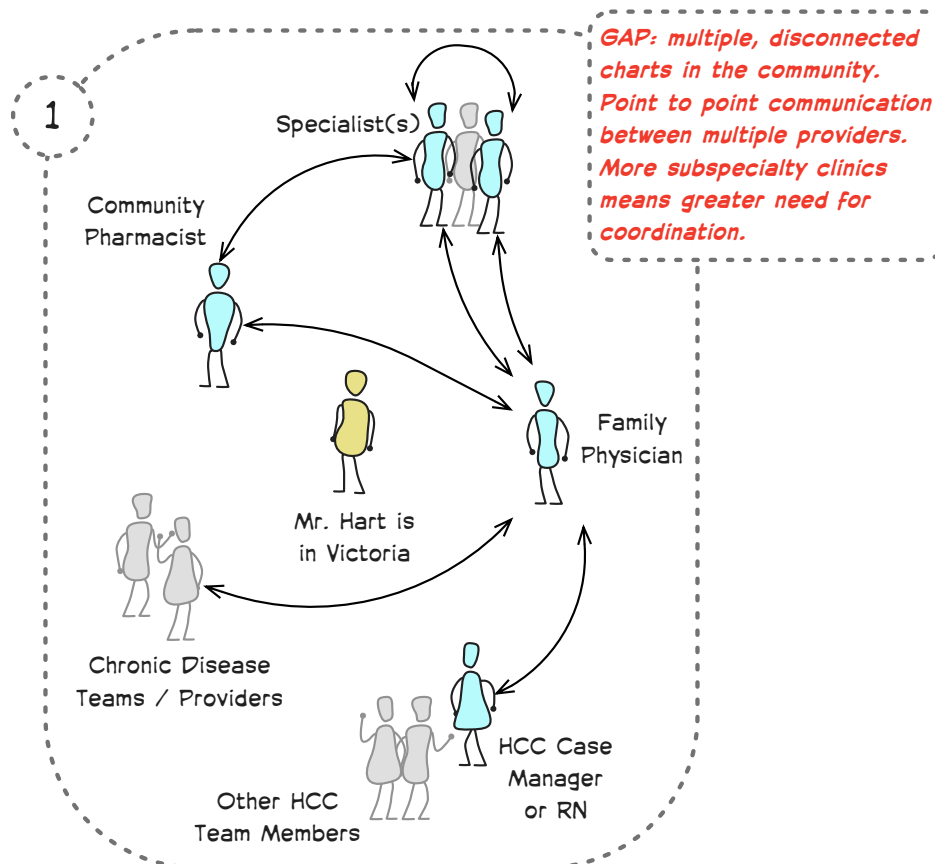


Figure 86: Mr. Hart is living in Victoria and he is ambulatory. There are several providers involved in his care, primarily coordinated by his family physician.

The issues found in Victoria at this stage in Mr. Hart's story were very similar to what was discovered in Duncan. The isolated charts and reliance on point-to-point communication was perhaps more of an issue in Victoria as there were, potentially, more providers in the Circle of Care as there were more sub specialized resources in the larger city.

Stage 2 – Mr. Hart has his First Stroke (Figure 87):

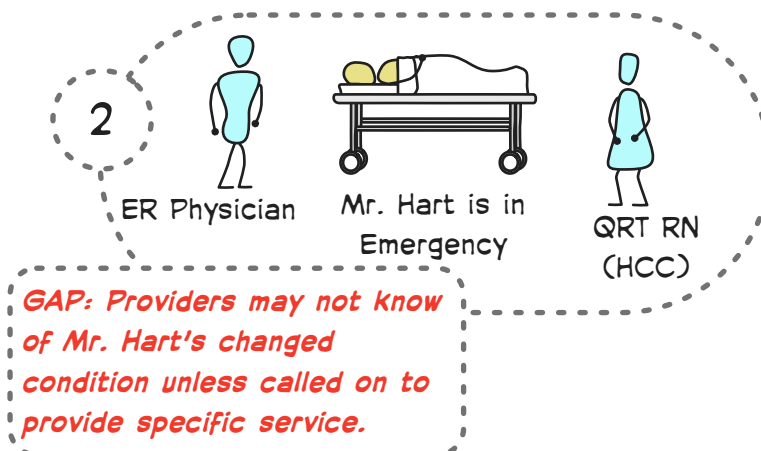


Figure 87: While in the community, Mr. Hart has a stroke and is sent to the Emergency Department. He is then sent home.

The ER physician would have a challenge knowing which physicians, other than (typically) the family physician, to notify of the stroke. It may not be clear which specialists had been consulted. In Victoria, there was a dedicated ‘Quick Response Team’ that was part of Home and Community Care. The quick response team nurse worked with the ER Physicians to try to get patients out of the ER with proper supports at home. This was felt to be an effective service that helped maintain some continuity and follow up after discharge from the ER:

“The quick response team want to work with us...that’s a wonderful service that started about 10 to 15 years ago. One of the few things that has actually worked.” (V13)

However, quick response team was not available all the time and it was not available in Duncan.

The family physician would not be involved in this encounter, except, perhaps to send in information or to speak to the ER physician on the phone.

Stage 3 – Mr. Hart is Admitted with his Second Stroke (Figure 88):

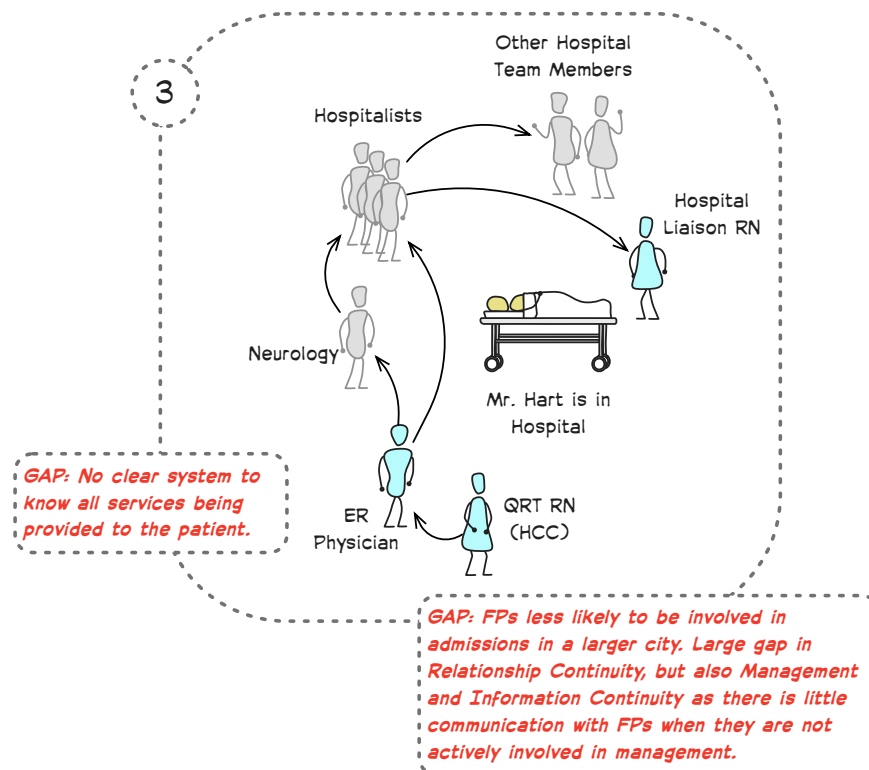


Figure 88: Victoria Mr. Hart has had a second stroke. This time he is unable to return home and is in hospital. He is admitted under his family physician.

The major difference that was highlighted in Victoria, again, was the lack of the family physicians in the hospital setting. This was a clear and major gap in Victoria. There were still some family physicians that admit in Victoria and when they did, it was a:

“Huge relief. Huge relief. GPs are never disgruntled... when they answer ‘Oh yeah, I know [Mr. Hart]. Oh, is he in trouble again? Ok... go ahead, I will look after him’. Versus the tenth call in the last three hours for the hospitalist - and they don’t know the patient. You know that’s a huge, huge burden. When you are looking after someone who you have no idea. This is why the GP has got to come back to the hospital.” (V13)

Clearly, the lack of family physicians was felt in the hospital.

Stage 4 – Mr. Hart is in Sunset Lodge (Figure 89):

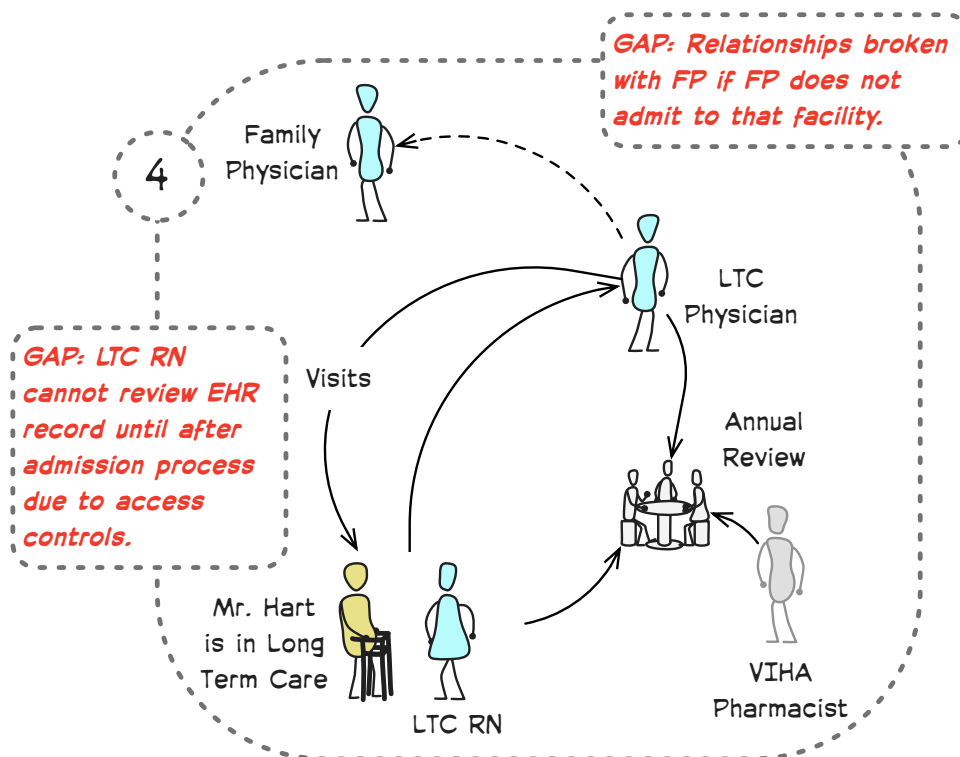


Figure 89: Victoria Mr. Hart is transferred to Sunset Lodge, a (fictional) VIHA long-term care facility in Duncan.

In Victoria, when Mr. Hart was transferred to Sunset Lodge, it was more likely that Mr. Hart would be again transferred to another primary care physician. This time, a family physician that was associated with Sunset Lodge. Relationship Continuity was given up so that better Management Continuity and Inter-Provider Continuity could be achieved. The nurses were thankful for the system of having dedicated doctors who were willing to take on patients and were more closely associated with their facility:

"Thank goodness [we have] a Rota system" (V05)

The long-term care nurses in Victoria had access to Cerner-PowerChart, unlike the nurses in Duncan. This was a significant improvement. However, they highlighted another issue. They did not have the ability to access PowerChart to review patient records on patients who were being admitted to them. They could only access PowerChart once the patients had arrived on their units. This was a significant gap in Information Continuity.

“At the admission process it would be very helpful [to have access to PowerChart] because if I had access right away, a lot of sending back of faxes would be unnecessary.” (V05)

Stage 5 – Mr. Hart has his Final Heart Attack (Figure 90):

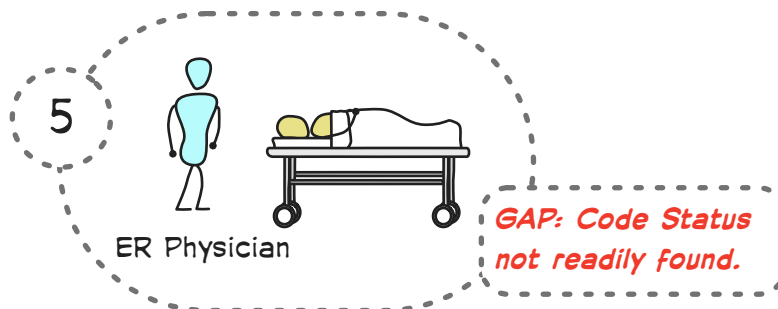


Figure 90: Victoria Mr. Hart has a heart attack and is transferred from long-term care to the Emergency in the night.

The key issue highlighted by participants here was the gap with the Advanced Directives. This was reviewed in the body of the dissertation (see the Results Chapter on Suggested Improvements).

Appendix J. Detailed Description of the Abstract Genres

This Appendix contains a description of the Abstract Genres, with examples from the participants and the corresponding SSM models. The SSM models include their Root Definition, “CATWOE” summary, and the graphical model of the Abstracted Genre’s purposeful activity.

CATWOE is the soft systems acronym used to capture elements of a system. CATWOE stands for:

- Customers who benefit (or are harmed) by the systems transformation.
- Actors who perform the activity that results in the transformation.
- The transformation (input to output)
- Worldview for the model
- Owners who can stop the Transformation
- Environmental Constraints that are outside the system but can affect it.

Communicate with Patient / Family - Figure 91

Engaging with the patient was central to providing care and a key part of ensuring Continuity of Care. Engagement or communication consists of several activities and can take several forms. At a high level, communication between providers and patients included activities such as: assessing the patient, educating, planning care, and providing treatment.

“This is the point we would have a long discussion with the patient and the family and the client in terms of End of Life... we would ask them if they want a DNR...we also discuss expected death at home and we explain what that is. We then we go into a lot of teaching.” (D08)

“Coming in and seeing what are his needs... it’s kind of like a contractual thing with myself and the person. How can I help you and how are we going achieve that together.” (D12)

Often in person, assessments and discussions also took place on the phone, by letters, by email, and can also be by videoconference (although the latter was not described by providers, but by IM/IT). The patient would often be the repository of the most up to date information to providers.

Often the patient’s family took a large role in these discussions, more so as patient function declines, particularly cognitive function. This kind of participation could be informal or formal, as when one was a surrogate decision maker. Families were also important in providing assessments into a patient’s level of function. Mr. Hart had no family. Participants typically picked up on this gap in the circle early on. As one family physician said,

“Without much family, to get that other view on how he’s functioning, that would be something missing.” (D01)

Another was hoping that the Mr. Hart’s son would be part of the Circle of Care:

“It’s too bad his son is estranged and at a distance” (V03)

Current care provider, patient or family need to better understand current or historical information about the patient in order to develop new knowledge around the patient's condition, and management plans in order to improve current and future care delivery and support the patient's wishes. The provider does this by asking the patient or family and/or by directly assessing the patient. Forms include: face to face encounter, phone conversation, email, messages through MOA.

- C: Patient, Current Provider; Family
 A: Current Provider in need of information from the patient
 T: Provider, patient or family with information gap --> Information gap filled
 W: Additional Information is required to improve care delivery that can be provided by the patient or family.
 O: Holder of information Patient, Family
 E: Patient Cognitive ability, presence / Knowledge of family; Local Scope of Practice; Provider Knowledge of condition and plans

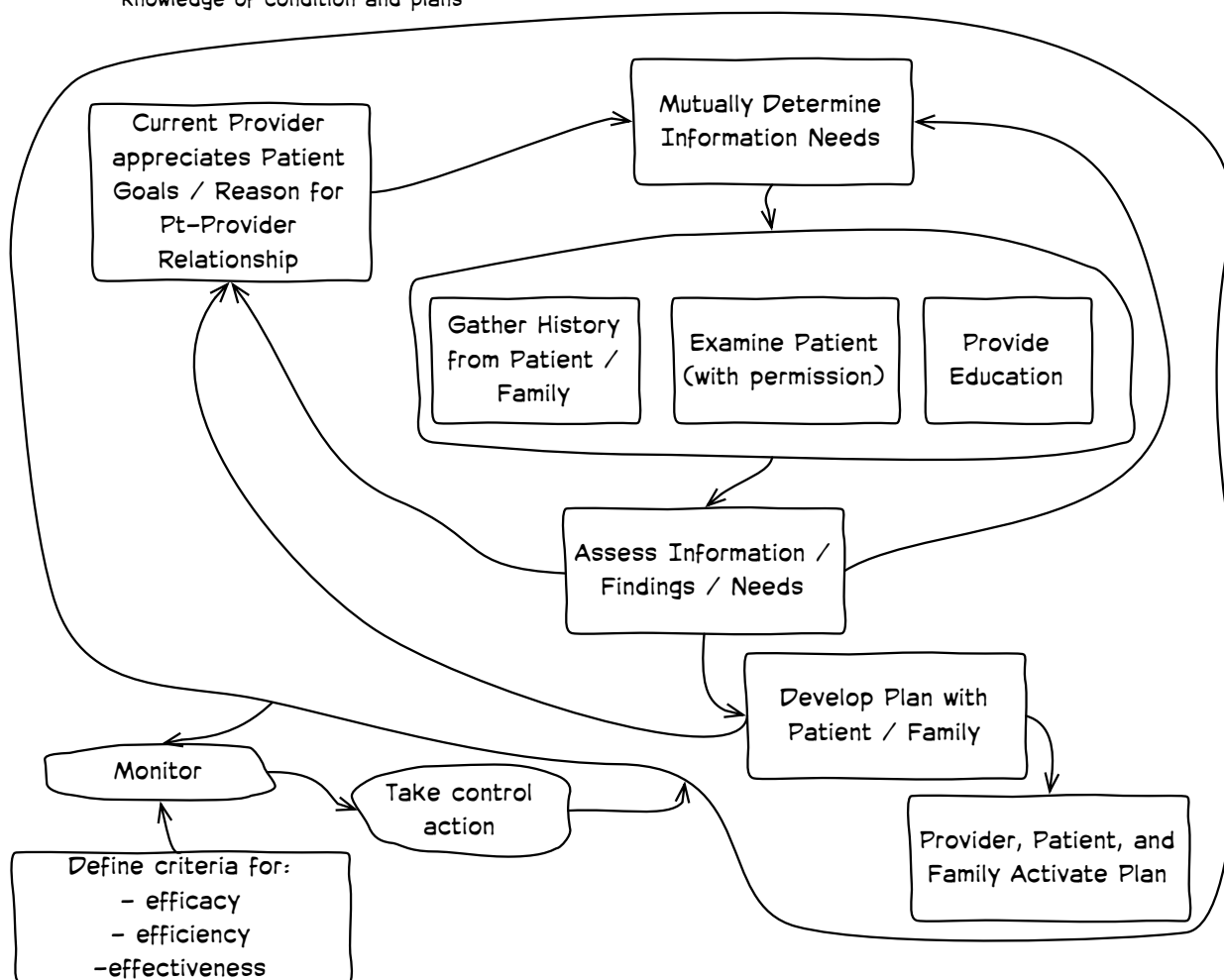


Figure 91: SSM Conceptual Model of the Communication with Patient / Family. Communication may be simple, or it may be complex, developing large changes in care plans.

At times of transitions, such as the end of life transition, providers communicate more with the patient and family:

“We’re doing a lot of communicating with the family. A lot of guidance, a lot of teaching and in this situation, even more so...Sitting down with the family and just talking to them about what’s going on what the changes are, what the changes mean, and what the future looks like in the next couple of weeks for her... and as much as possible trying to have that conversation with the patient there.” (V08)

Communication with the patient and family was central to care for the participants, even more so during the transition to end of life.

Request Historical Information - Figure 92

Historical information about patients was important in the overall management of care. History, such as previous medications or past procedures, often altered current treatment. Information was a foundational layer of continuity. As one participant said,

“We are so adamant about History” (V04).

When providers do not have access to information, or need collateral, they requested this information from other providers or organizations. This was particularly important during transitions to new Care Teams, such as when patients were admitted to long-term care facilities:

“We get the rest of the information from the hospital chart and sometimes it’s sketchy... doesn’t give us all the history from the community... We require a history and physical from the physician and that is really helpful...it’s a requirement, but we don’t always get it.” (D04)

Requests occurred throughout the Circle of Care. Hospice requested information of Oncology, family physicians sought information from hospital, many people asked the family physicians for information, and the list went on. The requests typically were on paper or were verbal. Official requests were on paper, with patient’s express permission.

These requests typically took time for a response and the information might not be back at the time of the encounter (especially outpatient and ER encounters). Urgent requests were more often made verbally.

A member of the Circle of Care (provider, family, patient) requires unavailable historical patient information in order to better understand the patient's clinical history and improve care. He/she requests access to this information from another provider (who is thought to have that information) with the patient's permission through a written request, an electronic request, or by phone.

- C:** Patient, Current Provider
A: Provider in need of information
T: Provider with suspected information gap --> Provider with information gap filled
W: Additional Information is required to improve care delivery and not available
O: Holder of information (Provider, Custodian of Information (e.g. Hospital))
E: Privacy Legislation; Professional Practice Standards.

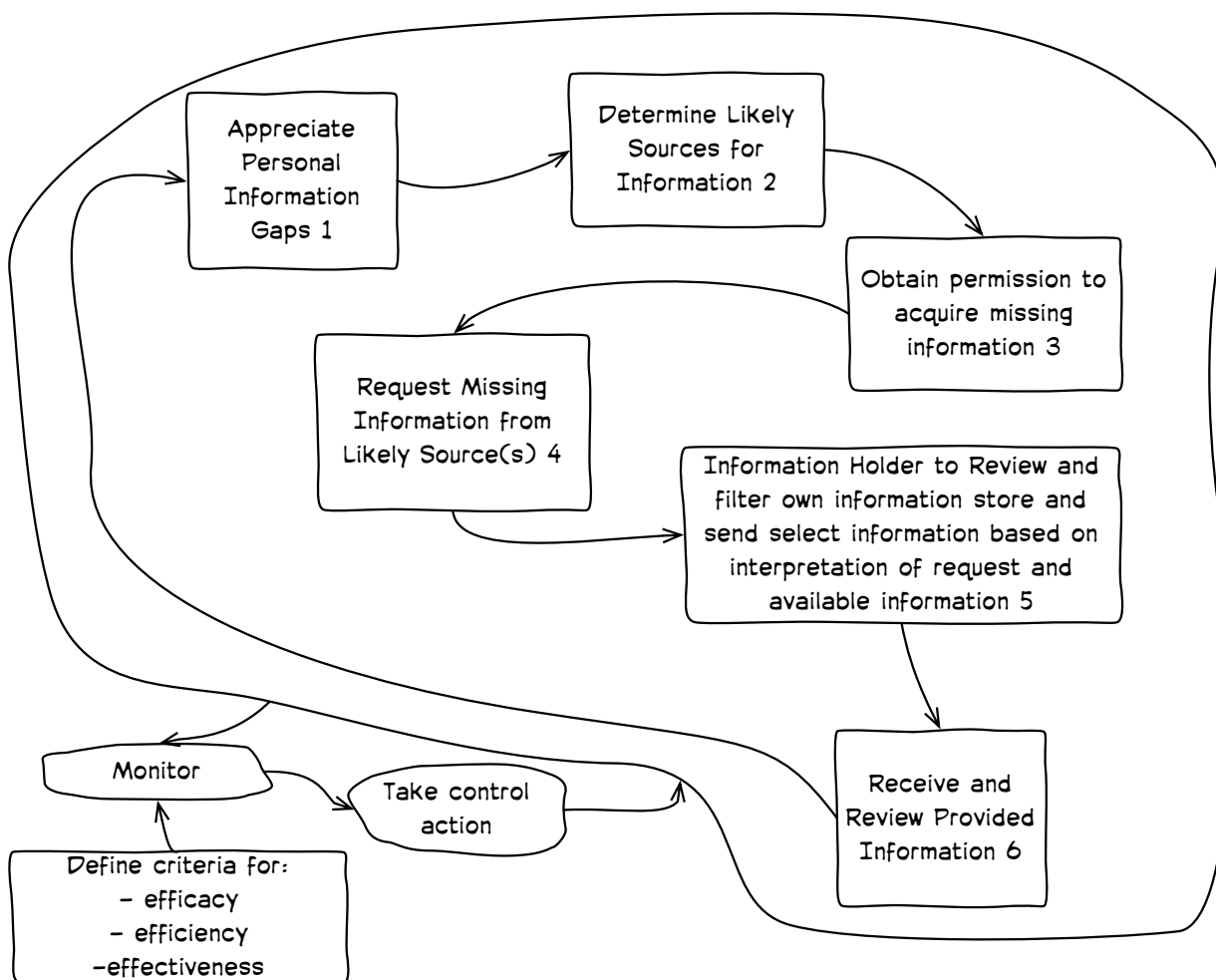


Figure 92: Request Historical Information. Note that the provider requesting needs to predict where the information might be.

Requests for information required that the requesting provider knew (a) that the information likely exists and (b) where it might be kept. As Continuity of Care was lost, for example, as a patient cannot recall their providers, it was harder to predict the sources of information. It may not be clear that a particular test was completed last week at a private lab or an ECG was ordered at a walk in clinic, for example. If the patient did not remember, these things could often go unchecked.

Provide Current Information - Figure 93

The complement to *Requesting Information* was to proactively *Provide Information* to other members of the Circle of Care. This was done, typically between care providers who do not share the same record, where it was felt that the information was important to continuity. This was targeted, point-to-point communication from one provider to another (or others). It did not persist in an accessible, shared record. Providers do also document the action and keep received information in their respective records, which may have been shared amongst a Care Team.

The form of communication varies on provider and on the urgency of the information. Two examples of this Genre were lab or x-ray reports and the dictated consult letter from a specialist to the family physician. Calls were typically reserved for when information needed to be shared quickly and where confirmation of receipt of the information was necessary (e.g. a critically abnormal lab result).

This Genre required that a provider be proactive and have some knowledge about who was providing care. If a provider was *not* aware of who was providing care, and when they might be seeing the patient, it became difficult if not impossible to predict whom to Provide Information. One participant highlighted this well:

“If we [Home and Community Care] know that a client is going down to see their oncologist and there are issues... we’ll phone the oncologist directly prior to the appointment” (D07)

Current care provider proactively shares their information or plans about a patient to other members of the Circle of Care through point to point communication (written, electronic or by phone) in order to ensure there is better Continuity of Care at information and management levels.

- C:** Providers in the patient's Circle of Care
- A:** Provider involved in the patient's Circle of Care with information to share
- T:** Current Provider with isolated information --> Provider's information shared to specific providers.
- W:** Expectation that information would be valuable to share with others
- O:** Provider with information
- E:** Privacy Legislation; Professional Practice Standards;
Availability / awareness of providers

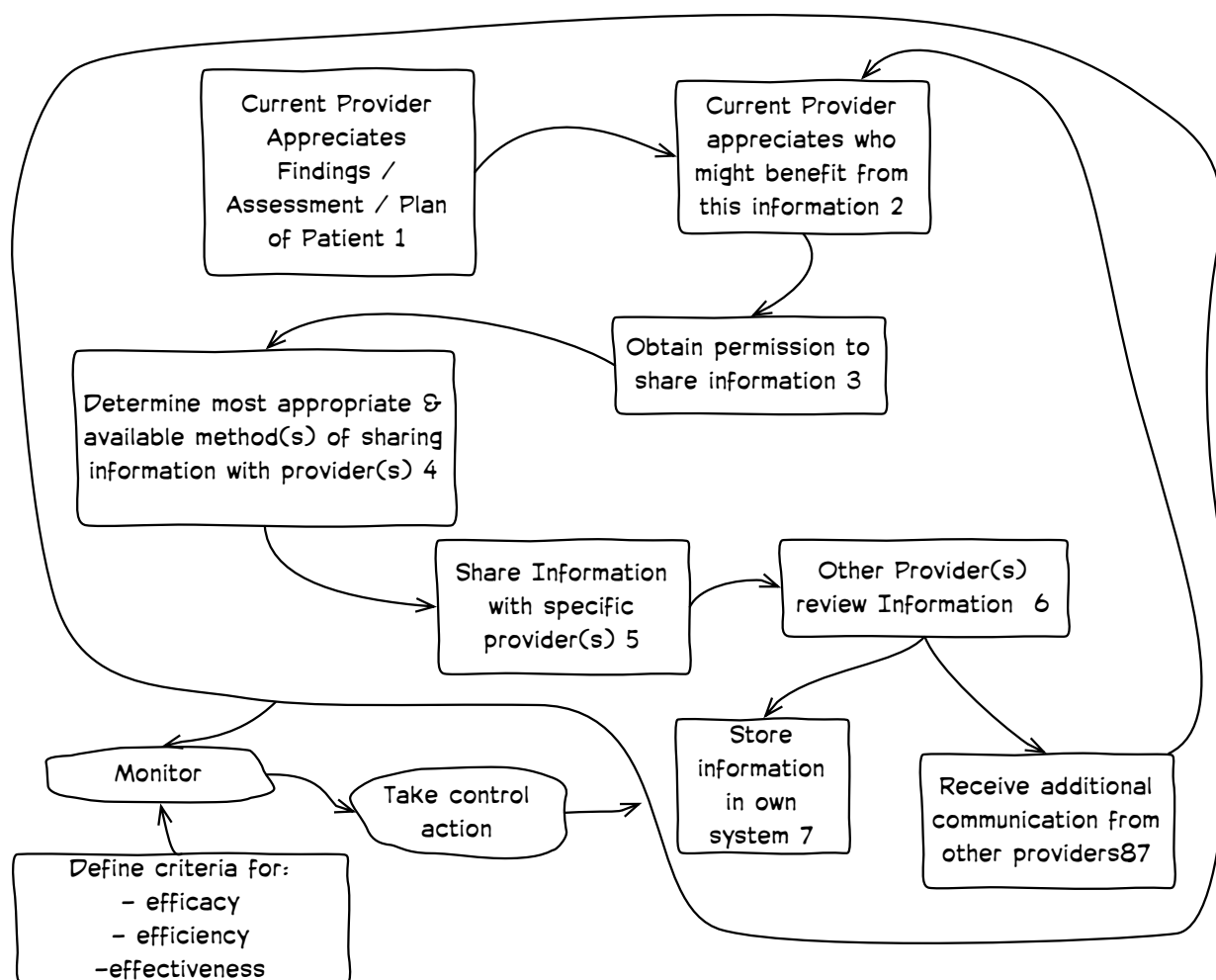


Figure 93: Provide Current Information. Note the provider needs to predict who might need the information in the future.

If not predicted well, other providers will need to Request Information in the future.

VIHA had systems in place to support Providing Information. VIHA Health Records (part of IM/IT) distributed information both paper and electronically. PHSA had similar systems in place. Specific routing could be challenging and these distribution systems did not always deliver the information where it needed to go. For example, one participant was particularly frustrated with how the systems worked in his community:

“The consult comes to my office and I have to send the consult up to the hospital where the patient is.” (D01)

And

“Provincial lab results, it’s crazy. The patient’s test is ordered in the hospital, the patient is in the hospital, the result...comes to my office.” (D01)

Still, without accessible shared records, providing information was one of the key and common ways today to be proactive about Continuity of Care. Even with shared records, there would be a need to notify specific providers of specific changes in information, such as new findings or changes in treatment plans. This was a key communication activity that would not go away with a shared electronic record.

Document in Shared Record(s) - Figure 94

Document in a Shared Record included activities such as recording findings, documenting plans, and logging activities / procedures in a place that was available to multiple providers over time. Shared Records allow for more ubiquitous information sharing amongst a Care Team⁶³ than Providing Information to specific providers. As one participant put it,

“Telling me is great, but I am only one member of the team” (V04)

Document in a Shared Record was more common in acute and residential facilities where teams are more physically integrated. It was less common for ambulatory records, although some smaller Care Teams did share records. Medical practices tended to be smaller group practices in Victoria and Duncan in this study (1-4 physicians / office) and records were accessible amongst the groups. There was little sharing of records in Home and Community Care. In Victoria and Duncan, Home and Community Care professionals (e.g. nurses, occupational therapist, social worker) each wrote in their own paper charts.

Documenting in a Shared Record allowed for more members of the team to be able to know information and plans. Shared documentation reduces duplication and provides a historical repository, reducing the need to both Provide Information and to Request Historical Information in the future. In Home and Community Care, a lot of time was spent *Providing Information*; this might not have been necessary with a Shared Record. One participant estimated she had, over her career, halved her capacity to see patients because of the demands of increased paperwork in Home and Community Care. Some of this time could be reclaimed if there was less duplication of paperwork in Home and Community Care through a shared record. However, if there were multiple Shared Records to document in (as was seen with the patient hospice binder), providers needed to determine where they could best record information if there were time constraints (which were common).

⁶³ A team of providers within a patient's Circle of Care who a common organizational structure such that they are either co-located or function in a virtually integrated manner and have a shared chart. Examples would include: the hospital based providers involved in a patient's care while in hospital.

Current care provider documents information and plans about a patient into a Shared Repository (paper, electronic record) so that to other members of the Circle of Care may review this information in the future. This is to ensure both that a record of care is complete and that there is better communication between providers and Continuity of Care at information and management levels.

- C:** Providers in the patient's Circle of Care (current and future) who have access to the Shared Record.
- A:** Provider involved in the patient's Circle of Care with information to share (history, observations, assessments, plans)
- T:** Current Provider with isolated information --> Provider's information shared to providers with access to the shared record.
- W:** Need for care to be documented and benefit / requirement in placing it in a shared record.
- O:** Provider with information; custodian of the shared record
- E:** Privacy Legislation; Privacy and Access Policies of the Custodian of the Record; Funding; Organizational Strategies / Priorities.

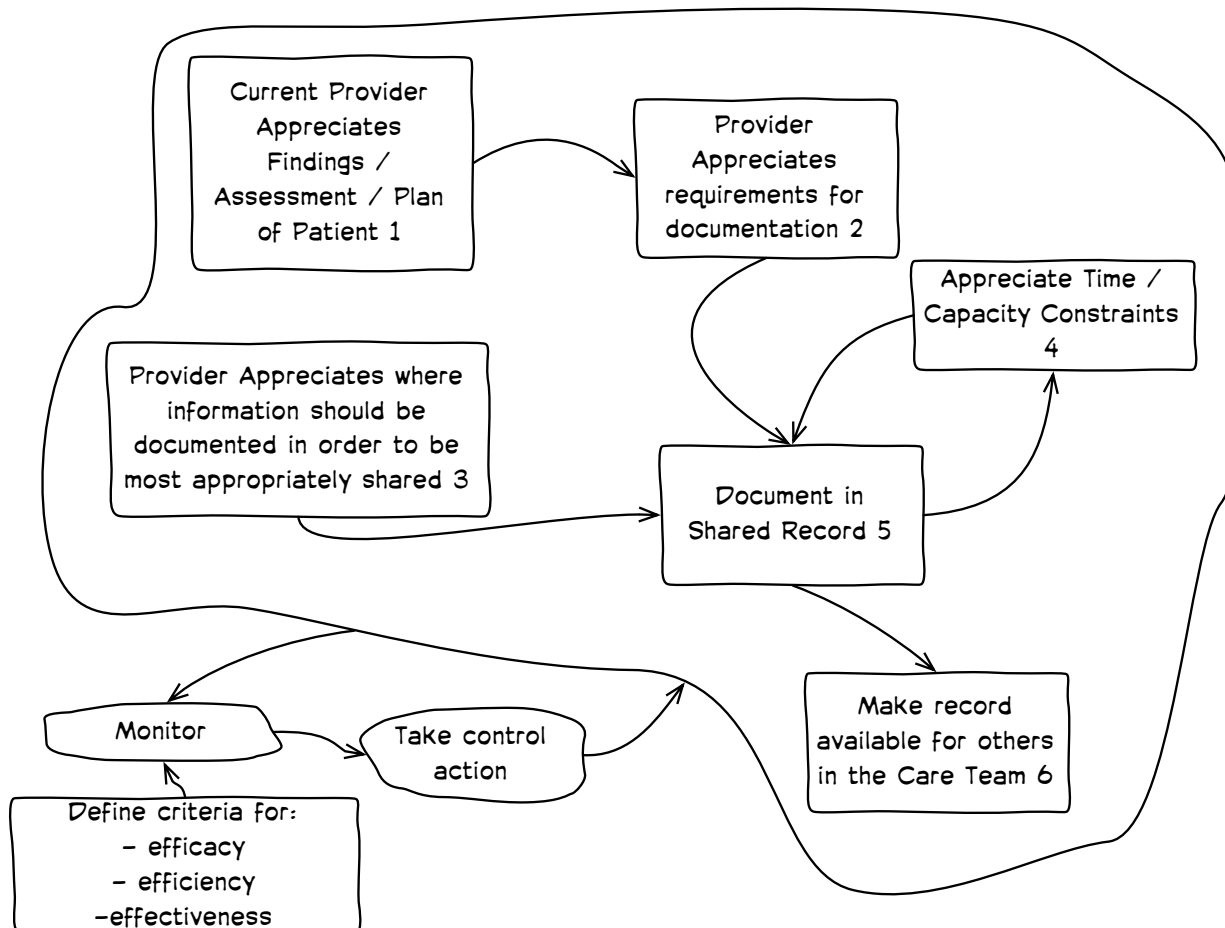


Figure 94: Document in Shared Record(s). Note: provider needs to determine most appropriately place to document (either most appropriate record and place in record)

Review Shared Record - Figure 95

Current care provider reviews available patient information that is in a shared repository in order to have a better understanding of the patient's clinical history and / or plans in order to improve care delivery or follow already established plans.

- C:** Patient, Current Provider
A: Current Provider, in need of information
T: Provider with suspected information gap --> Provider with information gap filled
W: Additional Information is required to improve care delivery and could be available in shared repository
O: Holder of information (Provider, Custodian of Information (e.g. Hospital))
E: Access Policies; Technical Infrastructure; Organizational Boundaries; Funding; Organizational Strategies / Priorities

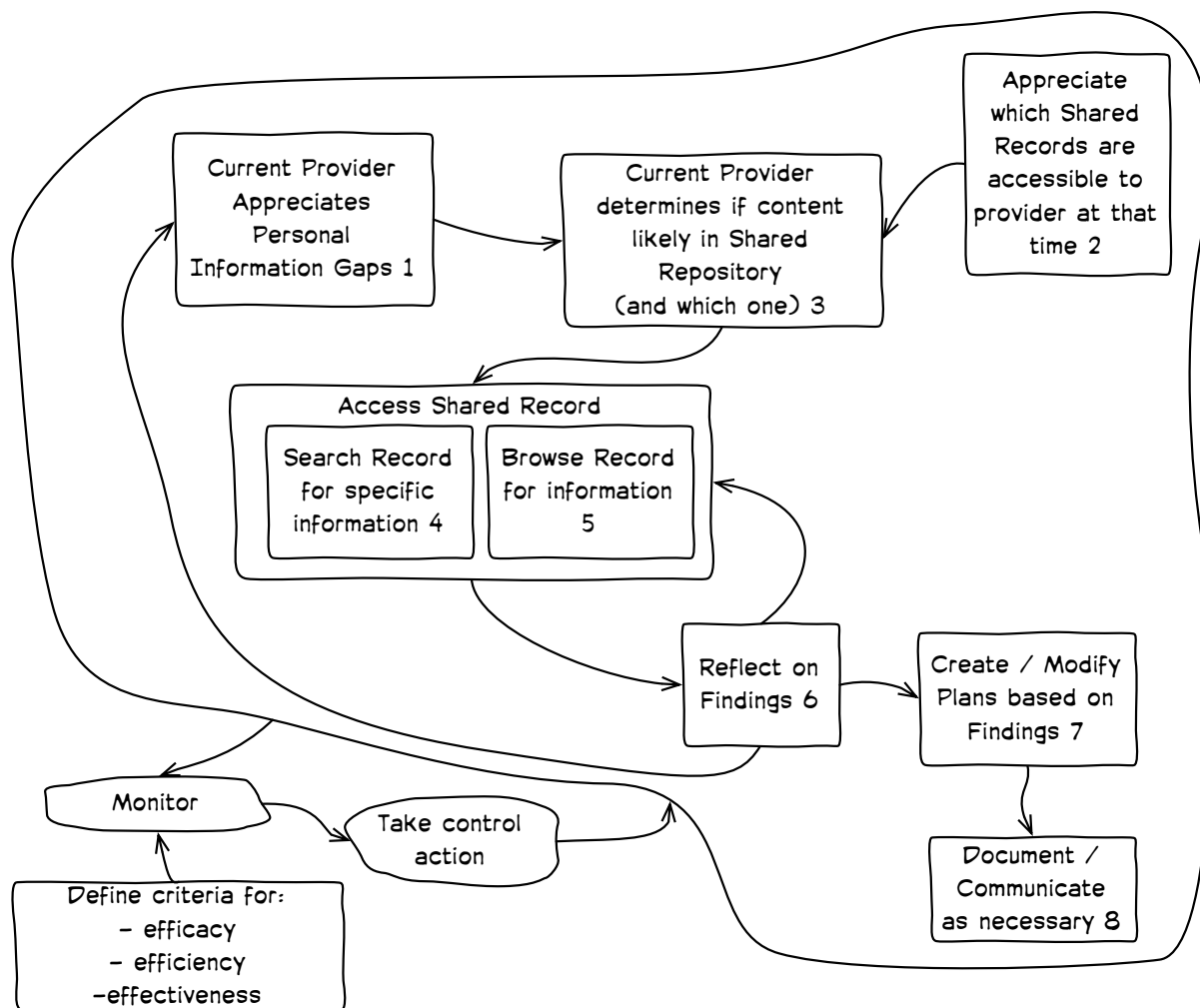


Figure 95: Review Shared Record(s). Note: Provider must predict which record the information might be in when there are multiple records to review.

For a shared record to be effective, it needs to be accessed, not just documented in. This Abstract Genre describes the activity *Review Shared Record* where providers with access then read the contents within that record. Providers might *Review Shared Record* in two ways – they might search for specific information (e.g. a result) or might browse the record to learn general information. Providers need to know what information was kept in the (various) Shared Records and know which to review and to predict when it might be valuable to review them (i.e. when there was new information to review).

Shared Records could be paper or electronic. Paper records limited physical accessibility – a provider needed to be at the chart and only a limited number of people could read the chart at one time. Paper charts were familiar and required little training. Electronic Records could allow access by multiple providers from multiple locations simultaneously, but they required more training and infrastructure. Some records were maintained in parallel both electronically and on paper in the study. If the records were available and their content and purpose was clear, they become more useful:

“We have a rounds book...all of us know to look in there”. (D04)

*“Our Cardex is the biggest communicator because it is for RN, LPNs, and all of our aids... write that in the Cardex and then highlight it and everyone will read it.”
(D04)*

Shared Records were less useful if access was limited. No shared record was found that was accessible to all members of either patient’s Circle of Care, with the exception of Mrs. Cann’s Victoria Hospice Binder, although this was not a formal record of care and was a duplicate record.

Physicians without VIHA privileges and nurses working in private long-term care facilities, for example, did not have access to Cerner. VIHA care providers did not have access to the BCCA record, CAIS. The nuances of limited access become more complex. In one VIHA Long Term Care facility, for example, there were two shared electronic records that were not

equally available to all members of the team, due to access and training issues. Lab results, X-ray reports, and medication orders were viewable in the regional CIS (Cerner PowerChart), but most of the clinical staff did not have access to Cerner. The shared, local electronic record for the facility was accessible to long-term care staff but it was not available to the family physicians, as they had not been trained to use that system, although they admitted to the facility. To work around these issues, information was printed out of both electronic records and placed in a parallel paper chart that all could access (but only when they were at the facility).

The Hospice Binder was an interesting Shared Record. It was another parallel paper book that the patient was encouraged to take with them throughout their journey and request that providers document in their binder. For patients and families that follow through with this, their binder became an increasingly useful shared record that was with them at the point of care, wherever that may be. Unfortunately, this did not always happen. Patients did not always bring the binder. Providers did not document in the binder, as it was a duplicate record. Still, the Hospice Binder was the only example of a patient centric record that could be accessible to all Care Teams at multiple points of care, regardless of location or organizational affiliation.

Request Generic Advice - Figure 96

The *Request Generic Advice* Genre consisted of the multiple ways in which providers communicated *around* patient cases. Unlike *Request for Assessment / Treatment and Order* (described below), these requests did not disclose patient identity. It was an important way of providing better management continuity without engaging more providers explicitly in the Circle of Care and it could be an important way of learning. Providers often communicated with other providers around patients, without sharing the patient's identity.

This Abstract Genre was often ad hoc and verbal (phone, face-to-face). When discussing the management of Mrs. Cann in a pain crisis, one family physician was not sure how best to image the source of pain to rule in or out a metastasis.

*“Would you just go straight to a CT? So I might discuss the issue with a radiologist”
(D01).*

These requests could also be part of educational opportunities, such as teaching rounds. This was the one Abstracted Genre that described communication outside of the Circle of Care. It was felt that it was important to include for two reasons: first, it was an important mechanism providers use to improve Management Continuity. Second, it often turned into a *Request for Assessment/Treatment*, bringing the advising provider into the Circle of Care.

Current care provider gets management support by requesting generic (e.g. non-patient identifiable) and informal advice on clinical care from another provider in order to better assess or manage a patient's current condition(s). Typically takes the form of a phone or face to face conversation, may be electronic (e.g. email).

- C:** Patient, Family, Current Provider
- A:** Current Provider, in need of diagnostic and / or treatment decision making support
- T:** Provider in need of recommendations for diagnostic / assessment / management --> Provider with increased knowledge / confidence in diagnosis / management option(s).
- W:** Patient would likely benefit from change in management, but the current provider is either aware of gaps in knowledge or unsure as to the preferred choice.
- O:** Other Provider(s) with appropriate knowledge;
- E:** Availability of providers, Local Scopes of Practice

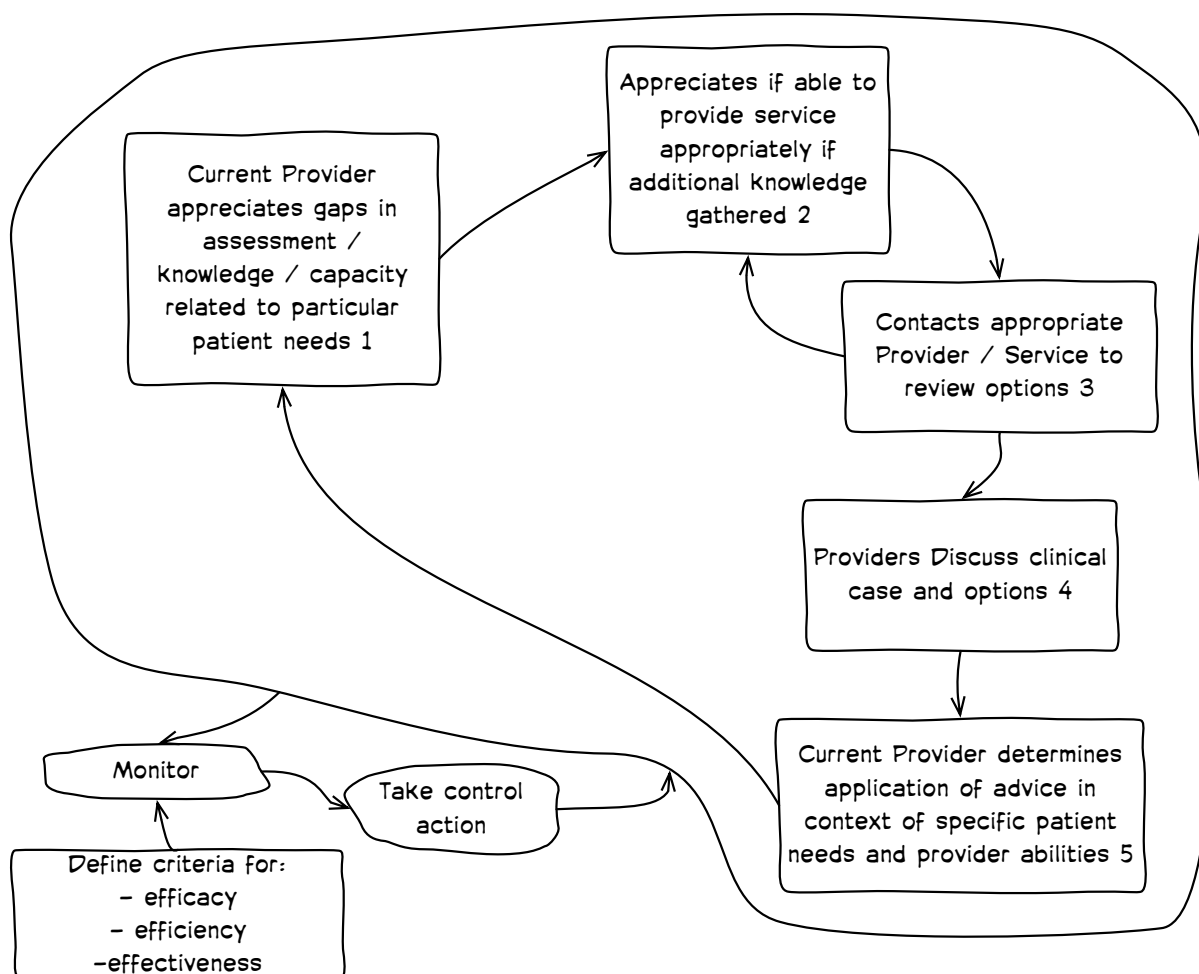


Figure 96: Request Advice. The Provider contacts another provider to generic advice on assessment / treatment options. This is better supported when there are existing relationships between providers.

Request Assessment / Treatment for Patient - Figure 97

Current care provider (provider, patient, family) requests focused support from another provider to better manage a patient's current conditions, improving patient outcomes or providing more options for care. This is done by providing select patient identifiable information to another provider with a request to review a particular aspect of a patient's condition. Paper, phone, or electronic.

- C: Patient, Family, Current Provider
- A: Current Provider (provider, patient or family), in need of diagnostic / treatment support
- T: Patient in need of improved assessment or treatment --> Patient with need met and communicated back to appropriate providers
- W: Patient would benefit from additional diagnostic or treatment support that go beyond the skills or scope of practice of the current provider.
- O: Other Provider; Patient; Family
- E: Availability / Awareness of Providers; Physical Proximity of Care; Professional Practice Standards

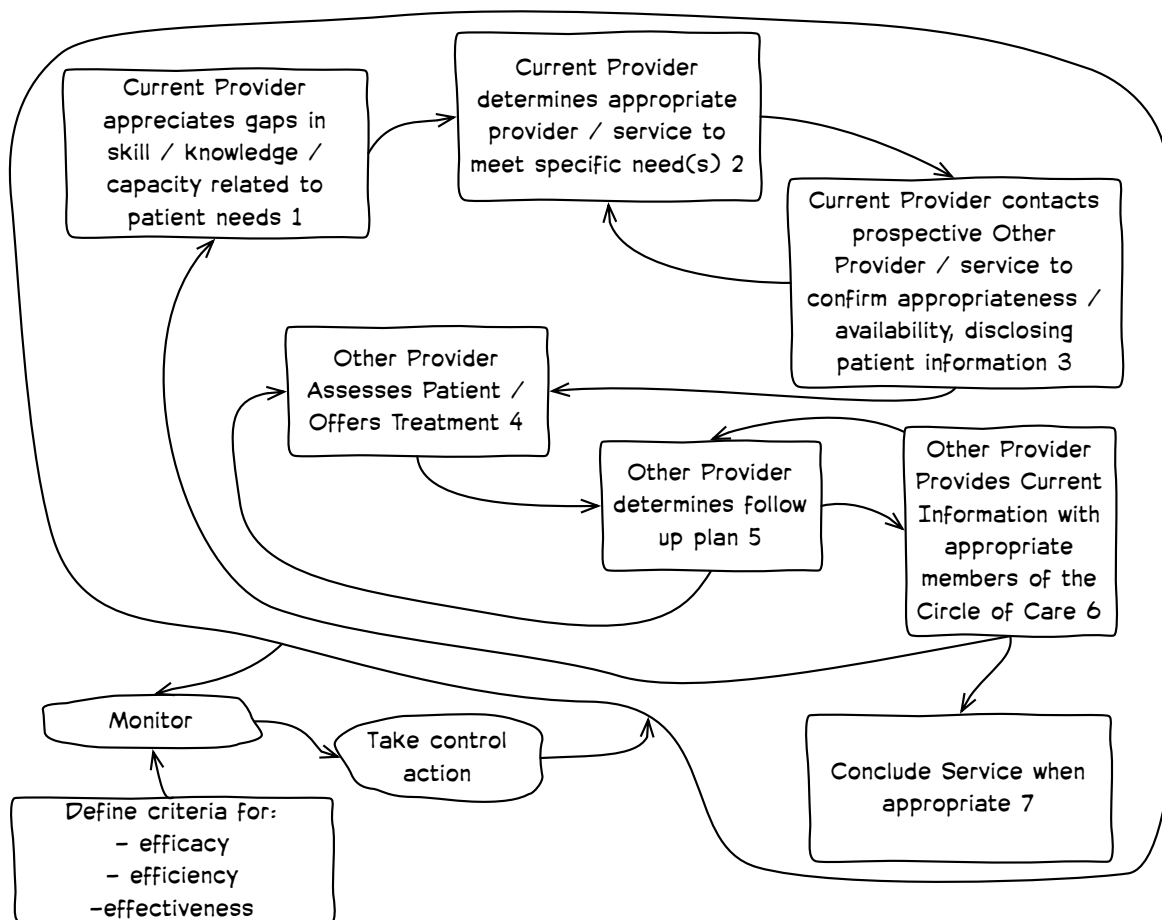


Figure 97: Request Assessment / Treatment. Assumes that services are available and patient has agreed to and wanting those services.

Requests for Assessment and / or Treatment occurred between providers of different skills or scopes of practice in order to provide better care to the patient. These requests were focused on specific issues and included the disclosure of variable amounts of information, depending on the situation.

Requests could be to new providers or to providers already within the Circle of Care. Examples included: a referral from family physician to Palliative Care Physician or a fax request from Home and Community Care nurse to family physician to assess blood pressure readings. The requesting provider was still involved in the patient's care and did not hand over care to the other provider (see *Transfer Care* below). Requests took several forms and could be paper, electronic and/or voice. The form depends on what was available, what was required, and the urgency of the request.

Requests involved disclosing a certain amount of information in order for the prospective provider to determine if they could address the request or if another option was preferable. The receiving provider may determine a follow up plan to further manage this aspect of care. They will often *Provide Information* back to the requesting provider (and possibly other members of the Circle of Care) after assessing / treating the patient.

Order - Figure 98

Order was a way of directing care activities between providers. Order differed from *Requests for Assessment / Treatment* in that *Order* was task oriented. Order was generated as part of a plan after an assessment of the patient. They come from healthcare professionals who have designated ability to delegate tasks to others who could receive them. The context provided with an Order was typically much less than with a *Request for Assessment/Treatment* and the instructions were more explicit on what needed to be completed. Examples of Orders included: prescriptions; laboratory or medical imaging requisitions; MD to nurse orders re vital signs; or nurse to Care Aid orders. Orders were often written, but could be verbal. Orders allowed delegation of tasks to lower skilled providers.

There was a grey area between *Requests for Assessment / Treatment* and *Orders*. Requests might be very explicit on the preferred treatment option and orders might require some interpretation (e.g. a pharmacist may review medications and recommend a different option

back to the MD). Still, this was a useful delineation as the intent of the provider initiating the request or the order was different. Requests relied on the second provider to decide on the appropriate course of action, orders assume that the initiating provider has made that decision.

Current care provider requires an activity be performed for a patient in order to improve the patient's condition and does so through explicit instruction to (an)other provider(s) by means of an order that explicitly states the activities required. A provider may Order through paper, verbal or electronic media.

- C:** Patient, Current Provider
A: Current Provider
T: Task to be completed --> Task completed by another provider, as per order instructions.
W: Patient requires task to be completed, which needs to be completed, or is more effectively completed, by an Other Provider with a different availability, skill, or scope of practice.
O: Other Provider; Patient
E: Availability / Awareness of Providers; Physical Proximity of Care; Professional Practice Standards

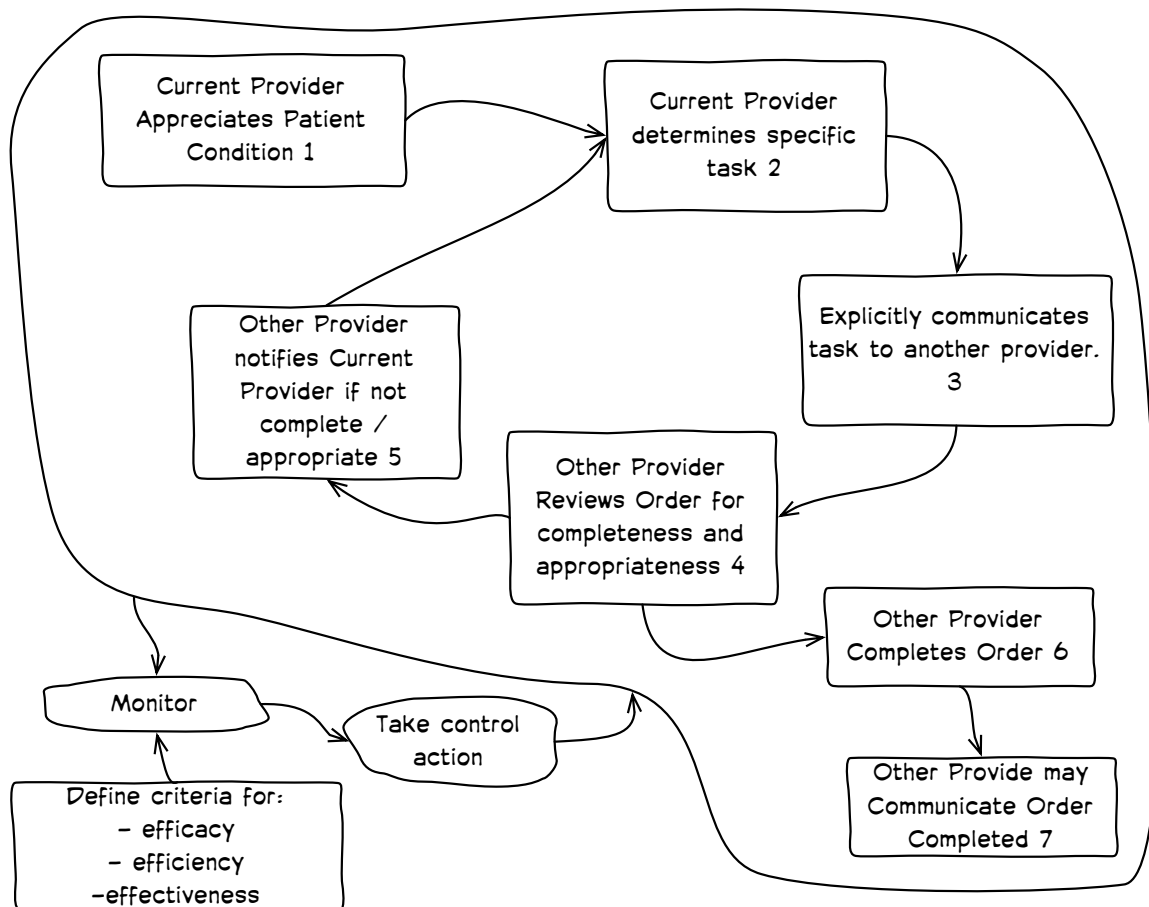


Figure 98: Orders. Orders are similar to Requesting Assessment / Treatment Genre, but are more specific and task oriented.

Transfer Care - Figure 99

Current Provider (provider, family, friend) hands over current care and management responsibilities to another provider (explicitly or implicitly) in order to ensure that continued and appropriate care is provided by a provider, who is able to provide that care for the patient at that time and location. This typically occurs between providers of similar or more appropriate capabilities relative to the patient.

- C:** Patient, Current Provider
- A:** Current Provider; New Provider
- T:** Patient in need of a new provider --> Patient with a new provider who is able to provide similar care
- W:** Changes in patient or provider status, location, or availability (e.g. time) require handover from a provider to a provider who is able to provide equivalent care.
- O:** Other Provider; Patient
- E:** Availability / Awareness of Providers; Physical Proximity of Care; Professional Practice Standards; Funding; Organizational Boundaries.

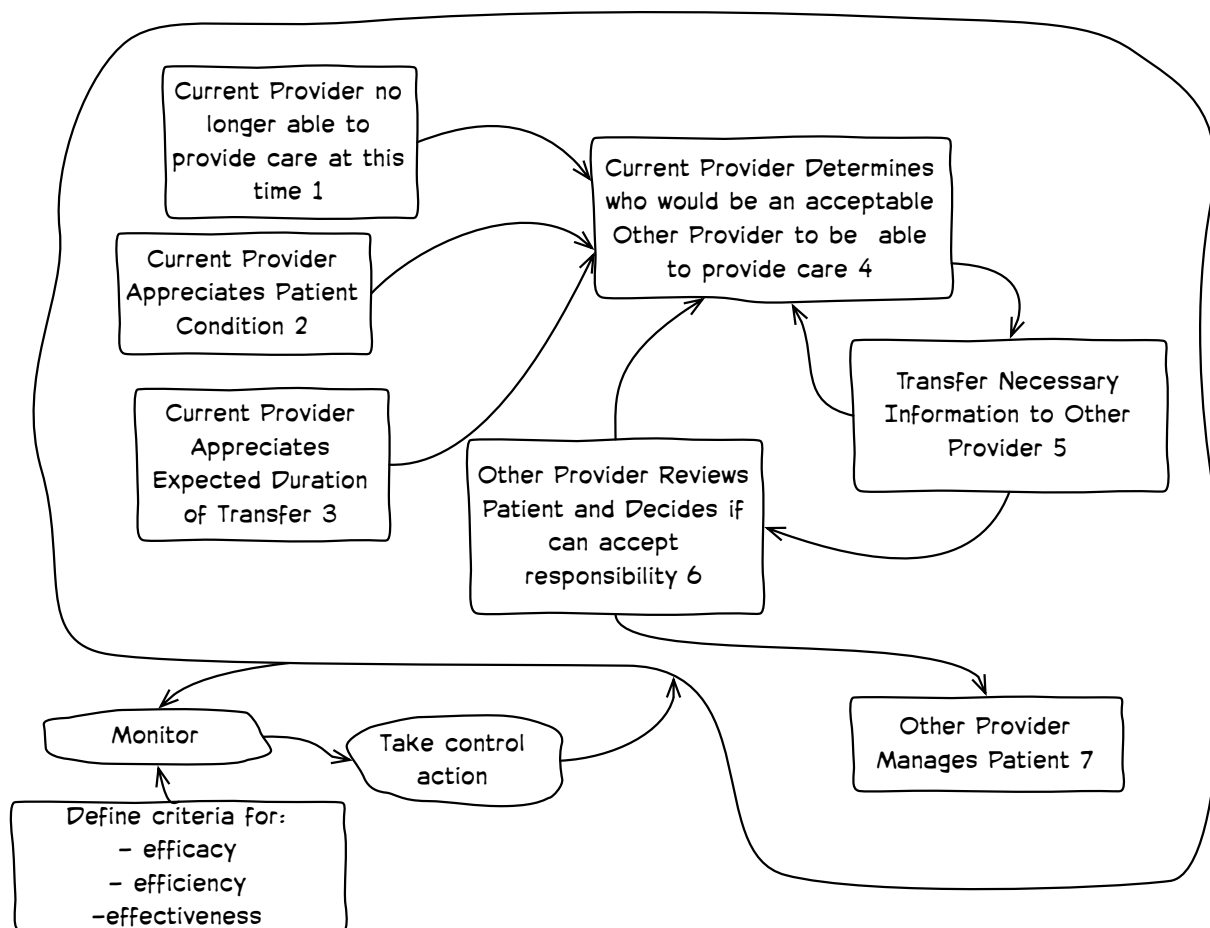


Figure 99: Transfer Care. Transfers may be implied, in which case the decision to accept responsibility is assumed.

Transferring Care occurred between two providers when one was to stop providing care to the patient and was handing over their active tasks and responsibilities to another provider. The other provider, typically, had a similar role. Transfers had several characteristics.

Transfers might be explicit. Explicit transfers required that the accepting provider agreed to the transfer. An ER Physician handing over Mr. Hart to a neurologist in the hospital was an explicit transfer. Transfers might be implicit, such as at shift change between nurses, where the routine and structure required transfers. Implied transfers also occurred between community support workers, Home and Community Care nurses and physicians while on call (for stable patients particularly).

A transfer might be permanent, such as when Mrs. Cann was placed in Chemanius hospice bed, or temporary, as when the patient's family physician handed over to the family physician on call for an evening or a weekend. Sharing information during Transfers took several forms, including: verbal, paper, and electronic (e.g. email). Transfers could also rely on shared records. In implied transfers no information was explicitly shared, the shared record was the only communication between providers.

Transfers of Care were common practice and were necessary to provide certain levels of care (e.g. 24 hour coverage, weekend coverage). These transfers could impact both Management Continuity and Relationship Continuity if handover was not done properly or transfers were too frequent.

Coordinate as Care Team - Figure 100

Coordinate as Care Team were real-time events that occurred between more than two providers to discuss a patient and come to a common perspective on the patient's current condition, prognosis, and/or management plans. Participants saw these Coordinate as Care Team events as useful to ensure that members of the team were working towards similar goals. Typically these were multidisciplinary, although that was not necessary. In long-term care, these were often multidisciplinary groups:

“[We have] about 8 or 9 people so it is a multidisciplinary team that sits down and discusses the individual resident.”

Providers often met face-to-face for this Abstract Genre. They could be virtual, either using voice or video conferencing. BC Cancer Agency made use of virtual conferences to discuss treatment options on complex cases, soliciting opinions from multiple providers across the province that could be involved. Patients or families may attend, or they may not.

Coordinate as Care Teams helped providers understand each other’s perspectives and allowed some socializing with each other.

There were two challenges voiced with Coordinate as Care Team. First, sharing of details might not be appropriate for all members and thus could waste time for some people. An example would be physicians discussing the details of medication options would not be necessarily relevant to the social worker in the meeting. The other issue was scheduling. It was difficult to get all people in the room at the same time. Family Physicians often did not attend rounds, as they were typically offsite at their own offices.

*“Ideally the doctor attends that [Annual Review] the doctors very often can’t [attend]”
(D04)*

A group of providers (from the patient's Circle of Care) meet synchronously in person or virtually to discuss a particular patient in order to explore multiple points of view and develop a common understanding of a patient's current state (information) and decide / share care plans (management).

C: Patient, Family, Current Providers

A: Current Providers; Patient; Family

T: Multiple Providers not sufficiently coordinated --> Providers Coordinated around the care plan of a patient.

W: For patients with multiple care providers, sometimes synchronous meetings are required to "get on the same page" in terms of health status, function, reviewing / creating management plans, or determining prognosis.

O: Providers; Patient;

E: Availability / Awareness of Providers; Physical Proximity of Care; Technical Infrastructure; Professional Practice Standards; Funding; Organizational Boundaries

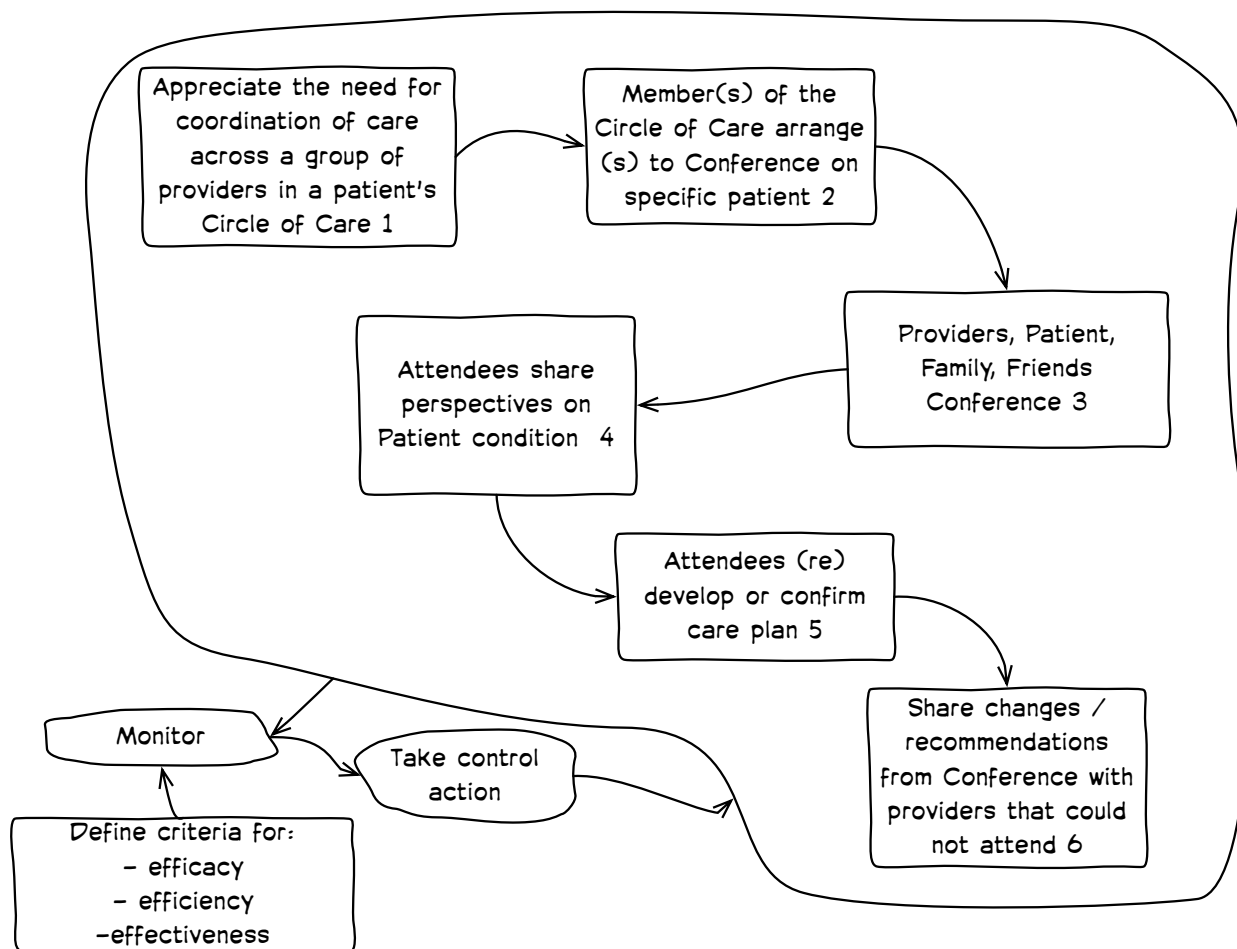


Figure 100: Coordinate as Care Team. The attendees are variable based on the specific purposes and availability. Patient, family, friends may or may not be invited.

Appendix K. Provider Views

In the study, the analysis of the provider view of the Circle of Care was quite detailed and was too extensive to capture all the models in the body of the dissertation. Individual models were created for each Continuity Provider role in each patient's Circle of Care for each of the two communities for two points in the patient's story. The Individual models were all designed to have the same format for easier comparison (Figure 101). The diagram highlighted the Circle of Care from the perspective of the Current Provider, who was at the hub. The Current Provider's view was a composition of all participants with the same role (e.g. all family physicians) in that community. The Initiating Provider was the provider who, in the study, named the Current Provider as a member of the patient's Circle of Care. Other Continuity Providers were highlighted in blue and were bolded. These were providers that were named by other roles. They had a larger role in communication across teams. Providers who were not Continuity Providers either were named by one provider or were named by more than provider, but there was little or no communication between the providers. The Community Support Workers were an example of this type of role – several providers were aware that they would be providing services, but they would not have any direct contact with them.

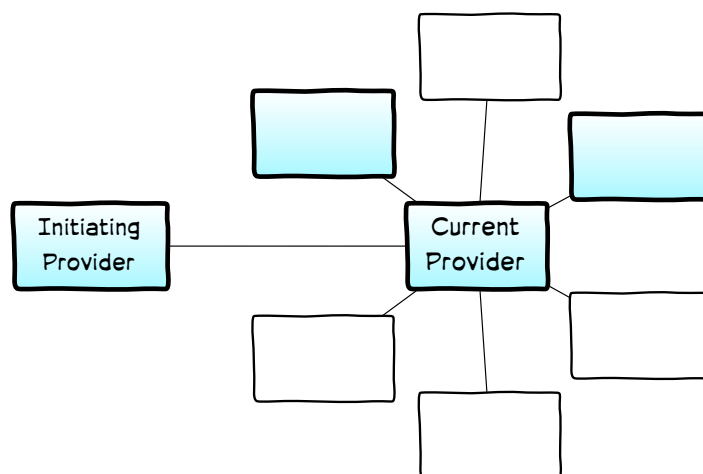


Figure 101: The individual model of the Circle of Care, as described by participants with the same role.

This appendix is organized as follows:

1. Mrs. Cann, Victoria
 - a. Early End of Life: Scenarios one and two from the Rich Picture. She is ambulatory, but starting not to cope at home. She has a pain crisis.
 - b. Late End of Life: Scenarios three and four from the Rich Picture. She is homebound at her daughter's house and then makes the transition to hospice.
2. Mrs. Cann, Duncan
 - a. Early End of Life: Scenarios one and two from the Rich Picture. She is ambulatory, but starting not to cope at home. She has a pain crisis.
 - b. Late End of Life: Scenarios three and four from the Rich Picture. She is homebound at her daughter's house and then makes the transition to a facility.
3. Mr. Hart, Victoria
 - a. Early End of Life: He is ambulatory and has a stroke that sends him to emergency twice, ultimately staying in hospital.
 - b. Late End of Life: He is in a residential care facility and is transferred to the emergency after a suspected heart attack.
4. Mr. Hart, Duncan
 - a. Early End of Life: He is ambulatory and has a stroke that sends him to emergency twice, ultimately staying in hospital.
 - b. Late End of Life: He is in a residential care facility and is transferred to the emergency after a suspected heart attack.

Mrs. Cann in Victoria, Early End of Life

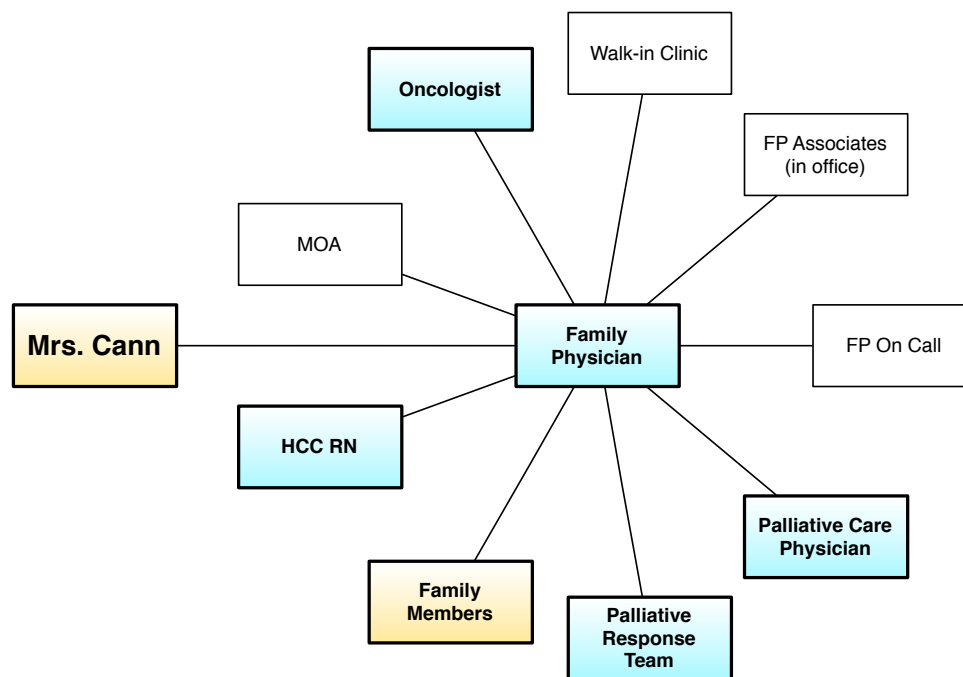


Figure 102: The members of the Circle of Care for Mrs. Cann in Victoria while she is still ambulatory, from the perspective of the family physicians

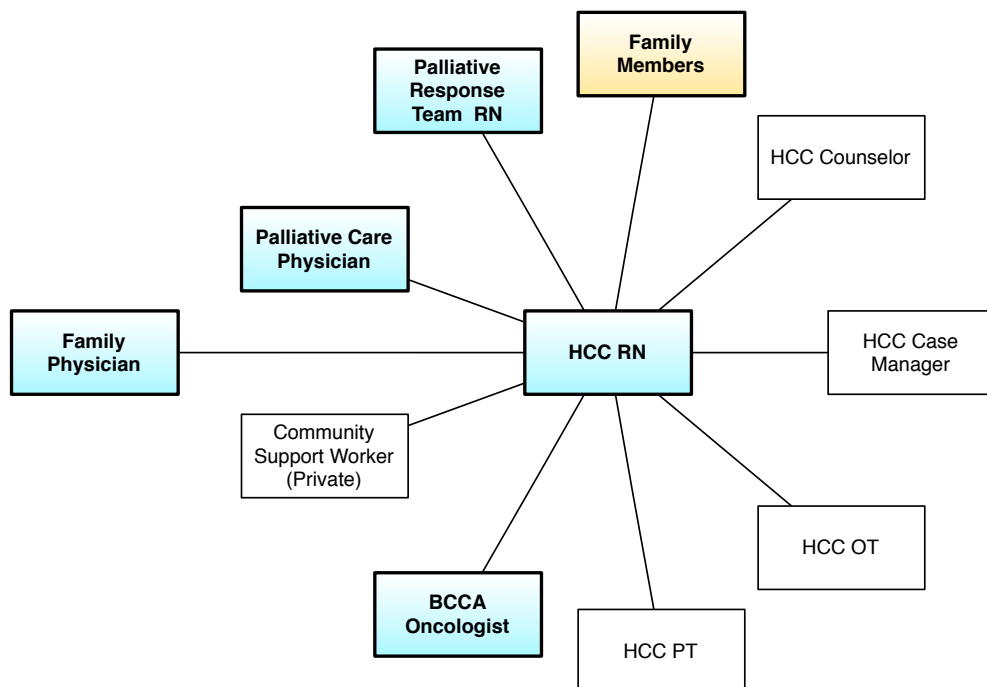


Figure 103: The members of the Circle of Care for Mrs. Cann in Victoria while she is still ambulatory, from the perspective of the Home and Community Care nurses.

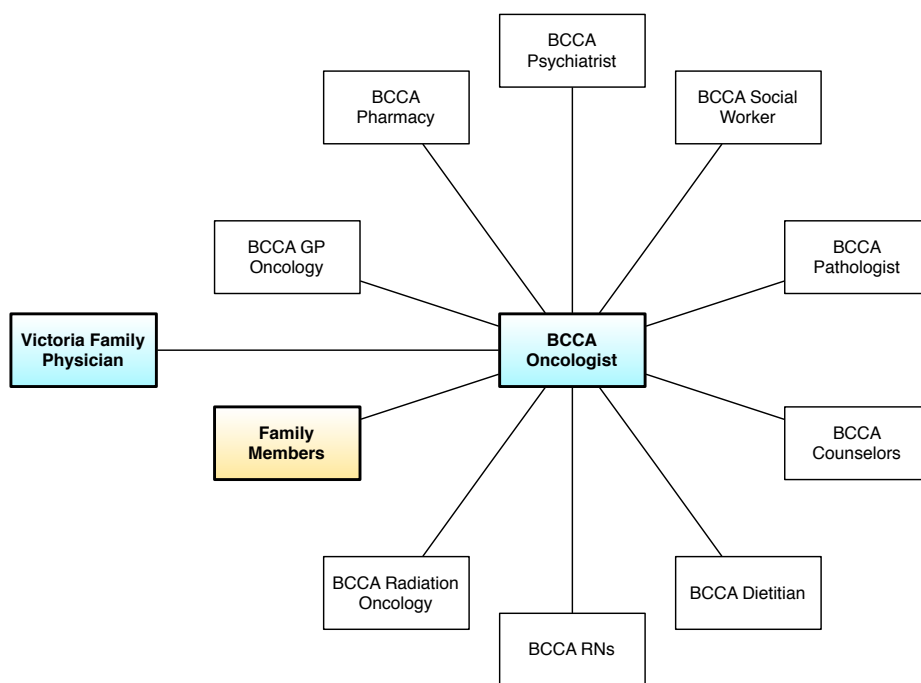


Figure 104: The members of the Circle of Care for Mrs. Cann in Victoria while she is still ambulatory, from the perspective of the Cancer Agency Oncologist.

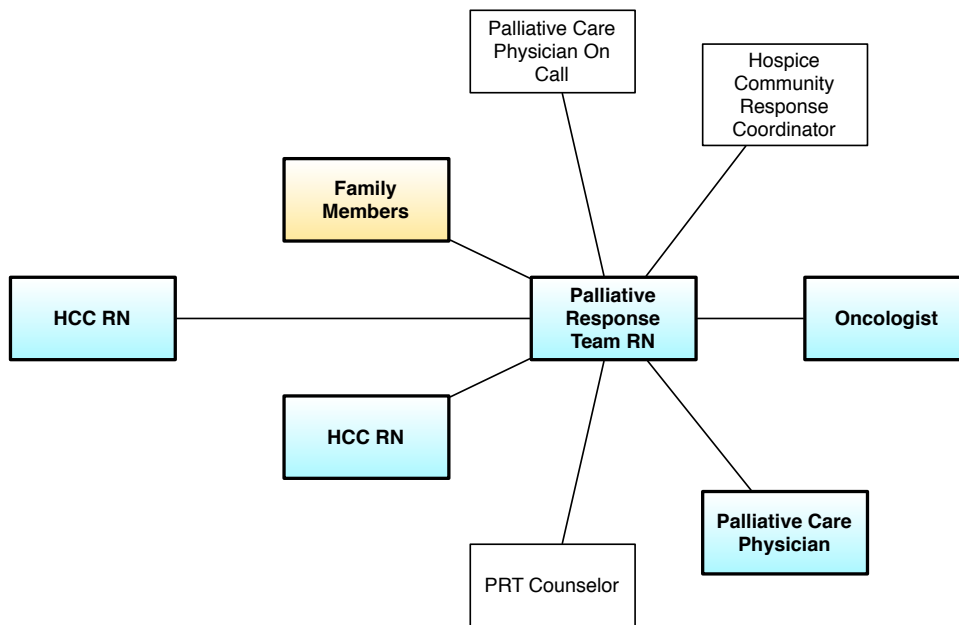


Figure 105: The members of the Circle of Care for Mrs. Cann in Victoria while she is still ambulatory, from the perspective of the Palliative Response Team nurses.

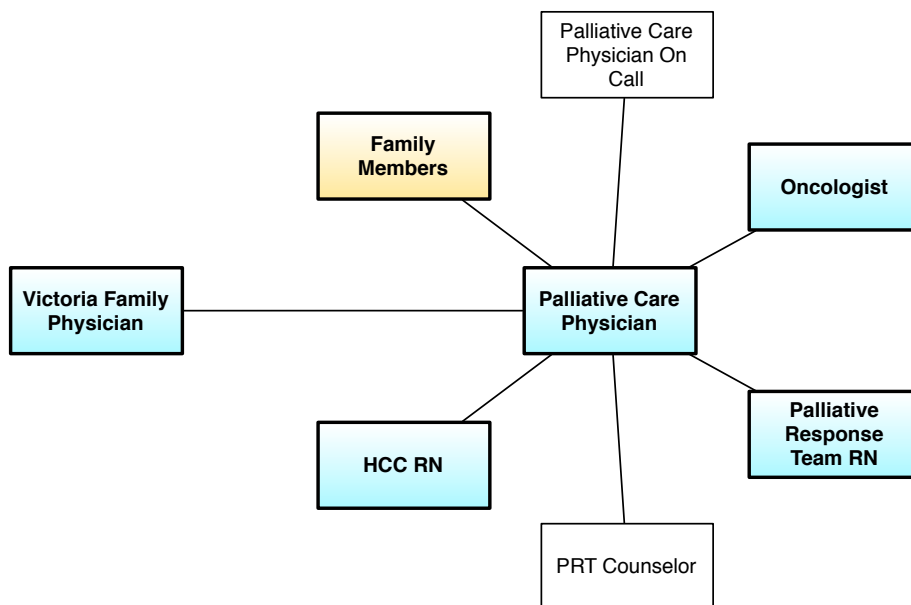


Figure 106: The members of the Circle of Care for Mrs. Cann in Victoria while she is still ambulatory, from the perspective of the Palliative Care Physicians.

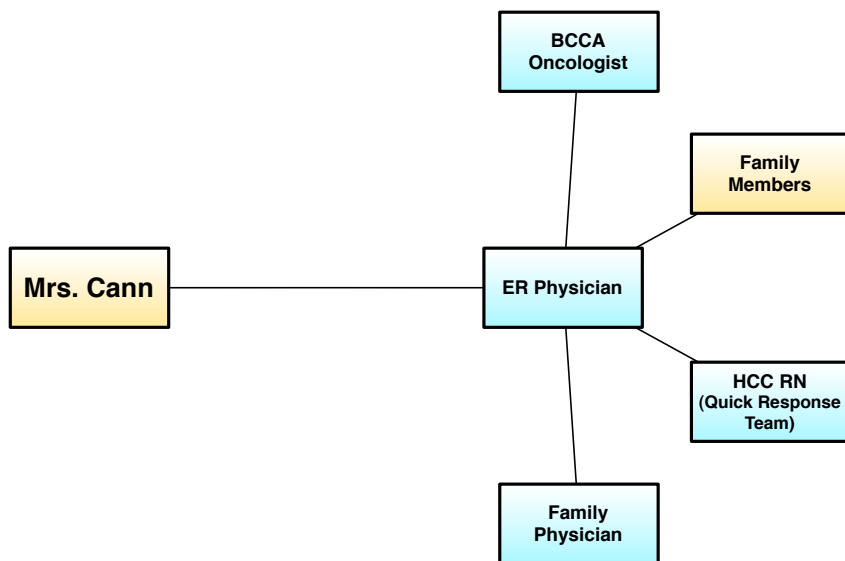


Figure 107: The members of the Circle of Care for Mrs. Cann in Victoria while she is still ambulatory, from the perspective of the ER physicians. (NOTE: while they were not, ultimately included in the scenario, they were asked to describe the members of Mrs. Cann's Circle of Care.

Mrs. Cann, Victoria, Late End of Life

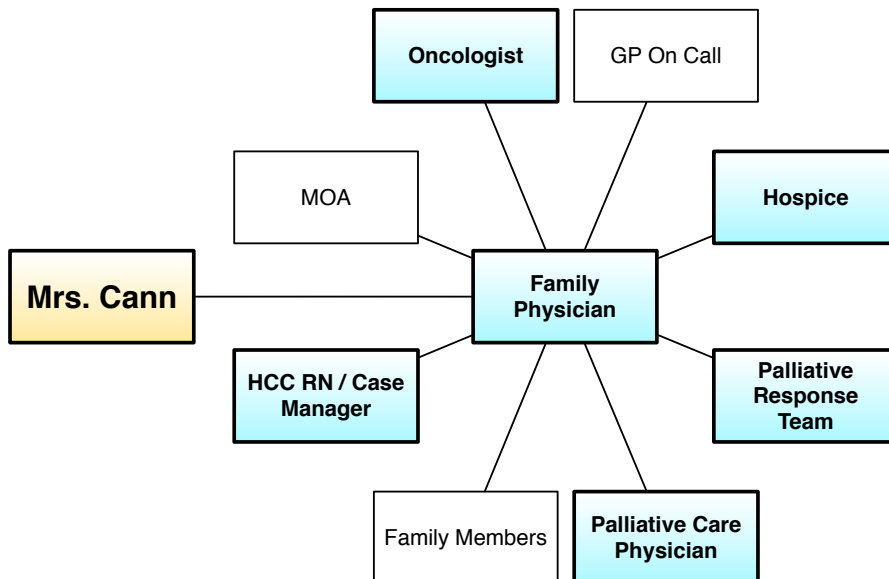


Figure 108: The members of the Circle of Care for Mrs. Cann in Victoria while she is homebound at her daughter's house and transitioning to Hospice, from the perspective of the Family Physician.

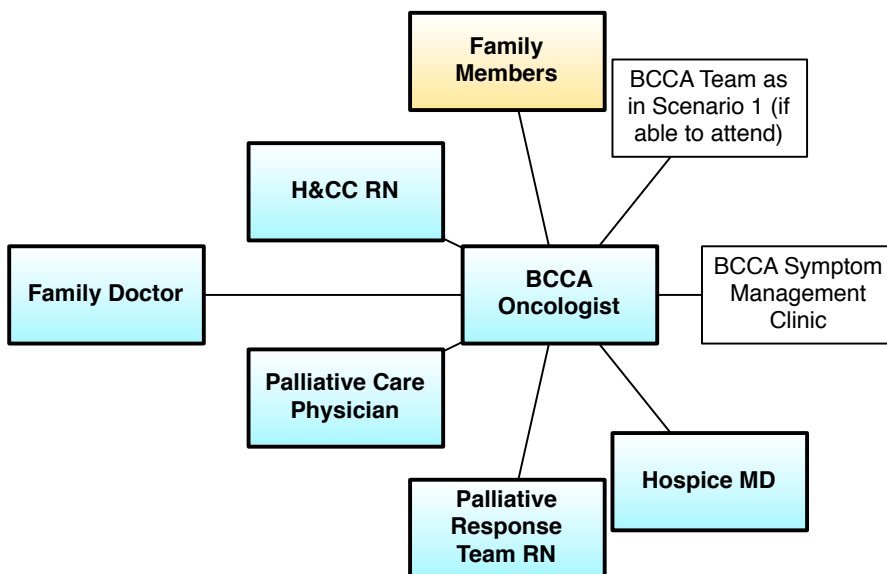


Figure 109: The members of the Circle of Care for Mrs. Cann in Victoria while she is homebound at her daughter’s house and transitioning to Hospice, from the perspective of the Oncologist. NOTE: the BCCA team members would only be engaged if Mrs. Cann attended or contacted the cancer centre.

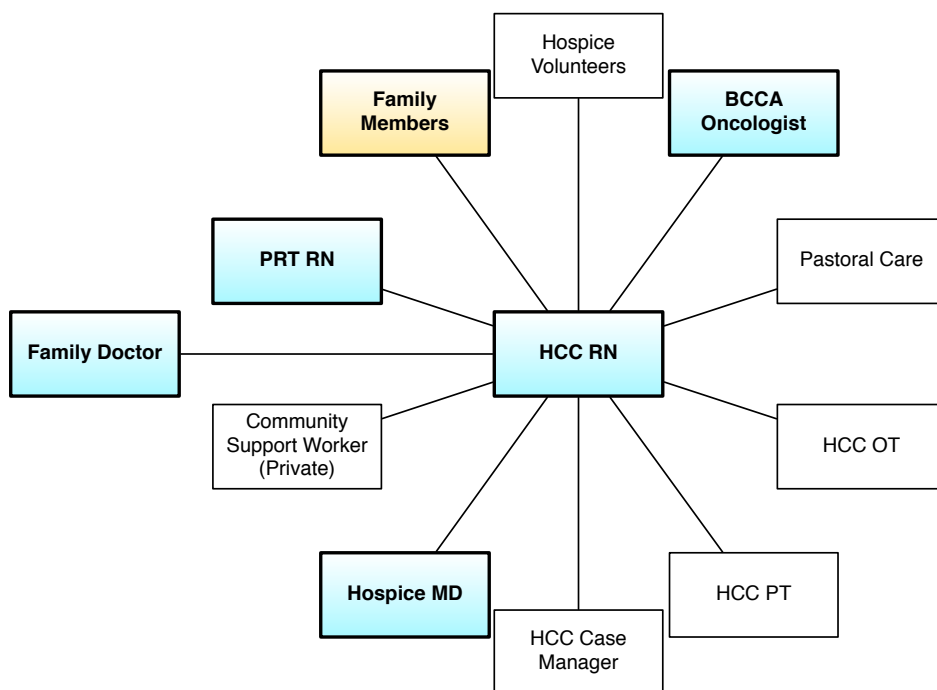


Figure 110: The members of the Circle of Care for Mrs. Cann in Victoria while she is homebound at her daughter’s house and transitioning to Hospice, from the perspective of the Home and Community Care nurse.

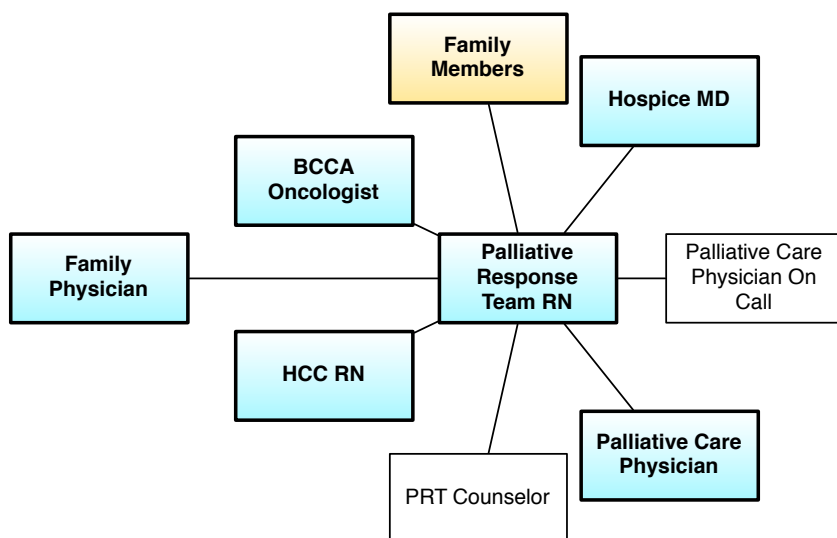


Figure 111: The members of the Circle of Care for Mrs. Cann in Victoria while she is homebound at her daughter's house and transitioning to Hospice, from the perspective of the Palliative Care Response Team nurse.

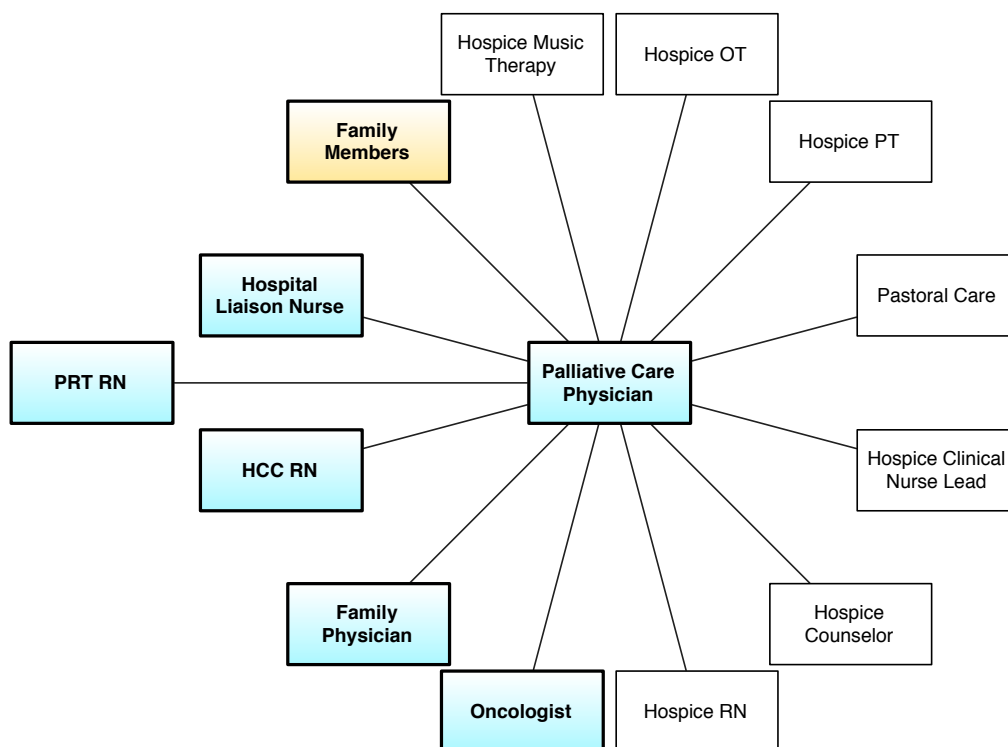


Figure 112: The members of the Circle of Care for Mrs. Cann in Victoria while she is homebound at her daughter's house and transitioning to hospice, from the perspective of the Palliative Care Physician / Hospice Physician.

Mrs. Cann in Duncan, Early End of Life

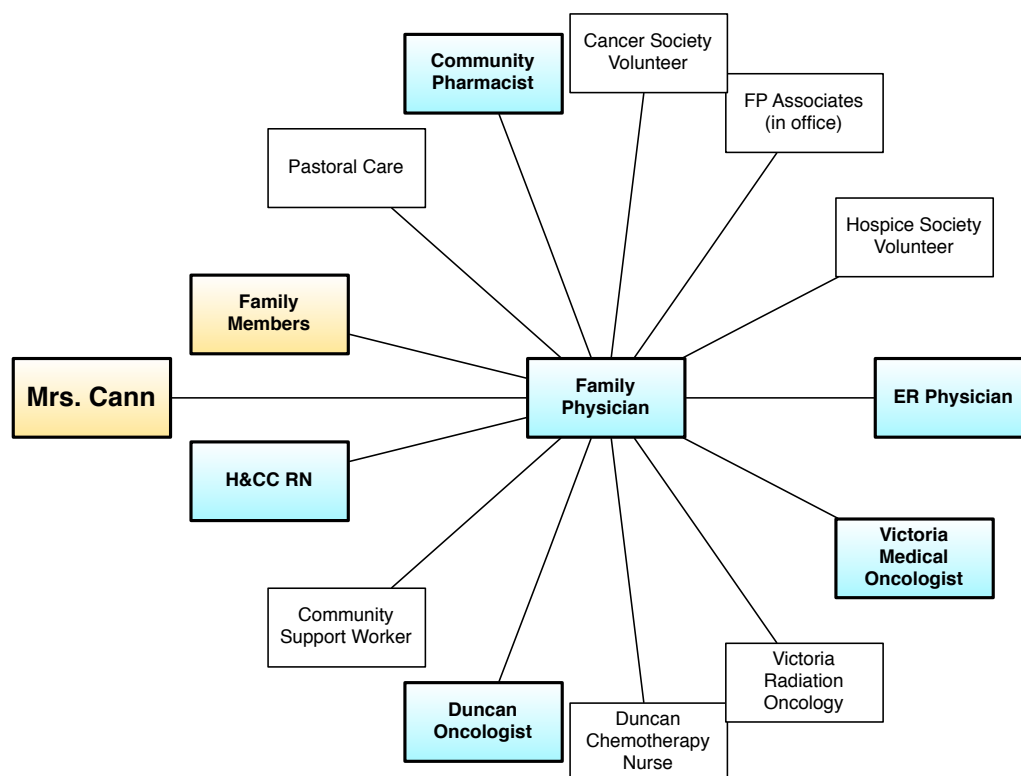


Figure 113: The members of the Circle of Care for Mrs. Cann in Duncan while she is still ambulatory, from the perspective of the Family Physician.

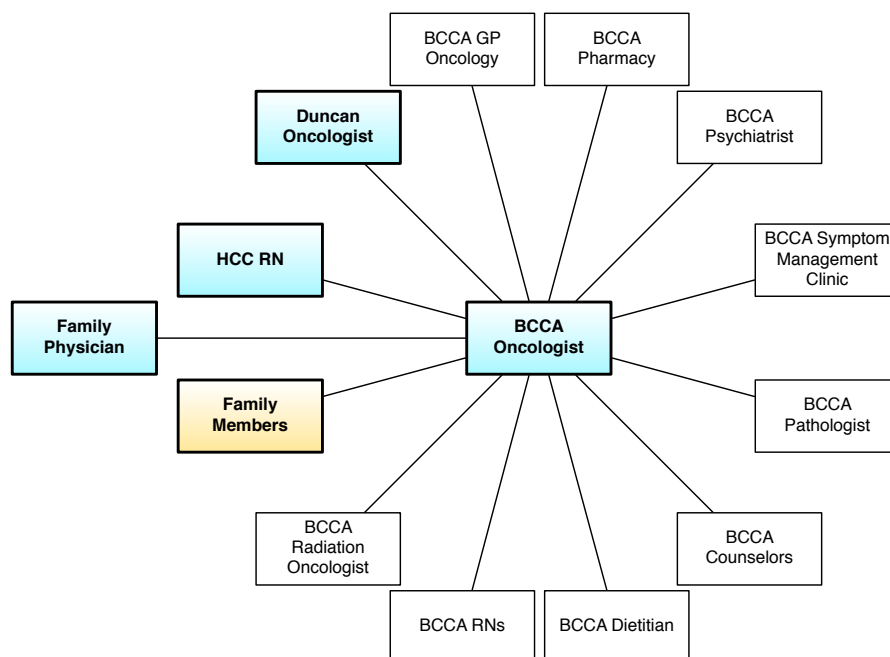


Figure 114: The members of the Circle of Care for Mrs. Cann in Duncan while she is still ambulatory, from the perspective of the Victoria based Oncologist.

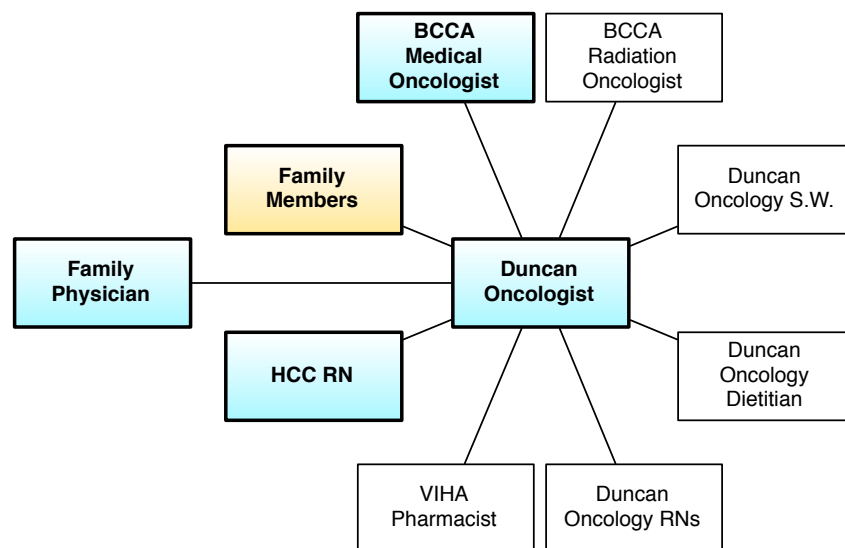


Figure 115: The members of the Circle of Care for Mrs. Cann in Duncan while she is still ambulatory, from the perspective of the Duncan Oncologist.

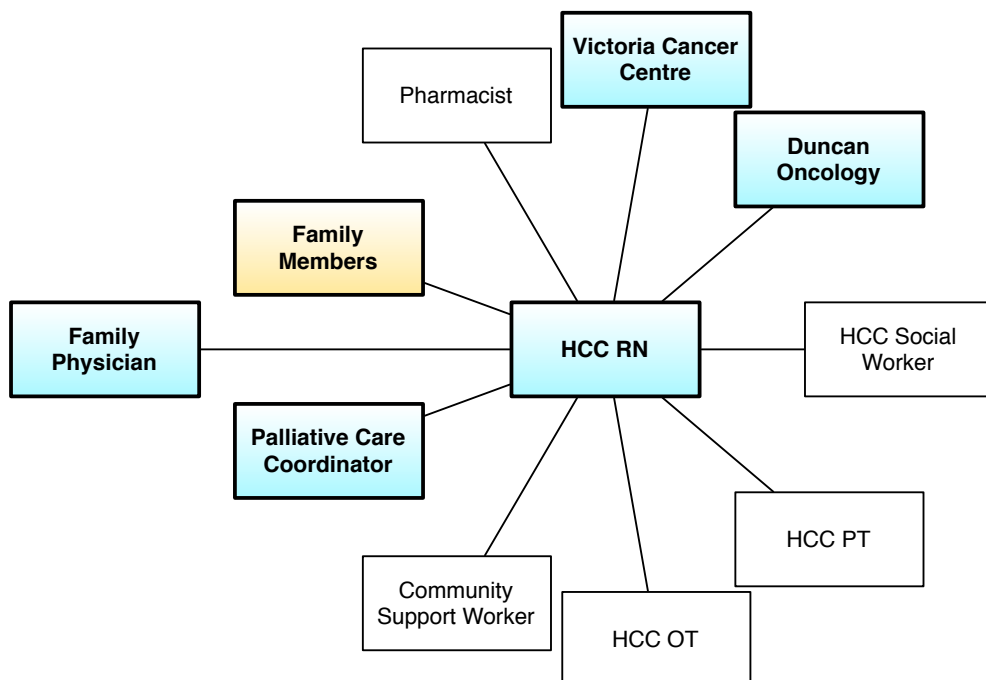


Figure 116: The members of the Circle of Care for Mrs. Cann in Duncan while she is still ambulatory, from the perspective of the Home and Community Care Nurse.

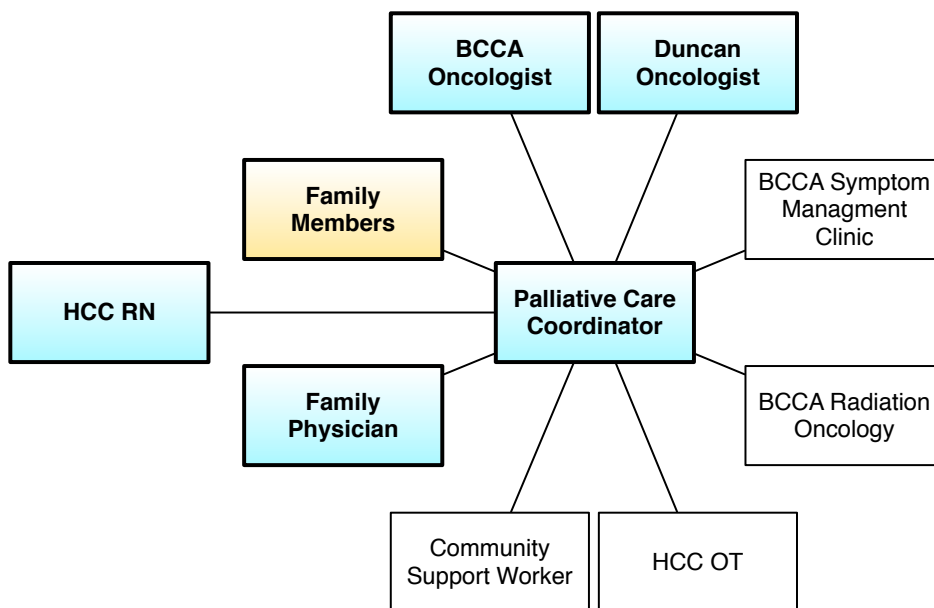


Figure 117: The members of the Circle of Care for Mrs. Cann in Duncan while she is still ambulatory, from the perspective of the Palliative Care Coordinator.

Mrs. Cann in Duncan, Late End of Life

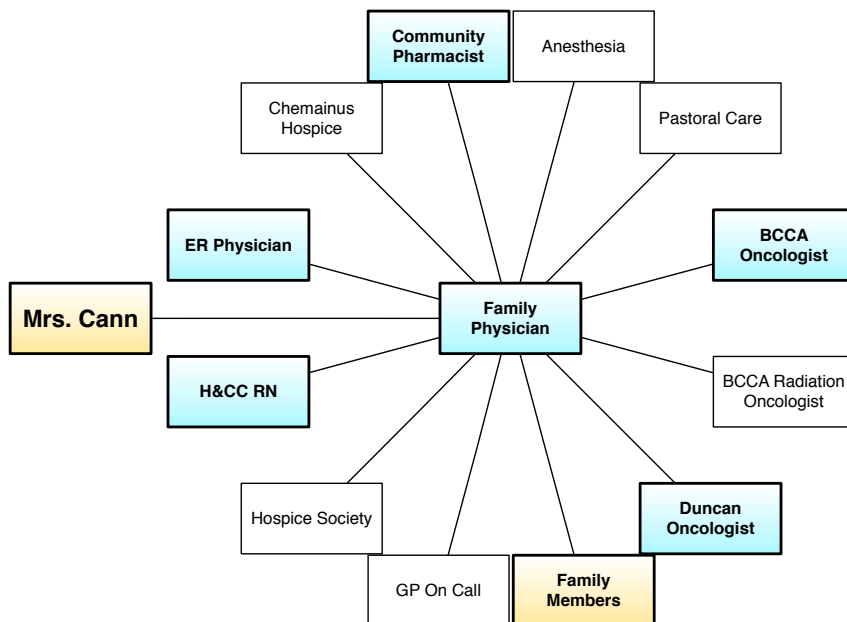


Figure 118: The members of the Circle of Care for Mrs. Cann in Duncan while she is homebound at her daughter’s house and transitioning to hospice, from the perspective of the Family Physician.

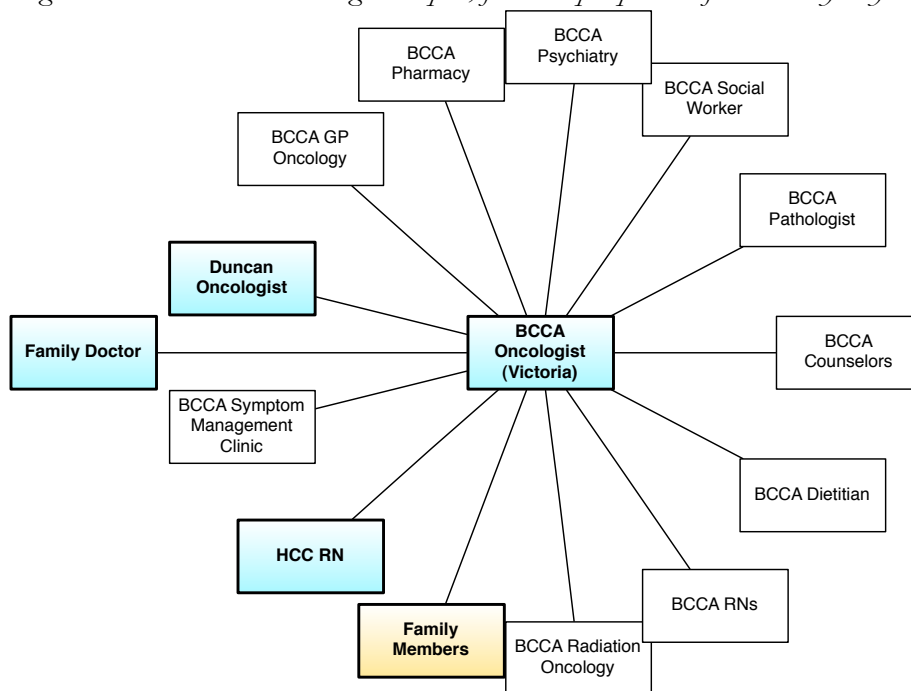


Figure 119: The members of the Circle of Care for Mrs. Cann in Duncan while she is homebound at her daughter’s house and transitioning to hospice, from the perspective of the Victoria based Oncologist.

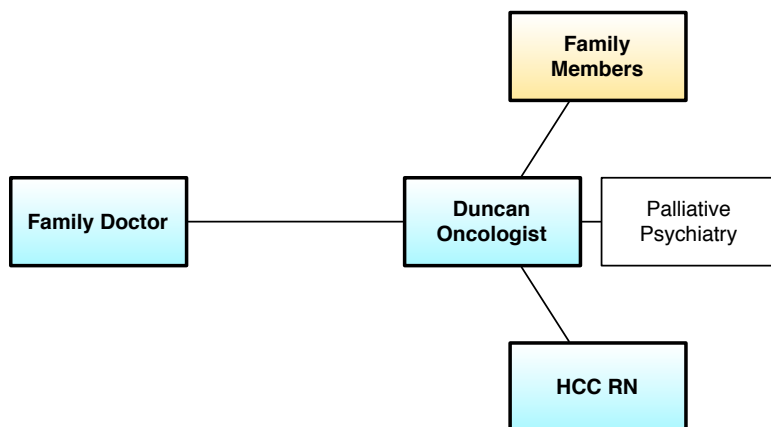


Figure 120: The members of the Circle of Care for Mrs. Cann in Duncan while she is homebound at her daughter's house and transitioning to hospice, from the perspective of the Duncan based Oncologist.

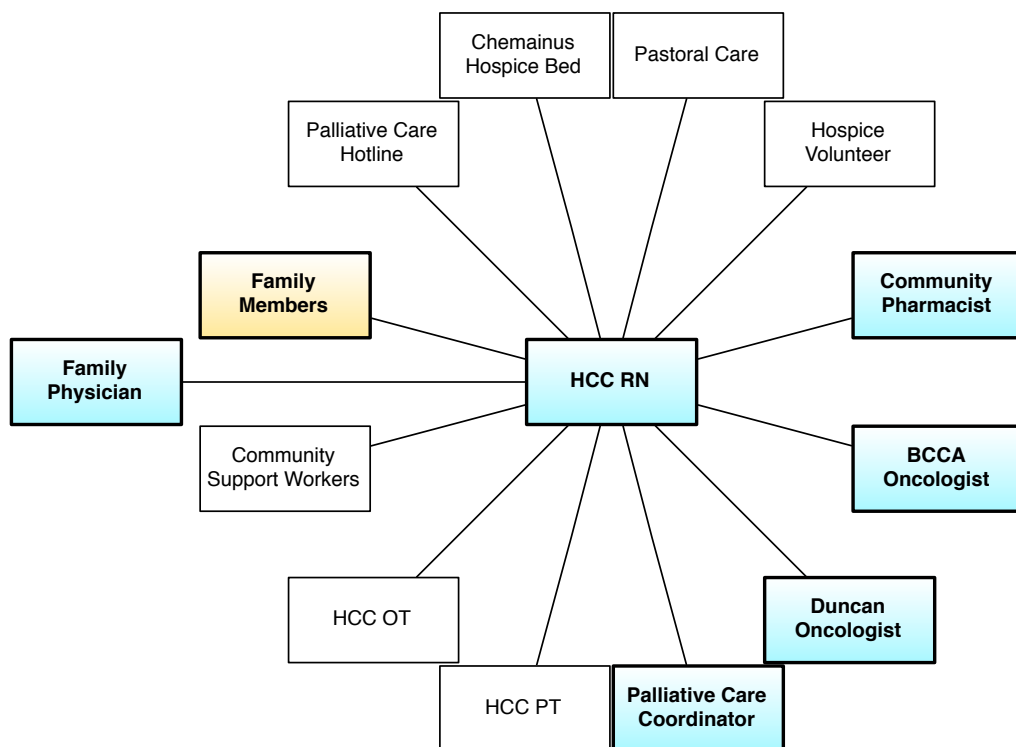


Figure 121: The members of the Circle of Care for Mrs. Cann in Duncan while she is homebound at her daughter's house and transitioning to hospice, from the perspective of the Home and Community Care Nurse.

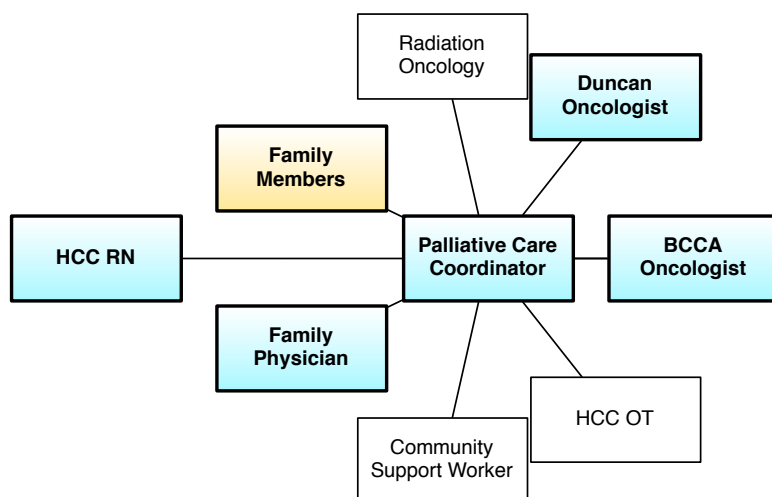


Figure 122: The members of the Circle of Care for Mrs. Cann in Duncan while she is homebound at her daughter's house and transitioning to hospice, from the perspective of the Palliative Care Coordinator in Duncan.

Mr. Hart, Victoria, Early End of Life

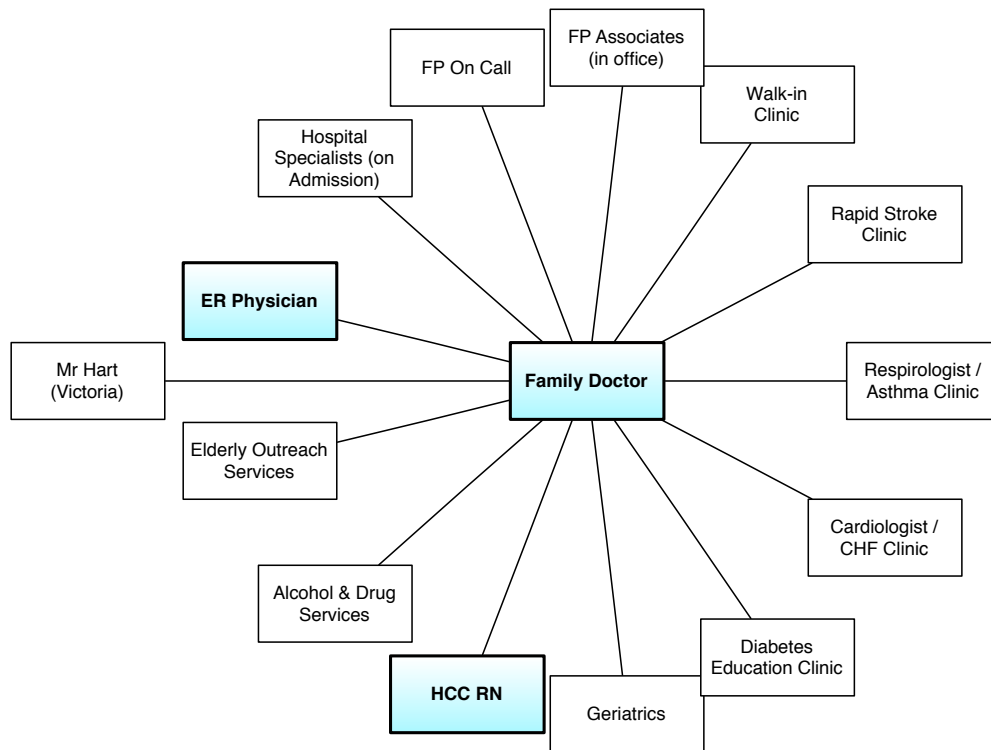


Figure 123: The members of the Circle of Care for Mr. Hart in Victoria while he is an outpatient (i.e. in the community, including visits to the emergency), from the perspective of the Family Physician.

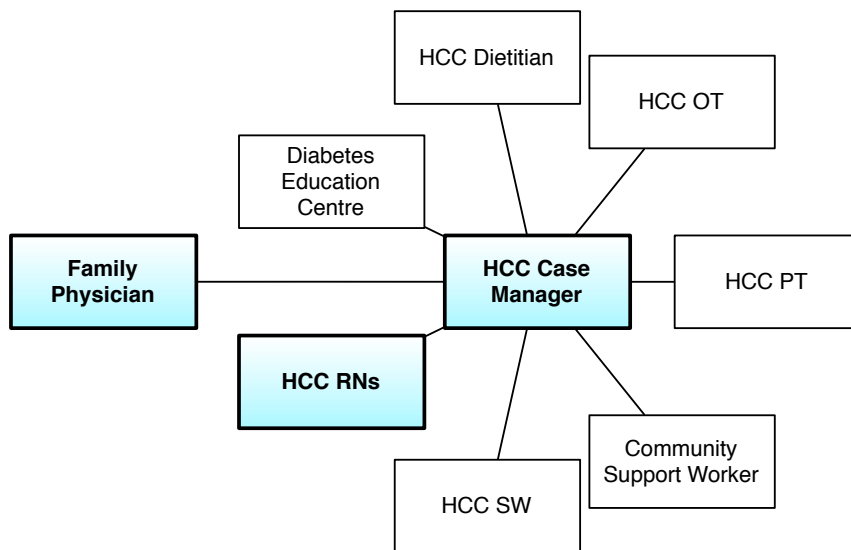


Figure 124: The members of the Circle of Care for Mr. Hart in Victoria while he is an outpatient (i.e. in the community, including visits to the emergency), from the perspective of the Home and Community Care Case Manager.

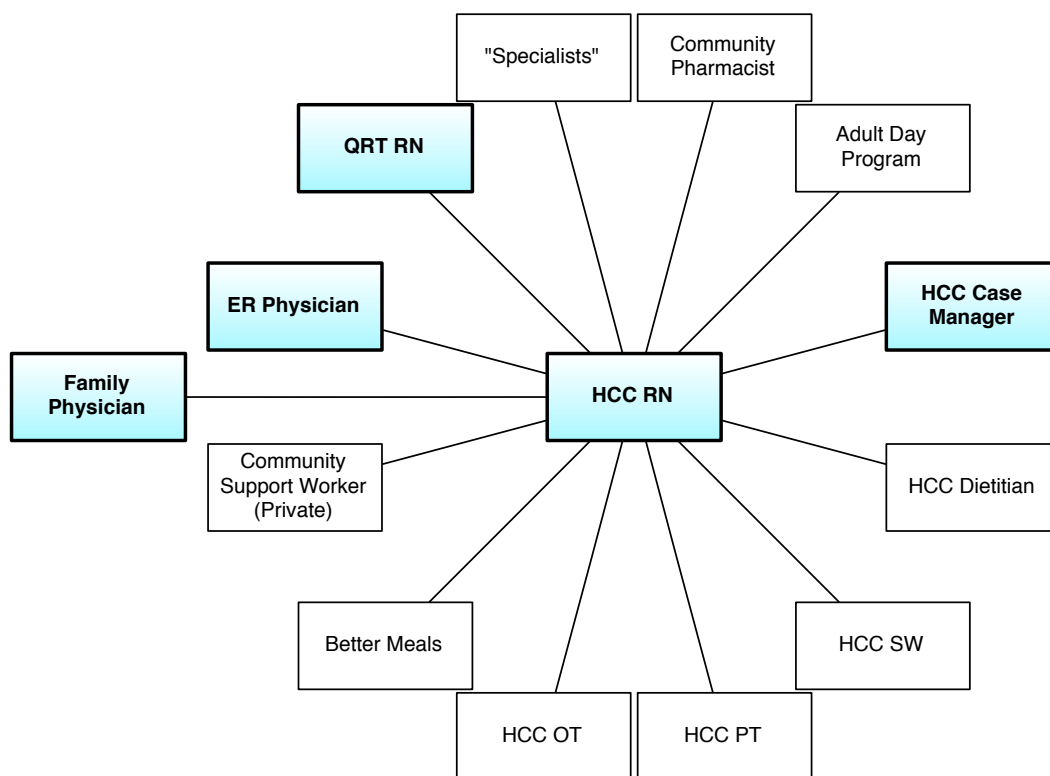


Figure 125: The members of the Circle of Care for Mr. Hart in Victoria while he is an outpatient (i.e. in the community, including visits to the emergency), from the perspective of the Home and Community Care nurse.

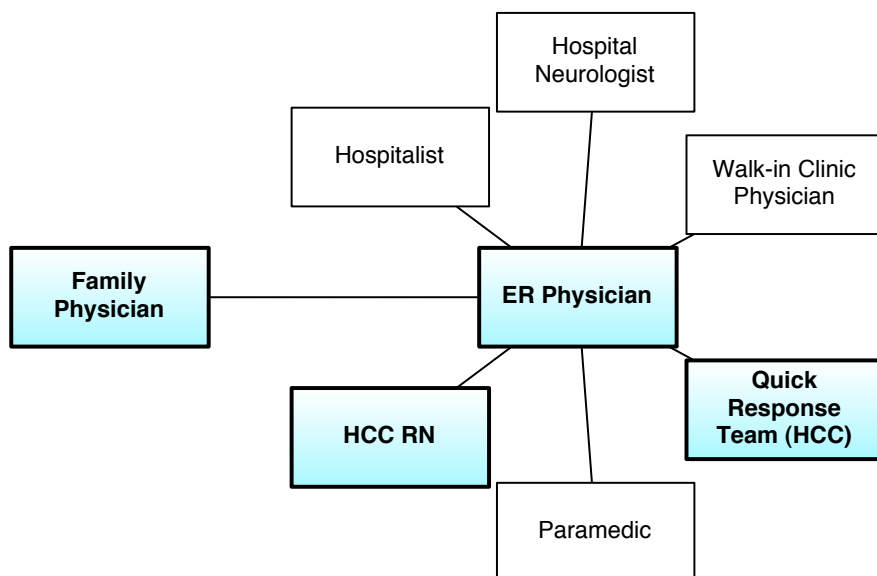


Figure 126: The members of the Circle of Care for Mr. Hart in Victoria while he is an outpatient (i.e. in the community, including visits to the emergency), from the perspective of the ER Physician.

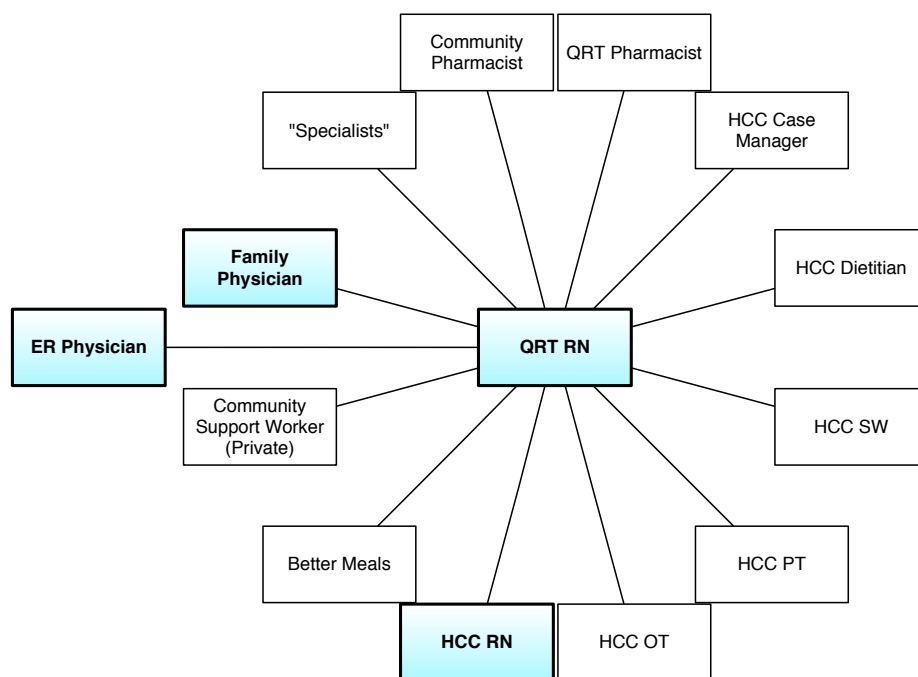


Figure 127: The members of the Circle of Care for Mr. Hart in Victoria while he is an outpatient (i.e. in the community, including visits to the emergency), from the perspective of the Quick Response Team Nurse, a member of Home and Community Care (NOTE: this is a composite view from Home and Community Care nurses and another member of quick response team as no quick response team nurses were recruited).

Mr. Hart, Victoria, Late End of Life

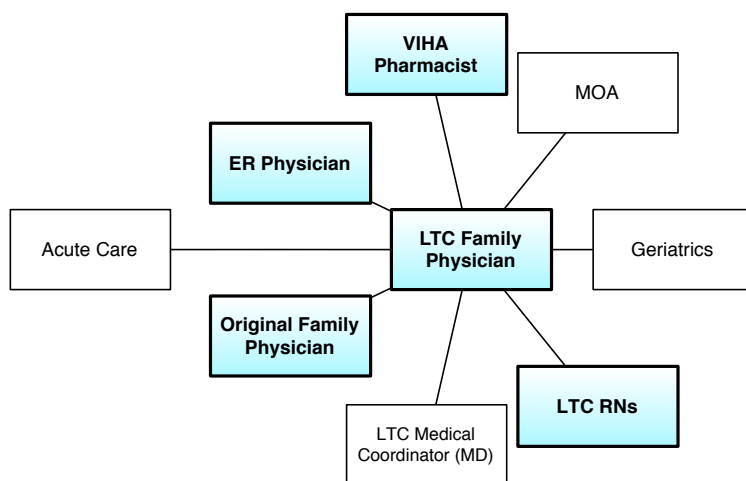


Figure 128: The members of the Circle of Care for Mr. Hart in Victoria while he is a resident in long-term care, including a visit to the emergency, from the perspective of his new Family Physician, who is associated with the facility.

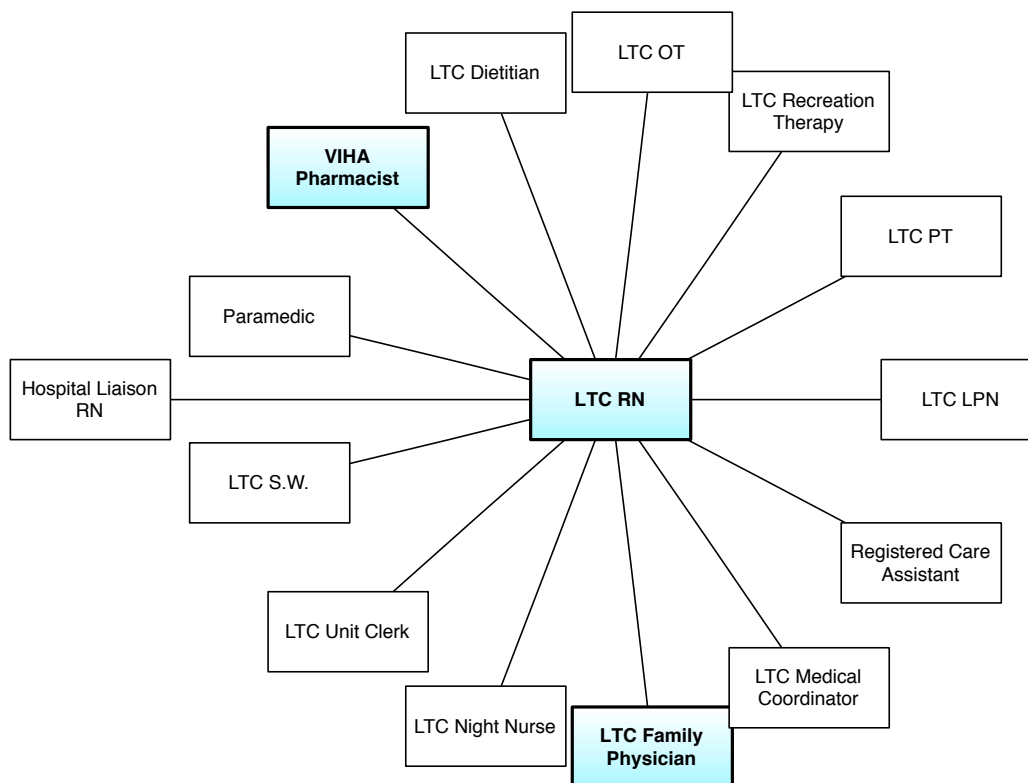


Figure 129: The members of the Circle of Care for Mr. Hart in Victoria while he is a resident in long-term care, including a visit to the emergency, from the perspective of the Long-Term Care Nurse.

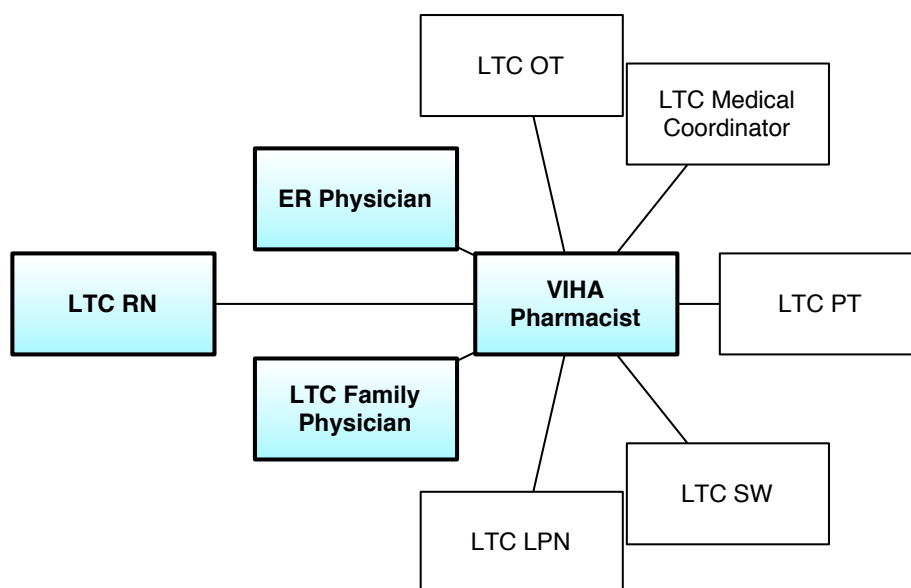


Figure 130: The members of the Circle of Care for Mr. Hart in Victoria while he is a resident in long-term care, including a visit to the emergency, from the perspective of the VIHA Pharmacist who dispenses Mr. Hart his medication both in the facility and in the Emergency

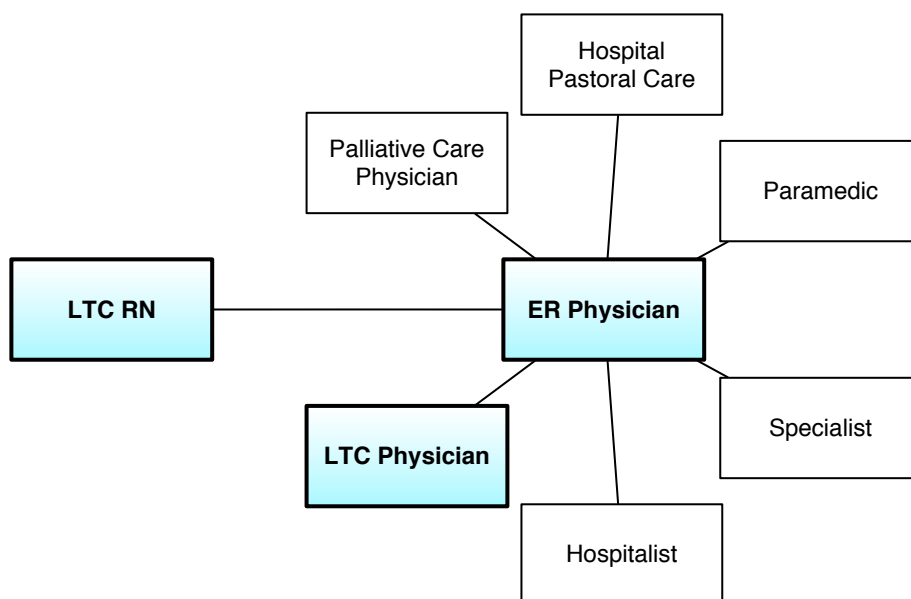


Figure 131: The members of the Circle of Care for Mr. Hart in Victoria while he is a resident in long-term care, including a visit to the emergency, from the perspective of the ER Physician.

NOTE: No Hospital Liaison Nurses were recruited in Victoria.

Mr. Hart, Duncan, Early End of Life

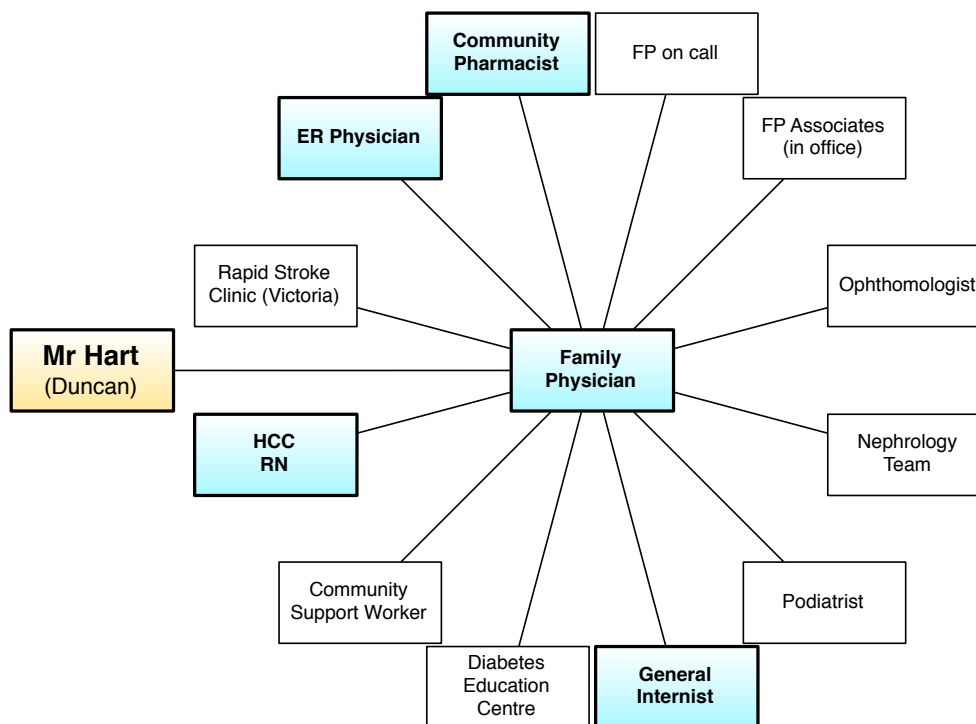


Figure 132: The members of the Circle of Care for Mr. Hart in Duncan while he is an outpatient (i.e. in the community, including visits to the emergency), from the perspective of the Family Physician.

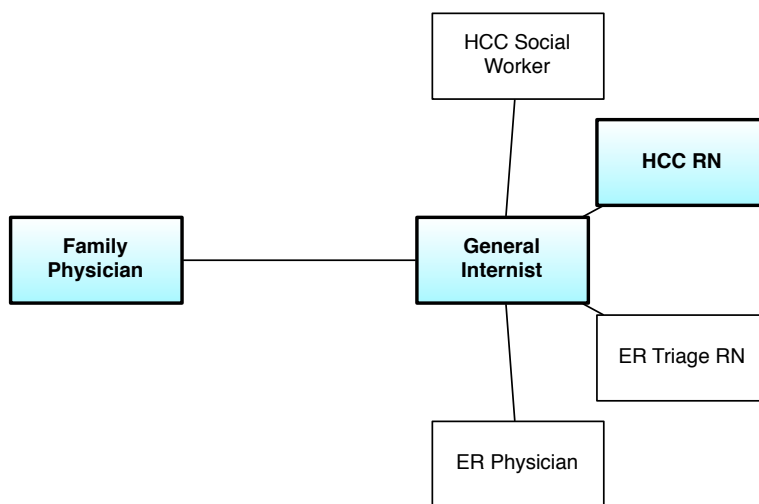


Figure 133: The members of the Circle of Care for Mr. Hart in Duncan while he is an outpatient (i.e. in the community, including visits to the emergency), from the perspective of the General Internist.

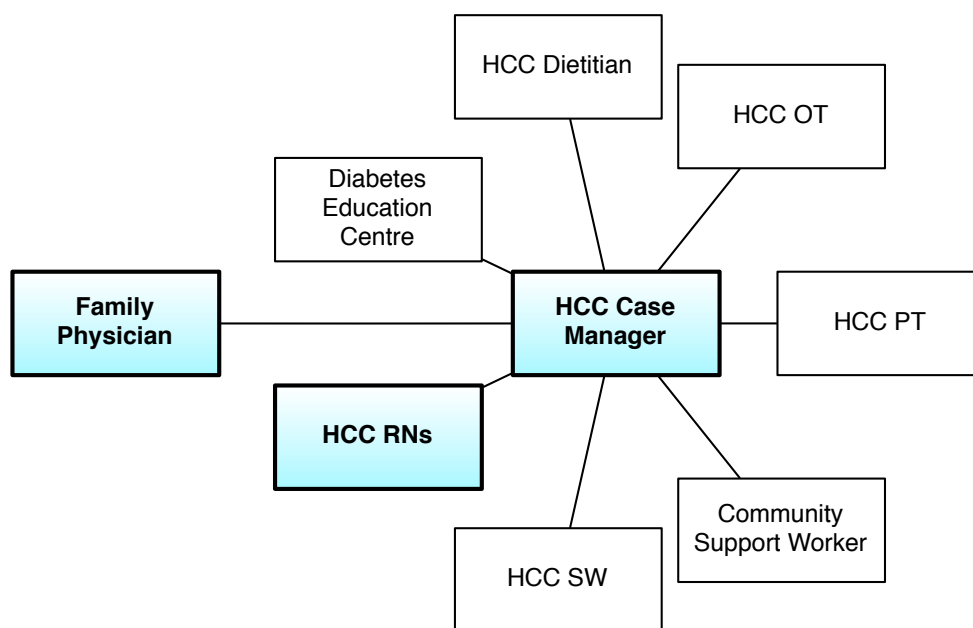


Figure 134: The members of the Circle of Care for Mr. Hart in Duncan while he is an outpatient (i.e. in the community, including visits to the emergency), from the perspective of the Home and Community Care Case Manager.

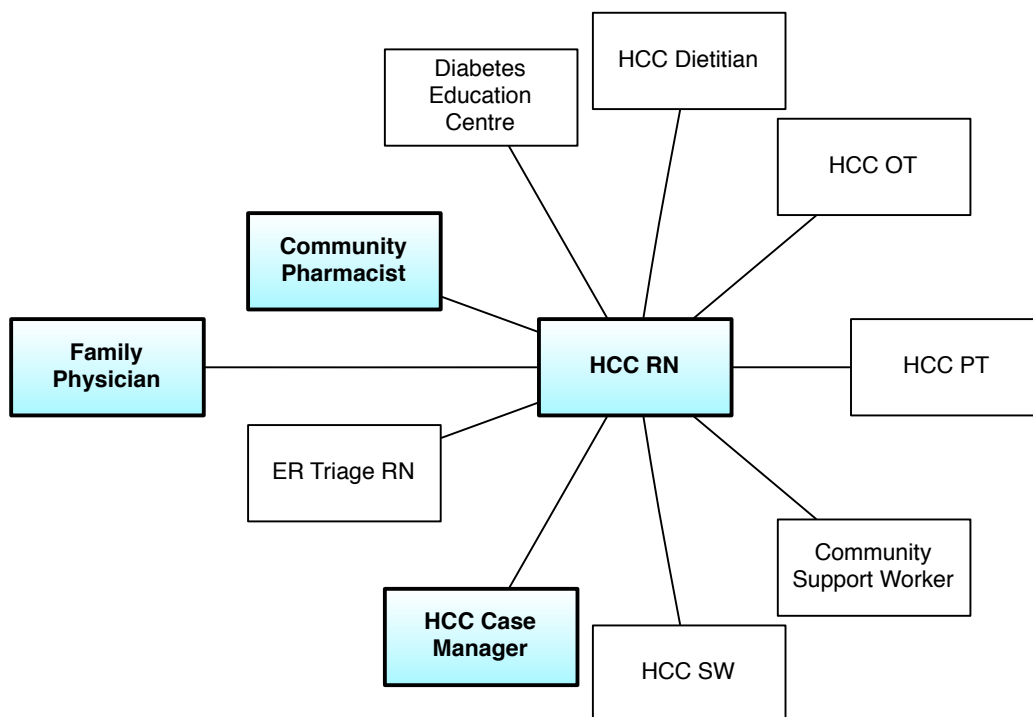


Figure 135: The members of the Circle of Care for Mr. Hart in Duncan while he is an outpatient (i.e. in the community, including visits to the emergency), from the perspective of the Home and Community Care Nurses.

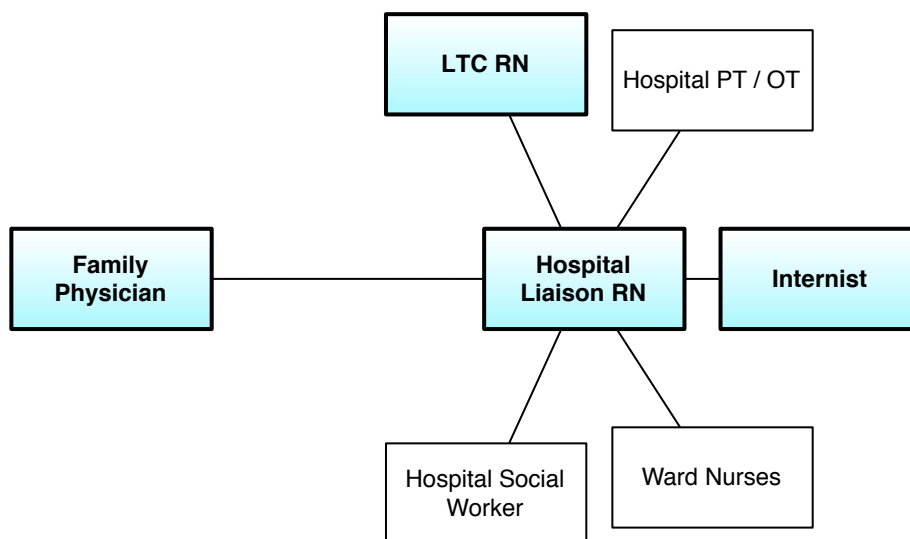


Figure 136: The members of the Circle of Care for Mr. Hart in Duncan while he is an outpatient (i.e. in the community, including visits to the emergency), from the perspective of the Hospital Liaison Nurse.

NOTE: Community Pharmacists and ER Physicians were not recruited in Duncan.

Mr. Hart, Duncan, Late End of Life

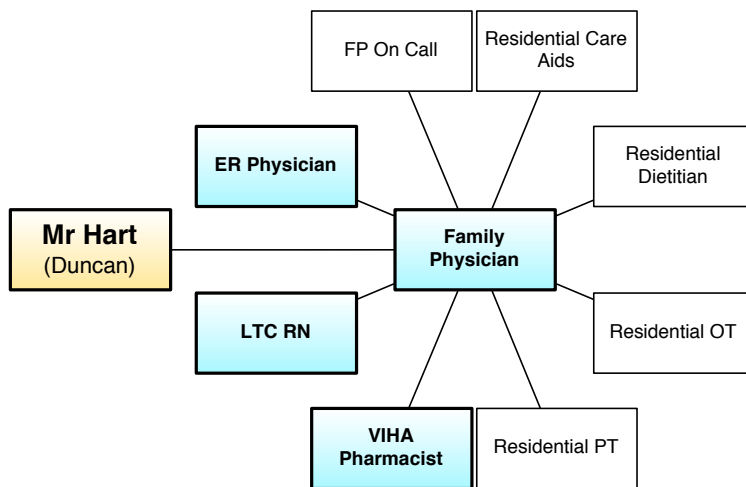


Figure 137: The members of the Circle of Care for Mr. Hart in Duncan while he is a resident in long-term care, including a visit to the emergency, from the perspective of the Family Physician.

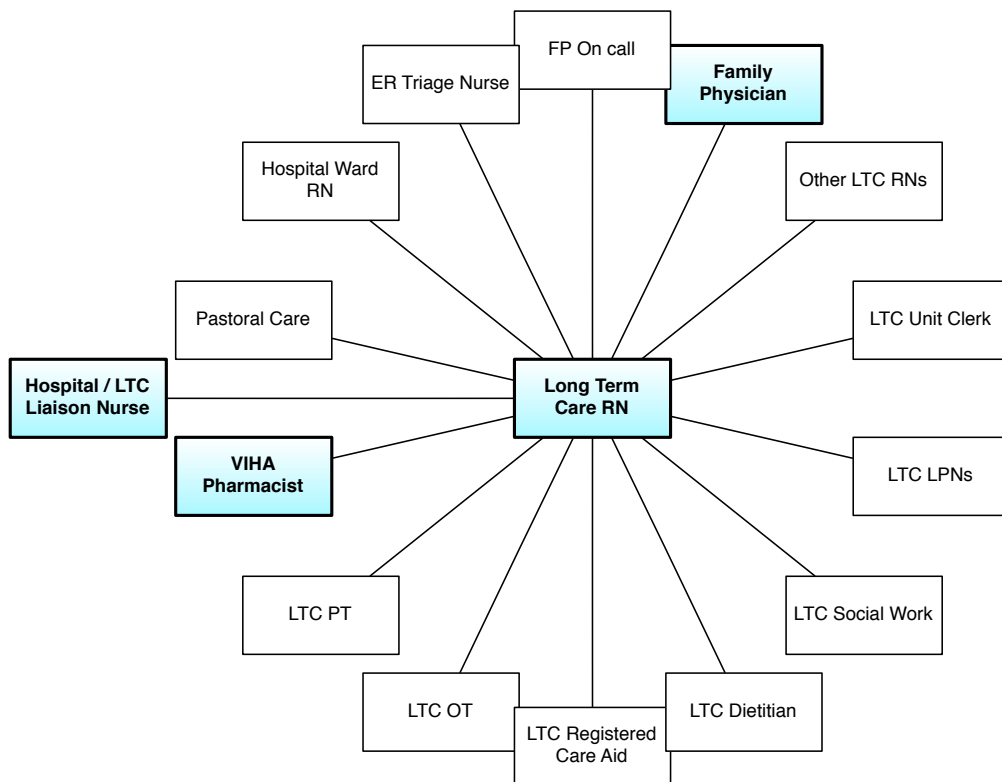


Figure 138: The members of the Circle of Care for Mr. Hart in Duncan while he is a resident in long-term care, including a visit to the emergency, from the perspective of the Long-Term Care Nurse.

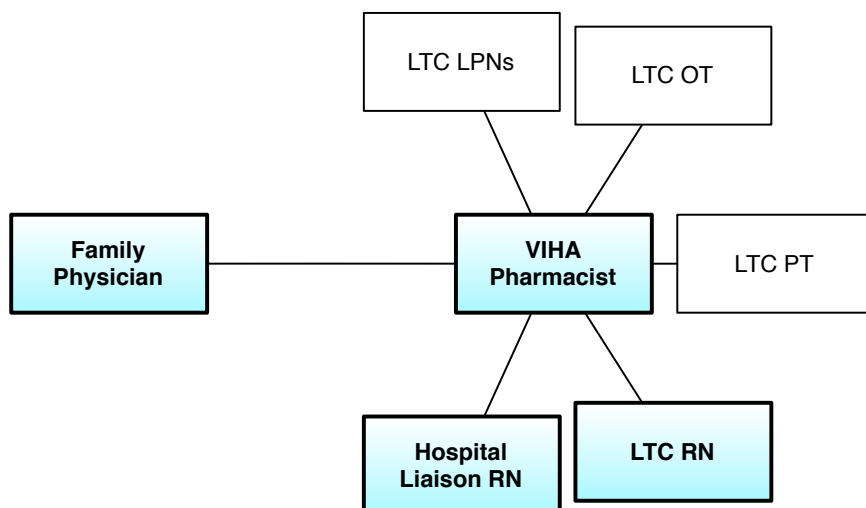


Figure 139: The members of the Circle of Care for Mr. Hart in Duncan while he is a resident in long-term care, including a visit to the emergency, from the perspective of the VIHA Pharmacist.

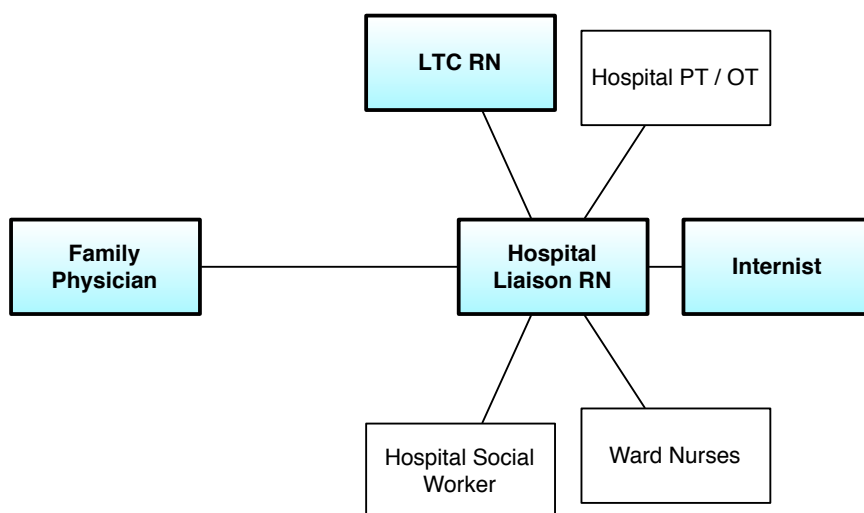


Figure 140: The members of the Circle of Care for Mr. Hart in Duncan while he is a resident in long-term care, including a visit to the emergency, from the perspective of the Hospital Liaison Nurse.

NOTE: The General Internist would likely not be involved at this stage (or they may receive a call for information / advice from the family physician or ER Physician).

NOTE: ER Physicians were not recruited in Duncan to be interviewed.

Appendix L. Communication Views

This appendix contains the remaining Communication Views from the study not shown in the results section. These diagrams were based on the UML 2.0 Communication Diagram notation, as described in the body of the dissertation. The Abstract Genres were used to describe communication. To simplify the diagrams, lines were not drawn from each provider to Mrs. Cann and her family as all providers communicated with the patient. The Abstract Genres were used to describe the communications. Nearly all communication - in both communities – was ad hoc and point-to-point.

Communication Views - Mrs. Cann

The two Mrs. Cann Communication View diagrams (Figure 52 and Figure 53) illustrated communication variation between the two communities. The Victoria Hospice appeared to simplify the communication paths, especially when the ED was not involved in pain control (although that was not always the case in Victoria). Both communities relied heavily on point-to-point communication between providers. This left many of the other providers potentially ill informed of changes in Mrs. Cann's condition.

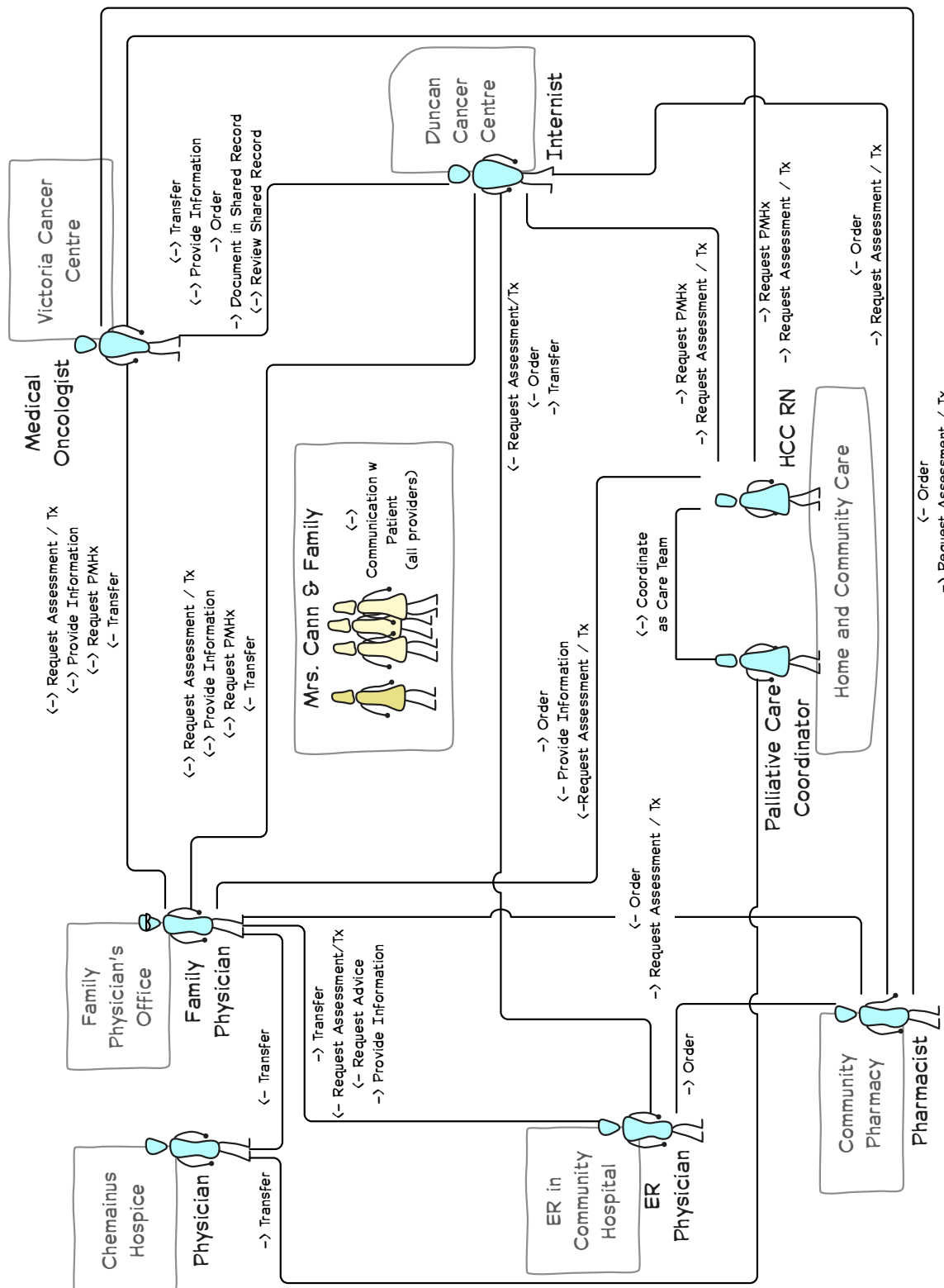


Figure 141: A modified communication diagram showing key communications between Duncan Mrs. Cann's Continuity Providers. Arrows indicate flow of the communication; double-headed arrows indicate flow can happen in both directions.

Communication Views – Mr. Hart

The members of Mr. Hart's Circle of Care were more strongly divided by his location. His active providers varied when he was in the community, in the hospital, or in long-term care. Therefore, three Communication Views were made for Mr. Hart for each community (six total). Comparing the Duncan Communication Views (Figure 143, Figure 144, and Figure 145) to the Victoria Communication Views (Figure 146, Figure 147, and Figure 148), Mr. Hart had more Relationship Continuity through his family physician in Duncan than he did in Victoria. This was due to the fact that family physicians often did not have admitting privileges in Victoria and, depending on the location of Sunset Lodge (the fictional long-term care facility); his family physician might not attend that specific lodge (even if they admitted elsewhere). Therefore, it was much more likely that there would be a transfer of care to another family physician (long term care physician in the diagram).

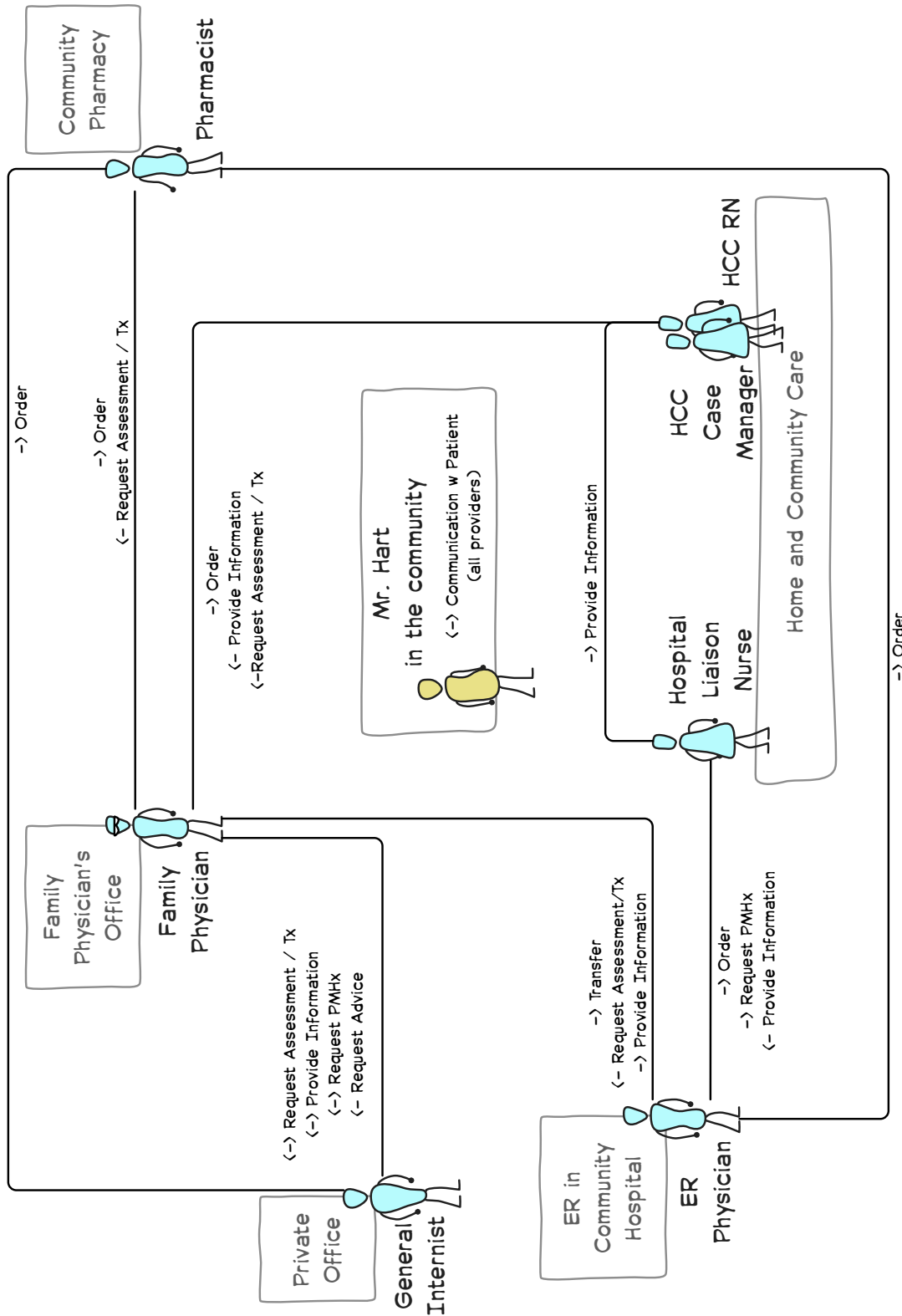


Figure 143: Communication Model for Mr. Hart when he is in the community in Duncan. This includes a visit to the Emergency Department with his first stroke.

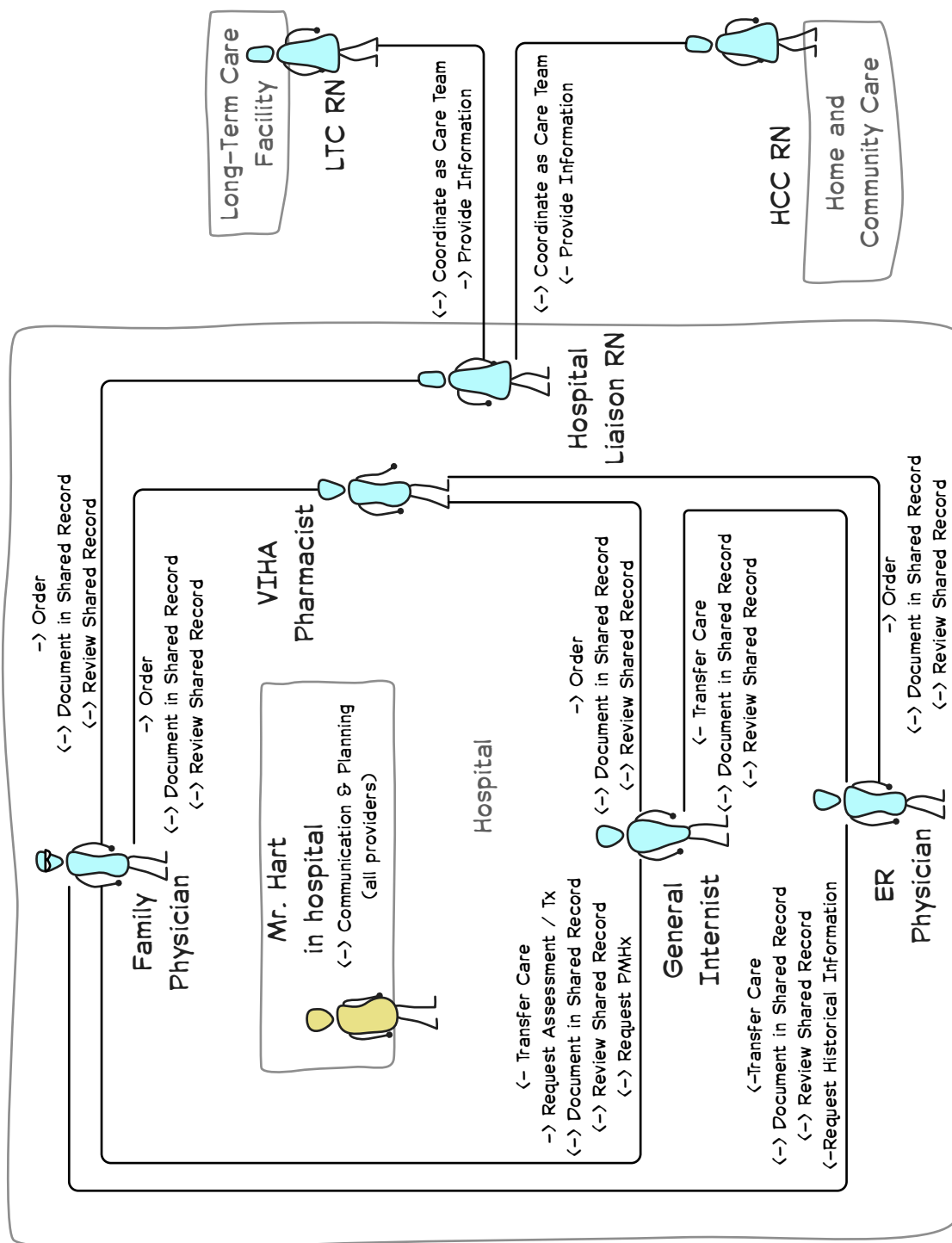


Figure 144: Communication Model for Mr. Hart when he is in the hospital in Duncan. This includes communication when coming into the hospital and being discharged to Long-Term Care.

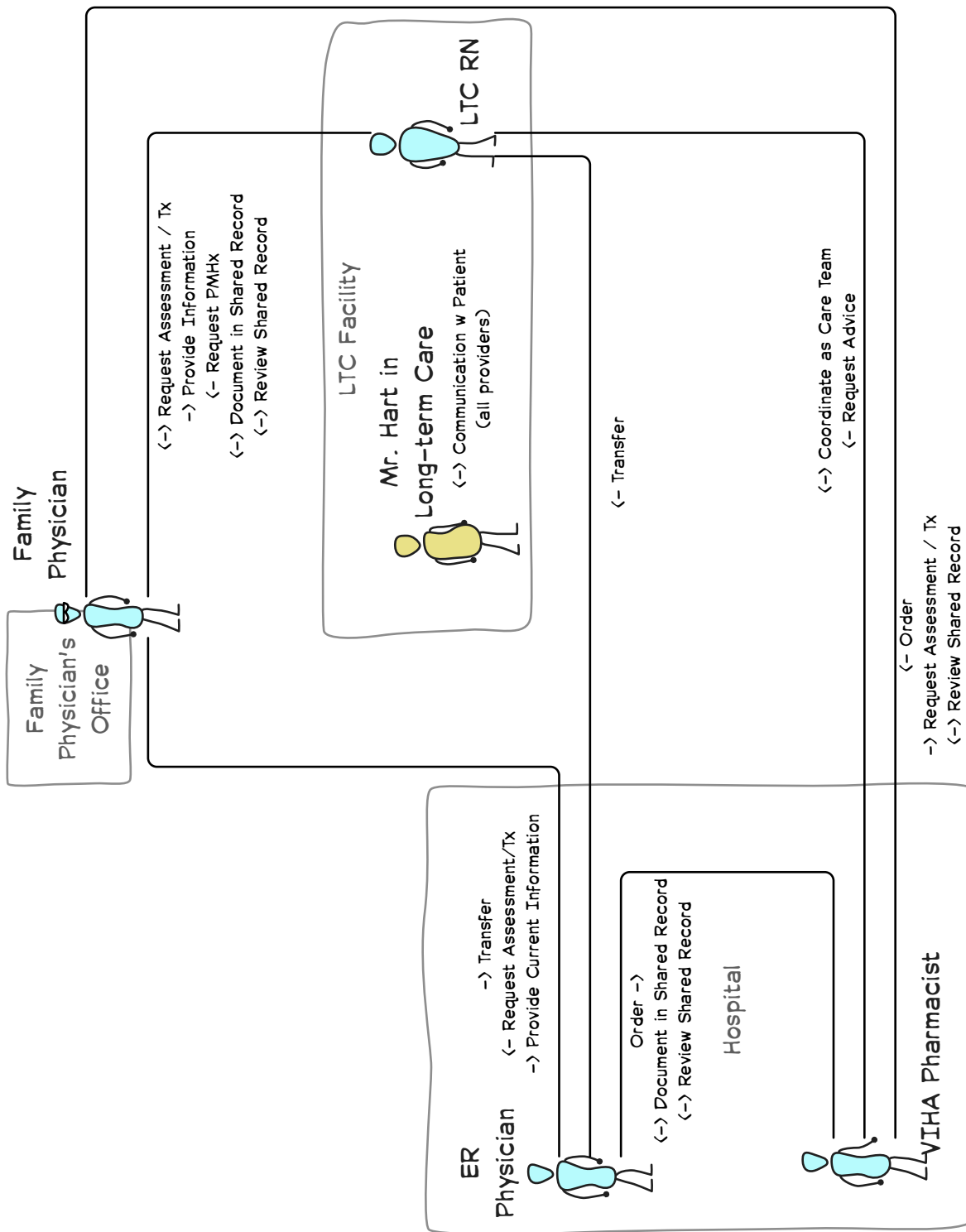


Figure 145: Communication Model for Mr. Hart when he is a resident in a long-term care facility in Duncan. This diagram includes his final transition to the Emergency with a heart attack.

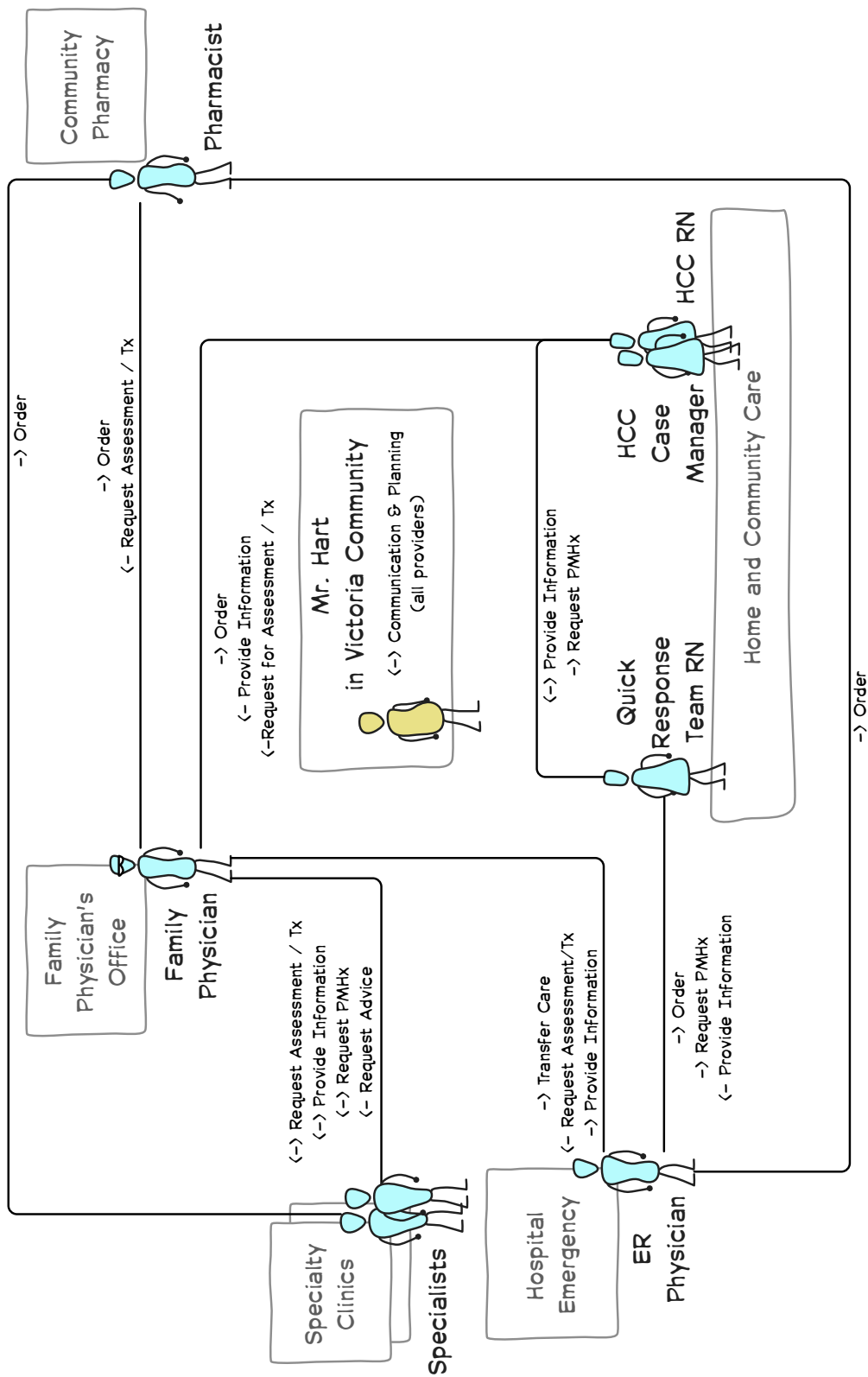


Figure 146: Communication Model for Mr. Hart when he is in the community in Victoria. This includes a visit to the Emergency Department with his first stroke.

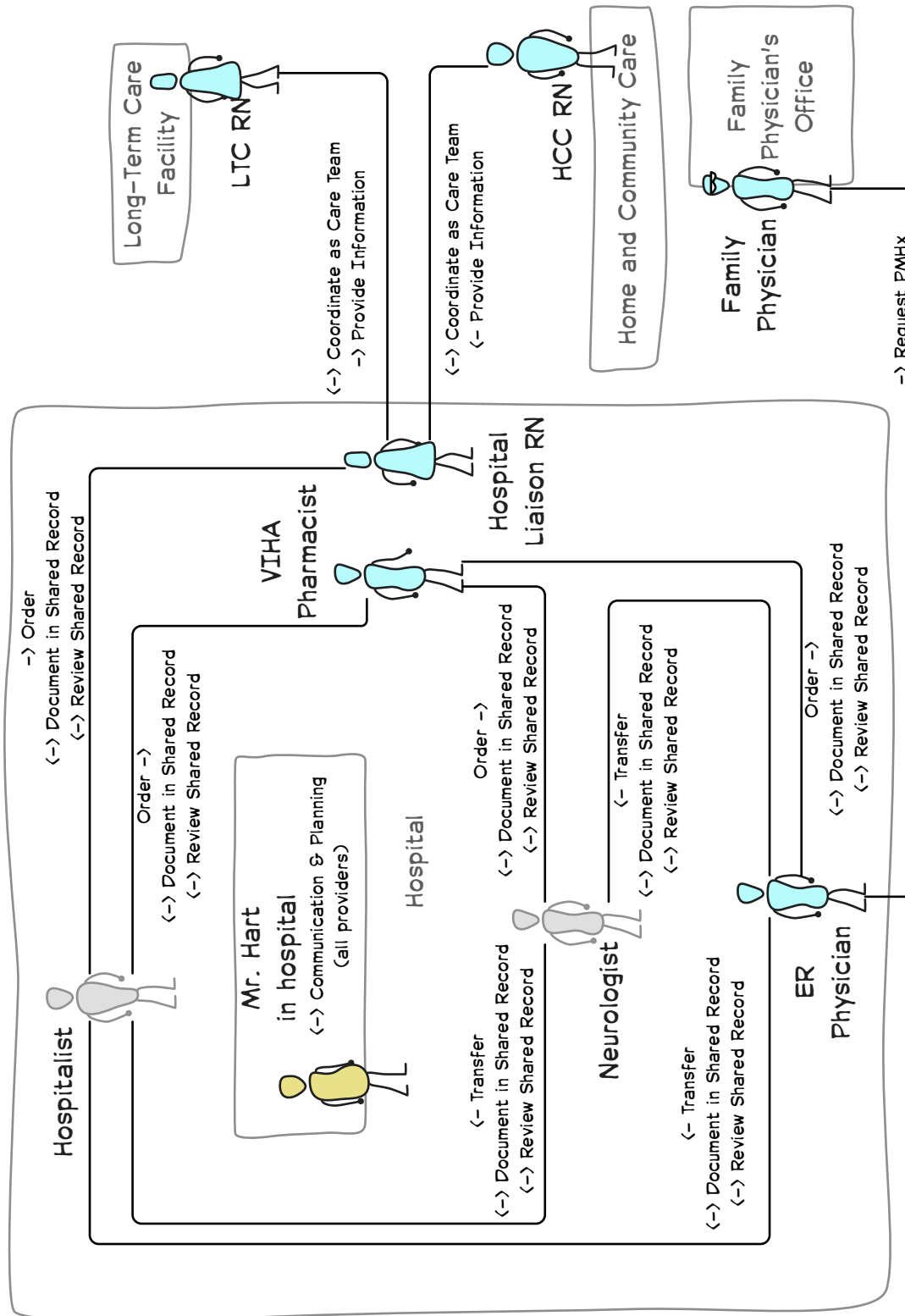


Figure 147: Communication Model for Mr. Hart when he is in the hospital in Victoria. This includes communication when coming into the hospital and being discharged to Long-Term Care.

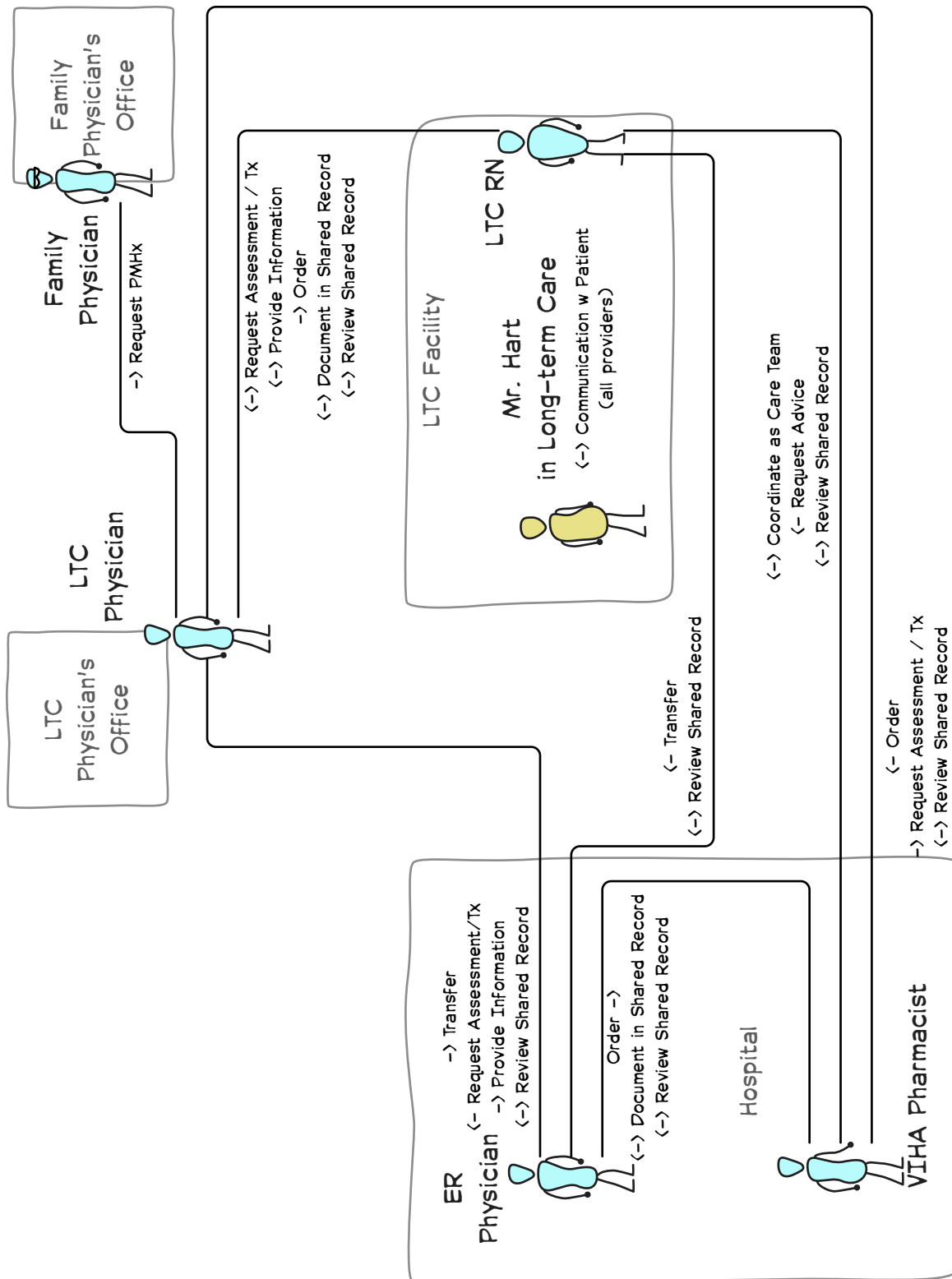


Figure 148: Communication Model for Mr. Hart when he a resident in a long-term care facility in Victoria. This diagram includes his final transition to the Emergency with a heart attack.

Appendix M. Victoria Information / Repository Views

This appendix contains the remaining two Information / Repository Views from this study. Please see the results section for Duncan Information / Repository Views for Mrs. Cann and Mr. Hart.

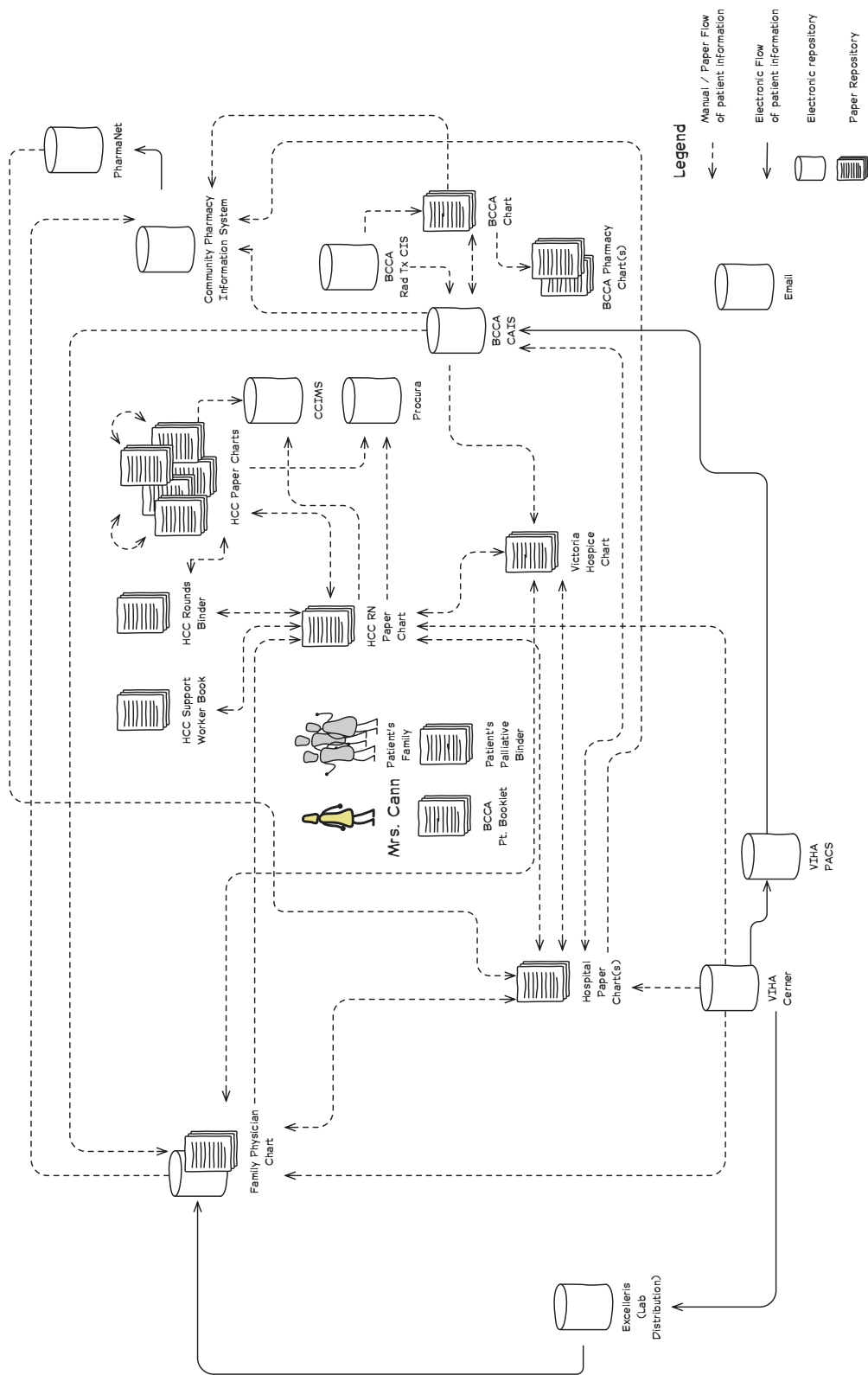


Figure 149: Victoria Mrs. Cann Repository View. Major persistent records are illustrated, with records containing information about Mrs. Cann.

