

Identification & Visualization of
Patient Information Elements
to Support Chronic Illness Care: A Scoping Review and Pilot Study

by

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BScN, University of Northern British Columbia, 2005

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

MASTER OF NURSING AND MASTER OF SCIENCE

in the Schools of Nursing and Health Informatics

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University of Victoria

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Supervisory Committee

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Abstract

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Purpose: The purpose of this thesis is to determine what is known from the literature about the use of Clinical Information Systems (CIS's) to support the information needs of individual health care providers (HCP), in particular the nurse case manager, and the inter-professional team providing chronic illness care in the community setting.

Methods and Analysis: This is a scoping review with a pilot study for feasibility. MEDLINE, CINAHL, and WEB OF SCIENCE were searched up to April 2017. Reference lists and a citation manager of included studies were searched to identify further studies. Relevant full text papers were obtained and screened against inclusion criteria. Data from eligible articles was extracted using a predefined extraction form. Thematic narrative descriptions and descriptive statistics were used to summarize findings. Nurse case managers were recruited from diabetes and chronic kidney disease clinics for an exploratory questionnaire and follow up interview. Descriptive content analysis and nonparametric statistics were used to summarize findings of the pilot study.

Results: 45 articles were identified meeting the inclusion criteria. Three themes emerged (1) patient information elements (2) visualization formats, techniques, and organization and (3) visualization of patient information elements. Diagnostics and observations were the most frequently mentioned information elements. Text was the main representation format. Four participants completed the pilot study initial questionnaire and one completed the follow up interview. There was 100% agreement for 11 elements. Six themes emerged (1) required information can change (2) information is required for different purposes (3) information required for communication is related to nurse case manager concerns (4) required information varies depending on the discipline reviewing it (5) certain types of information need to be grouped together and (6) it is difficult for a HCP to visualize what is necessary in a CIS without first seeing or trying it.

Recommendations: The recommendations are a concept-oriented view customizable to the role of the HCP to display: diagnostics, outcomes and comparisons as graphs and colour coded, observations, medications, problem lists, clinical events, guidelines, the care plan, clinician to clinician communication, patient to clinician communication and clinician to patient communication as text, and clinical events as a timeline.

Conclusion: This review and accompanying pilot study is a starting point for a framework of guidelines with the recommendations of proposed patient information elements and the visualization formats, techniques and organization.

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Acknowledgments

I would like to say a big thank you to my support network. This has not been a linear journey. It has had many stops and starts. I have reached out to many academic, professional and personal people along the way for guidance, motivation, and just general support. I would like to thank Dr. Martha McLeod, Dr. Elizabeth Borycki and Dr. Karen Courtney who took time out of their busy schedules to talk me off the ledge and give me suggestions for moving the work forward when things looked hopeless. Without those conversations I would not have seen a path forward.

I would like to extend my gratitude to my supervisors Dr. Karen Courtney and Dr. James Ronan who looked outside the box to help me find a thesis solution that allowed me to preserve the work I had done along the way. Karen, thank you for reaching out to colleagues and friends and for researching alternative options for me. Of course thank you for your feedback and patience with me as I made the many revisions it took to get here.

To my cohort and my friends, your virtual support through Facebook and email was motivating and sustaining.

To my colleagues at Northern Health, for providing co-op placements, expertise and guidance in the ‘real world of Health Information Technology’ in my hometown that has led to a fulfilling career as a Clinical Informatics Specialist.

Finally to my family, my loving husband and three beautiful children, and my mother without your support and love this would not have been possible. It’s time to move on to new adventures that do not involve evenings and weekends of writing and researching.

Dedication

I dedicate this thesis to my three children: Emmett, Cordelia and Josephine, and my loving husband. I am done, your move my love.

Chapter 1

Identification & Visualization of Patient Information Elements to Support Chronic Illness Care:

A Scoping Review and Pilot Study

Introduction and Background

Chronic illnesses such as diabetes, heart disease, cancer and chronic respiratory conditions are the leading cause of death and highest source of healthcare expenditures worldwide (World Health Organization, 2014). Therefore it is not surprising that chronic illness care is a primary focus of research, clinical guidelines and policy changes worldwide. A primary recommendation for improving the outcomes and quality of care for people with chronic conditions is the use of Health Information Technology (HIT) (Dorr, Bonner, Cohen et al., 2007). An international example of this recommendation is the World Health Organization's (WHO) Global Action Plan (2013) for non-communicable diseases (NCD). The plan describes specific actions each country should take to reduce the mortality rate from NCD's including the use of information and communication technology to assist with health promotion and monitoring. The recommendation sounds simple, however, chronic illness care is complex and multifaceted requiring special information-based processes and an interprofessional team-based approach for effective care. This complexity makes the design, implementation and use of HIT to improve chronic illness care challenging. The design and implementation must take into consideration all of the components of health care delivery necessary for providing effective and quality care to this population.

Chronic care model. The WHO has adopted an evidence-based framework for improving care delivery design for adults with chronic illnesses called the Chronic Care Model (CCM) (Epping-Jordan, Pruitt, Bengoa, & Wagner 2004). The CCM has been widely evaluated

and implemented, with evidence that initiatives using this model improve patient outcomes and reduce healthcare costs (Coleman et al., 2009; Kadu & Stolee, 2015; Kretin, Shortell & Keeler, 2004). Ed Wagner, one of the creators of the CCM was also the director of the national program office called improving chronic illness care which ran from 1998 to 2011 and provided resources and support for implementing the CCM (MacColl Centre for Health Innovation, 2017, <http://www.maccollcenter.org/about-us/our-team>). In 2011 the MacColl Centre for Health Innovation was founded by Ed Wagner and took over developing and disseminating the resources and support for the CCM, as well as other innovations focused on the delivery of health care (MacColl Centre for Health Innovation, 2017, <http://www.maccollcenter.org/about-us>). The CCM (Figure 1) has six interacting components: 1. community resources; 2. the health system; 3. delivery system design; 4. self-management support; 5. decision support; and 6. clinical information systems (CIS) (Epping-Jordan, Pruitt, Bengoa, & Wagner, 2004).

The community resource component involves partnerships with community resources that support and meet patient needs (Barr et al., 2003). This component involves supporting patient participation and engagement and emphasizes that this should be done through community programs (Gee et al., 2015). Additionally, this component includes the enforcement of policies to improve chronic illness care (Epping-Jordan et al., 2004). It is not clear what kinds of community policy are necessary for supporting chronic illness care. There is no mention of policy in the components of the health system or the delivery system design. This is surprising because these components seem the more likely areas where policy would be enforced. For example, enforcing policies that support culturally informed health care practices would be expected within the delivery system design component. Furthermore, enforcing policy that

supports quality improvement and error handling would be expected within the health system component.

The health system component should enable providers and organizations to foster productive interactions with patients (Gee et al., 2015). In CCM, the health system and organization of health care must involve quality improvement. This involves quality improvement practices such as incentives, error handling, care coordination, and system change, as presented by the MacColl Center for Healthcare Innovation (2017) within the health system page. Epping-Jordan et al. (2004) advocate that support for the health system component must begin with senior leadership. As a result, senior leadership in the health system and organizations should be focused on program planning mechanisms that include measurable goals to improve health outcomes (Barr et al., 2003). Although there is still a gap in knowledge because the model does not specify what these goals are or define productive interactions.

The third component, delivery system design, includes a significant focus on teamwork, including expanding the scope of practice of each member to support chronic care (Barr et al., 2003). Activities within this component should include role definition and task distribution among team members to enhance efficiency. Task distribution and role definition involves providing clarity on who is providing the care coordination for complex case management (MacColl Center for Healthcare Innovation, 2017). The clarity allows the team to know who is responsible for the planned interactions with specific tasks and regular follow-ups (Barr et al., 2003). A nurse case manager usually provides this follow-up. All of the care provided by the team and the nurse case manager must align with the patients' cultural values to enable effective delivery system design for successful chronic illness care (Epping-Jordan et al., 2004). This

component seems to be very vague and likely interacts with every other model component although this is not evident from the description or the diagram.

The self-management support component emphasizes the patient's role in primary health care activities including goal setting, assessment, action planning, problem solving and follow up management (MacColl Center for Healthcare Innovation, 2017). Resources should be organized and provided to the patient to support this self-management (Barr et al., 2003). The patient's role in managing their own care is considered central and the activities of chronic illness care should support an informed and activated patient (Gee et al., 2015). The model is not prescriptive on how this support should occur and to what extent.

Another component is decision support. This component emphasizes embedding guidelines, protocols and standards of care into everyday practice using proven educational methods (Gee et al., 2015). Furthermore, these guidelines should be widely disseminated (Barr et al., 2003). This component also recommends integrating specialist and primary care expertise allowing the healthcare team to receive specialist support when necessary (MacColl Center for Healthcare Innovation, 2017). It is not evident from the model if decision support should be provided within the clinical information system (CIS) although the CIS component does suggest decision support as a necessary functionality. There is also no mention of the patient receiving any of the decision support in the original CCM. For example there is no recommendation to provide evidence and guidelines to the patient directly to the patient depending on outcomes and trajectories.

Finally, the last component is the use of clinical information systems to provide relevant client data to health care providers. This includes decision support features such as reminders, recalls and alerts (Barr et al., 2003). It also involves surveillance functionality to support

proactive panel management and follow up. The MacColl Center for Health Innovation (2017) discusses how this type of practice and health system performance monitoring data should be extractable from the CIS on the website under the description of the model elements. Another suggested CIS functionality is patient-centered individual care planning. There is an additional focus on information sharing among providers (Gee et al, 2015). Given that there are no standards to which a CIS should be built to support chronic illness care this component could use more precise descriptions of functionality and requirements to guide provider and organization decisions in selecting and implementing a CIS for the purpose of supporting chronic illness care. This component emphasizes patient centered care planning, but only emphasizes using the CIS to provide relevant health care data to the providers rather than both patients and providers. Furthermore, the surveillance and panel management suggest that the provider is driving the care and the schedule not the patient which seems counterintuitive to the self-management component. An improved focus on patient centered care and an improved model for self-management are reflected in the eHealth enhanced CCM (eCCM), which will be discussed next.

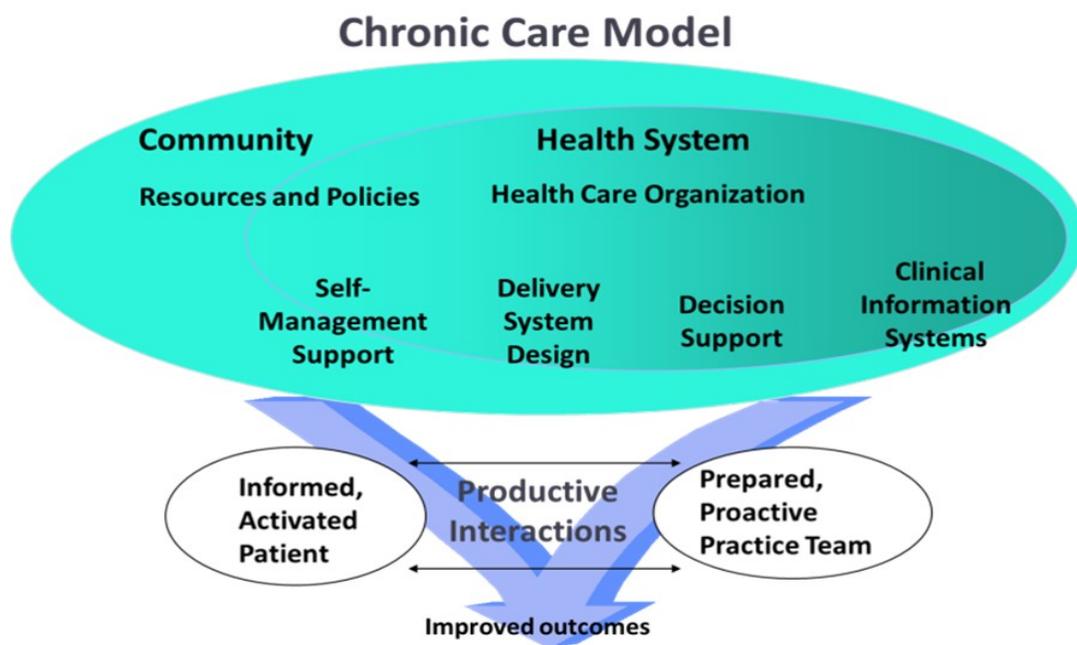


Figure 1. The Chronic Care Model. Developed by the MacColl Institute © ACP-JSIM Journals and Books. Reprinted with permission from CopyRight Clearance Centre on behalf of the American College of Physicians

eHealth enhanced chronic care model (eCCM). HIT can be utilized within each of the CCM components. A recent study in the literature enhanced the CCM by supplementing the recommendations of the components of the CCM with current eHealth tools (Gee et al., 2015). The study used a literature review to apply the components of eHealth to the CCM generating an updated model called the eCCM.

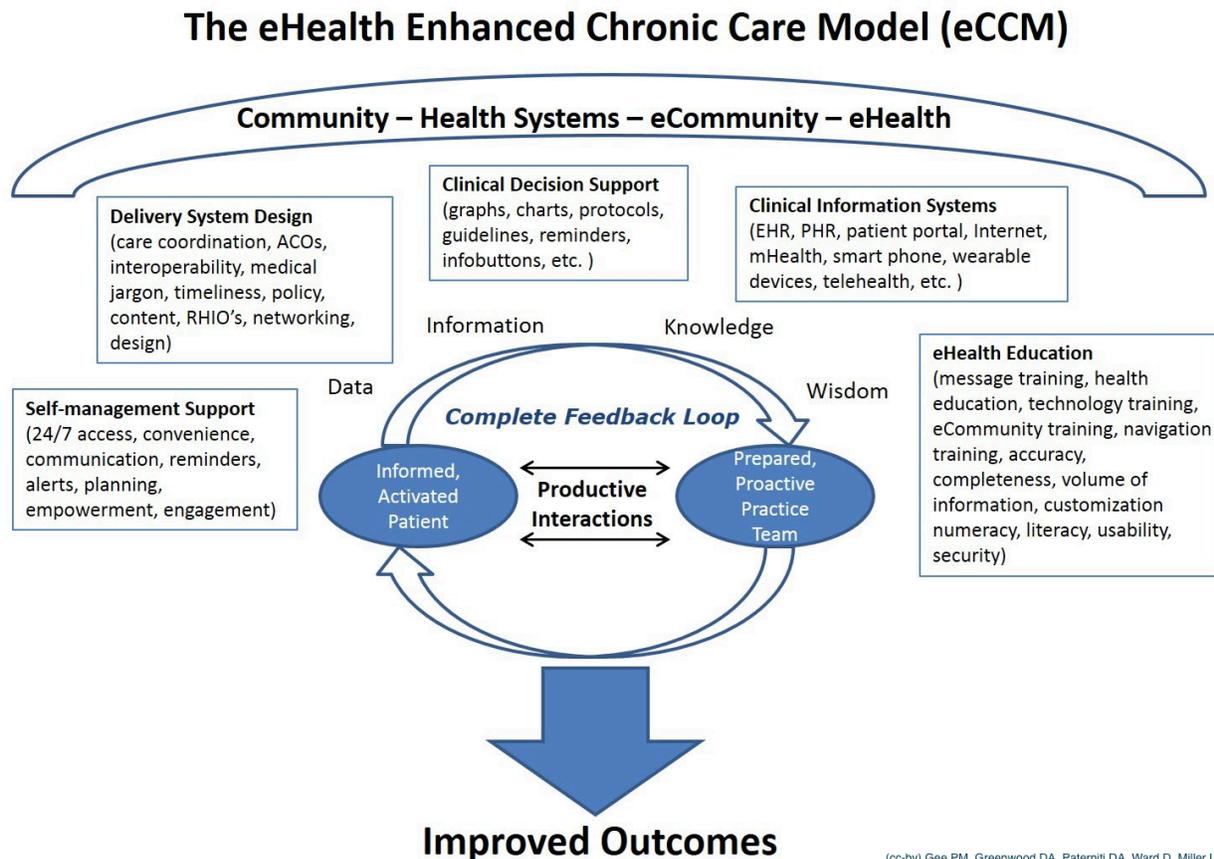


Figure 2. The eHealth Enhanced Chronic Care Model. Created by Gee, et al., (2015). Adapted from the Chronic Care Model. (See Figure 1). Image is not copyrighted and is reprinted per the permission of the authors.

Gee et al. (2015) highlight that HIT can be used to supplement the CCM beyond the original recommendations. The main additions to the original model from this study include HIT's utility for: improving patient and provider interactions with a complete feedback loop; expanding community support to social networks and online communities; and improving self-management tools. There is also more detail in the other components. For example, the authors noted the increased use of Electronic Health Records (EHR), Personal Health Records (PHR) and patient portals as an opportunity to improve guideline adherence, information sharing and interaction with these systems. However, no guidance is provided in the study as to how these improvements are to be achieved or what data is relevant or how it should be viewed. It is important to explore the data relevance and presentation to provide guidance to vendors and clinical informatics specialists about design features and functionality, as well as support implementation. The CCM and the additions of the eCCM will be used as the theoretical underpinnings of this study. See Table 1 for a comparison of the CCM and eCCM. The CCM and eCCM provide a model for enabling effective chronic illness care. The CIS is one component that is integral to the models. However, significant challenges exist with the design of these CIS's in the context of chronic illness care.

Table 1

Comparison of the CCM and eCCM. (Gee et al., 2015)

Components of the CCM	Additions of the eCCM
Health System and Organization	Implement eHealth technology such as PHR's mhealth, telehealth and internet use to improve patient engagement, satisfaction and self-management support
Self-Management Support	The use of tools such as the PHR, mhealth and telehealth applications to improve patient activation
Decision Support	Incorporating the patient specific needs including access to data, protocols and care standards, info buttons for clinical guidelines and

	reminders for patients
Clinical Information Systems	Tethered patient portals and PHRs, mhealth and mobile devices into the use of the CIS
Delivery System Design	Improve access to and control over personal health data using policy change and interoperability
Community Resources and Policies	Inclusion of eCommunity and health related social networks
	eHealth Education as an added component that allows health systems to offer eHealth tools and solutions to improve health literacy
	Complete feedback loop to improve the productive interactions between providers and patients supported by the internet and tools such as the PHR to support secure patient-provider messaging

Challenges in the use of HIT to support chronic illness care. There are three main challenges to improving the effectiveness of CIS design to support chronic illness care: 1. information overload, including information identification and presentation; 2. multiple chronic conditions; and 3. interprofessional team based care, including the role of the nurse case manager. The discussion that follows explains these challenges.

Information overload. Frameworks, policies, and research worldwide have mandated improving the effectiveness of HIT in support of chronic illness care. However, the literature suggests that HIT often fails to support the special information-based processes necessary for improving chronic illness care (Dorr et al., 2007; Samal et al., 2011). Both the eCCM and the original CCM emphasize CIS's as a type of HIT critical for summarizing patient information in order to support the tracking and planning of efficient and effective care (ICIC, 2006-2015; Gee et al., 2015). While it is true that CIS's are effective in collating, categorizing and transferring

this information, the increase in the amount of information and tendency to present it all on one screen can also cause negative consequences, including information overload (Clarke et al., 2013; DeClercq, 2008; Samal et al., 2011). The presence of extraneous data makes it difficult for health care providers to identify relevant information.

Information identification. Effective chronic illness care requires health care providers to be able to identify all relevant information at the point of care in a way that supports care coordination, planning and clinical decision making (MacColl Center for Health Innovation, 2017). However, chronic illness care presents a challenge in identifying what information to present and how to present it. This challenge is in part due to the large amount of information generated for a patient with one or more chronic illnesses. The longitudinal nature of the interactions by the chronic illness population with the health care system also includes multiple settings and multiple providers and spans years. The information needed today could have been captured several years ago in another health care professional's notes. Chronic illness care requires relevant health condition-oriented information to be filtered and easily identified (Samal et al. 2011). Planning and coordinating chronic illness care requires the information to be aggregated and synthesized in a way that identifies relevant information and supports decision making that is based on several factors the clients health status and history, preferences, clinical guidelines, the scope of practice of the health care provider and much more. Very few HIT tools provide this type of synthesis and aggregation (Laxmisan et al., 2012). The lack of this type of information aggregation and synthesizing in a CIS can represent a significant barrier in a health care provider's ability to plan and coordinate care. In addition to the problem of identifying relevant information to reduce information overload, there is another challenge of presenting the information in a way that supports thought processes and workflow.

Information presentation. It is known that the current organization and presentation of information by date, time and source in most CIS fails to identify trends, relevancy or care needs (Samal et al., 2011). There may likely be a different folder for every source. Sources include health care providers involved; diagnostic areas; and health care settings. There may also be a different file in every folder for each event or interaction that person has with a source. Health care providers (HCP) must consult various folders and files to attempt to obtain a complete picture of the relevant patient information. This is time consuming, ineffective and error prone. The challenge of ineffectively organizing and presenting relevant patient information in the clinical record also leads to duplicate data capture, which is frustrating for the patient and clinician. As a result, current CIS are ineffective tools to support care coordination and decision making in chronic illness care. Improving the design of CIS to support care coordination, planning of care, and guideline based decision making, requires narrowing the knowledge gap of what information is necessary, at what points in time, and how to present it.

Multiple chronic conditions. Determining the information requirements of health care providers performing chronic illness care presents a challenge for several reasons. First, there are a variety of illnesses classified as a chronic disease (World Health Organization, 2013). Although it is known that health care professionals need condition-oriented information, this represents a significant challenge because each disease has different symptoms, guidelines of care and evaluations. Some of the symptoms and treatments may interact, and there may even be conflicting evaluations and guidelines. This makes it difficult to apply one CIS to multiple diseases.

To compound the problem of multiple chronic illnesses, there is a significant portion of the population that suffers from comorbidity, or in other words has more than one chronic illness

(Public Health Agency of Canada, 2012; WHO, 2013; Andolsek et al., 2013) An estimated 24% of seniors have three or more chronic conditions and account for 40% of health care use (Canadian Institutes of Health Research, 2013). The comorbid subset of the chronic illness population represents an inherent challenge in in patient management due to interactions between the diseases and their treatments (Andolsek et al., 2013). It is difficult to identify what information is relevant for these patients based solely on logic of disease process or clinical guidelines. Although integrated care models such as the CCM and eCCM that transcend a specific disease are emerging as a worldwide solution to improving chronic illness care (Epping-Jordan et al., 2004). HIT research for chronic disease and clinical guidelines are not following suit. The research and guidelines often only focus on one disease, primarily diabetes, likely due to the challenges described above. This limits the generalizability of the research findings for use with another disease or multiple diseases to support integrated health care, or the comorbid population. In addition to the need for CIS design to be effective for multiple chronic diseases, there is a final challenge to the design, which requires incorporating the information needs of the interprofessional team led by the nurse case manager.

Interprofessional team based care. The third and final challenge in identifying information requirements for HCP in chronic illness care relates to the need for an interprofessional team-based approach to care. Team-based care is vital in improving chronic illness outcomes (Milani & Lavi, 2015 & Porter, Pabo & Lee, 2013). It is important to understand and address the challenge that each member of the team has different information needs depending on their role and responsibilities. In order to promote optimal health outcomes, true collaborative interprofessional practices must be promoted (Ash & Miller, 2012 The care team must communicate and work together effectively. Within the care team there is usually a

coordinator or a leader role (Ash & Miller, 2012). This role can be fulfilled by any discipline but it is usually fulfilled by a nurse care manager (Van Dongen et al., 2016). This is likely due to the broad scope of practice and skills of nurses. Nurses are the most likely case managers in the community setting and the most frequent point of contact in both primary and secondary care (Forbes & While, 2009). These case management nurses must act as the knowledge workers collecting, encoding, interpreting and synthesizing patient information on a daily basis in order to coordinate and provide care. Therefore it is important to understand the role of the nurse case manager.

Nurse case managers are considered a clinical nurse specialist (CNS) under the advanced practice nurse (APN) role. The primary focus of the CNS is direct patient care and they are prepared with national certifications beyond basic nursing preparation (Ash & Miller, 2013,). In Canada, there are several certifications related to chronic illness care provided through the Canadian Nursing Association (CNA), including chronic illness care such as cardiovascular, oncology, nephrology and psychiatric and mental health (Canadian Nurses Association, 2017). There are also certifications that are recognized as providing the additional skills necessary to perform the functions of a CNS such as the clinical diabetic educator certification that is recognized by CNA. The common services of a CNS role that enable the components of the CCM and eCCM include: planning and coordinating care; advocating for individualized health and social services; leading quality improvement initiatives; developing and implementing evidence based guidelines; influencing policy; and advocating for health promotion and education. In summary, the interprofessional team and the CNS in the nurse case management role are integral to effective chronic illness care. This means that the development of CIS to

support chronic illness care must pay particular attention to the information needs of the team and the nurse case manager.

Studies of information needs for CIS primarily focus on physicians and to a lesser extent nurses. While there are some similar information needs between nurses and physicians, there are also important differences in perspectives and usage of information (Clark et al., 2013; De Clercq 2008; Munkvold & Ellingsen 2007). For example, nurses assess and treat the patient's response to the chronic illness and treatments, as well as educating and advocating for the patient (Clark et al., 2013). In contrast, the physician has the primary goals of identifying, validating and ascertaining the status and treatments of the patient's illness when summarizing the information for a patient (Reichert et al., 2010). The differences in the goals of patient care for nurses and physicians suggest that different information is necessary to support each while managing the same patient. Even though nurses are often the case managers within interprofessional teams (Wagner, 2000; Wagner et al., 2001), it has been shown that current EHR-based patient summaries do not support the cognitive work of nursing (Staggers et al., 2011). The lack of support for nursing cognition may be a result of the majority of the research on clinical patient summary screens focusing on physicians as the primary users.

Other disciplines such as pharmacy and nutrition are also lacking representation and would likely benefit from research into their information needs. The information needs of these members of the interprofessional care team require representation in the CIS. However, the focus of disciplines, such as pharmacy or nutrition, is much narrower due to their clinical role. A nurse case manager has a broader focus and more responsibilities and therefore greater information needs in order to coordinate and optimize a patient's chronic illness care. The focus on physicians as primary users leaves a gap in the knowledge of what other disciplines require in a

CIS. Due to the case manager's key role, further research on nursing information needs is the priority. Furthermore, CIS are rarely developed with role specific user interfaces therefore one design is supposed to satisfy each role's needs. The determination of which information is relevant for the entire interprofessional team, in particular for the nurse case manager, as well as how to present the information within a shared CIS is complex and represents a key challenge that must be addressed.

Objective

The purpose of this study is to determine what is known from the literature about the use of CIS to support the information needs of individual health care providers and the interprofessional team providing chronic illness care in the community setting. The results of this research may serve to identify recommendations for the design of CIS to support collaborative team-based chronic illness care, as well as gaps in the research that need to be addressed. The operational definition of a CIS for the purpose of this study is an electronic system used by health care providers to capture, store, maintain and retrieve health related patient information.

Research questions. There is extensive research highlighting the use of CIS as beneficial in supporting effective chronic illness. However, there is sparse literature providing guidance on which clinical information is relevant and how to present this information in shared CIS. This knowledge is necessary to support the selection, design, and customization of the CIS used to support effective chronic illness care. Based on a preliminary review of the published literature and a pilot study the research questions are:

1. What recommendations have been made in the literature about how to identify and present relevant information using clinical information systems to support HCP performance in community based chronic illness care?

2. What methodologies are used to identify HCP information needs and information presentation in clinical information systems for chronic illness care?

The next chapter will discuss the research design employed to answer the research questions.

Chapter 2

Scoping Review Methodology

Scoping Review Study Design

Scoping reviews are useful for summarizing and analyzing the nature, features and volume of literature in a given field of interest, as well as synthesizing and disseminating the evidence (Arksey & O'Malley, 2005). This type of review is most useful when the literature is heterogeneous, complex, not suitable for a systematic review, and not extensively reviewed (Khalil, Peters, Godfrey et al., 2016). The research questions this study intends to address have all four of the characteristics listed above that make a scoping review particularly useful.

An initial appraisal of the literature was conducted in order to determine if the literature had been reviewed before on the topic of HCP information needs within CISs for chronic illness care. This appraisal identified two systematic reviews and one scoping review that were related to the topic. The systematic reviews identified what components or features HIT should include to support chronic illness care: clinical decision support, self-management support, outcome assessment, order entry for care teams and disease specific, patient centric, population based reporting and feedback (Dorr, Bonner, Cohen et al., 2007 & Young, Chaney, Shoai et al., 2007). The scoping review incorporated the CCM and technology (Gammon, Berntsen, Koricho et al., 2015). This latter review identified technology supports for patient-provider interactions, provider-provider interactions and decision support. The main findings emphasized that the technology being used is not unique to chronic illness care and is not modern or innovative. Although these reviews provide necessary knowledge on the use of HIT to support chronic illness care there is still a gap in the research. In other words even though it is important for those selecting, designing and implementing clinical information systems to know what features and

tools are helpful for chronic illness care, it is not all of the necessary information. None of the identified reviews addressed information needs or information presentation for the purposes of supporting HCPs in chronic illness care. This scoping review is therefore adding to the knowledge base by addressing this gap in the research and not repeating what has already been done. The prior reviews identified a wide variety of study designs, clinical settings, and participants. The variety in the literature, as well as the complexity and vague nature of the research questions make a scoping review an applicable research methodology for this study. The design of the scoping review is discussed below.

The phases of the scoping review were based on the five steps identified by Levac et al. (2010) with a change to step three because this was a graduate student thesis and a team approach was not feasible. The optional sixth step of a consultation exercise was not conducted.

1. Identify the research question
2. Identify relevant literature using a four-step literature search
3. Selection of relevant studies using an iterative approach
4. Chart the data using numerical summarization and thematic analysis
5. Collate, summarize and report the results and identify implications

An additional step was included in this study to apply the findings of this scoping review to the results of a pilot study of the information needs of nurse case managers in a chronic disease outpatient setting.

Scoping Review Methods

One researcher completed all the research steps. Conflicts and revisions were discussed with two academic supervisors.

Search strategy. To identify pertinent studies, a three-step search approach was conducted of the English language literature in the databases Medline, Web of Science, CINAHL. The first search was conducted in January 2017 and the last search April 2017. Searches were limited to the English language due to the cost and time associated with translation services. This restriction may have excluded relevant studies. Editorials, commentaries and opinion articles were excluded. Published reviews were included but not specifically searched through review databases such as the Cochrane Collaboration. No restrictions were placed on date range or study design and both prospective and retrospective studies were included. To reduce publication bias, conference proceedings were also included. Other forms of grey literature were excluded based on time and resources. A research librarian was consulted to confirm the selection of databases, search terms and search strategy for article identification. The search strategy was composed of five snowballing steps.

1. Limited search in the databases with a screening for keywords
2. Search in all databases with all identified keywords and indexing terms (See Appendix A)
3. Screening of titles and abstracts in search results to identify relevant studies
4. Retrieval and analysis of relevant studies from reference lists of included studies
5. Use of a citation manager to find studies that cited the main studies

The Medical Subject Heading (MeSH) terms used were Problem Oriented Records, Medical Records, Problem Oriented, Data Display, Electronic Health Record, Patient Record Systems. In

the preliminary search of the literature, it was identified that when the terms for chronic disease and information needs were included no relevant articles were identified and known articles meeting the criteria were excluded. Therefore, chronic disease and information needs were purposefully left out of the search terms. Both of these criteria were screened for in the full text. For detailed information on the combinations that were used in each database please refer to Appendix A. The keyword general search terms are below.

1. "Concept Oriented View" OR "Problem Oriented Medical Record" OR "Data Display" OR "Visualization" OR "Clinical Summarization"
2. EHR OR EMR OR "electronic health record*" OR "Clinical Information System" OR "electronic medical record*" OR "computerized patient record*"

Article screening and selection. The search results were exported to Mendeley © (Version 1.17.6). (2016) for identification, as well as duplication and review management. Titles and abstracts were screened to determine which articles would receive a full document review. The selection criteria for inclusion was purposefully broad and included any article that mentioned the display, visualization, organization of clinical information or information needs of HCP and clinical information systems. The exclusion criteria included:

- no mention clinical information systems
- an acute care setting
- patient information needs
- aggregated clinical data not used for direct clinical care
- no mention of chronic illness

The search terms were also related to other concepts such as diagnostic imaging, bioinformatics, and precision medicine. These articles were excluded by title and abstract review. These were

classified as excluded due to no mention of a clinical information system. Any articles that met the inclusion criteria were retrieved for full text review.

Charting the data. Data was extracted from the citations for the included citations using a predefined data extraction form (see Appendix B). Ten random articles were selected to identify alternative classification categories. These were then added to the data extraction form.

In order to collate and summarize the data, both numerical and thematic analyses were completed on the selected articles. Thematic analysis was used to identify themes in each of the categories of the extracted data. The numeric data were then exported into Minitab ® Statistical Software (Version 17). (2016). Descriptive statistics were calculated to summarize the data. Frequencies and percentages were used to describe nominal data. The themes were applied to the pilot study results of the interview and survey responses. The results of these methods are presented in the next chapter.

Chapter 3

Scoping Review Results

This section presents the results from the scoping review. The research questions were:

1. What recommendations have been made in the literature about how to identify and present relevant information using clinical information systems to support HCP performance in community based chronic illness care?
2. What methodologies are used to identify HCP information needs and information presentation in clinical information systems for chronic illness care?

The search yielded 604 potential articles. After reviewing the titles, abstracts, and full texts as well as correcting for duplicates, 36 articles fulfilling the inclusion criteria were identified. Many articles were rejected because the setting was acute care, focused on aggregated clinical data, did not mention chronic illness or did not mention a CIS. A further nine articles were identified from hand searching reference lists and forward citations of the original 36 articles. Figure 3 describes the selection process from the databases and the exclusion reasons. In total 45 articles were included in the scoping review.

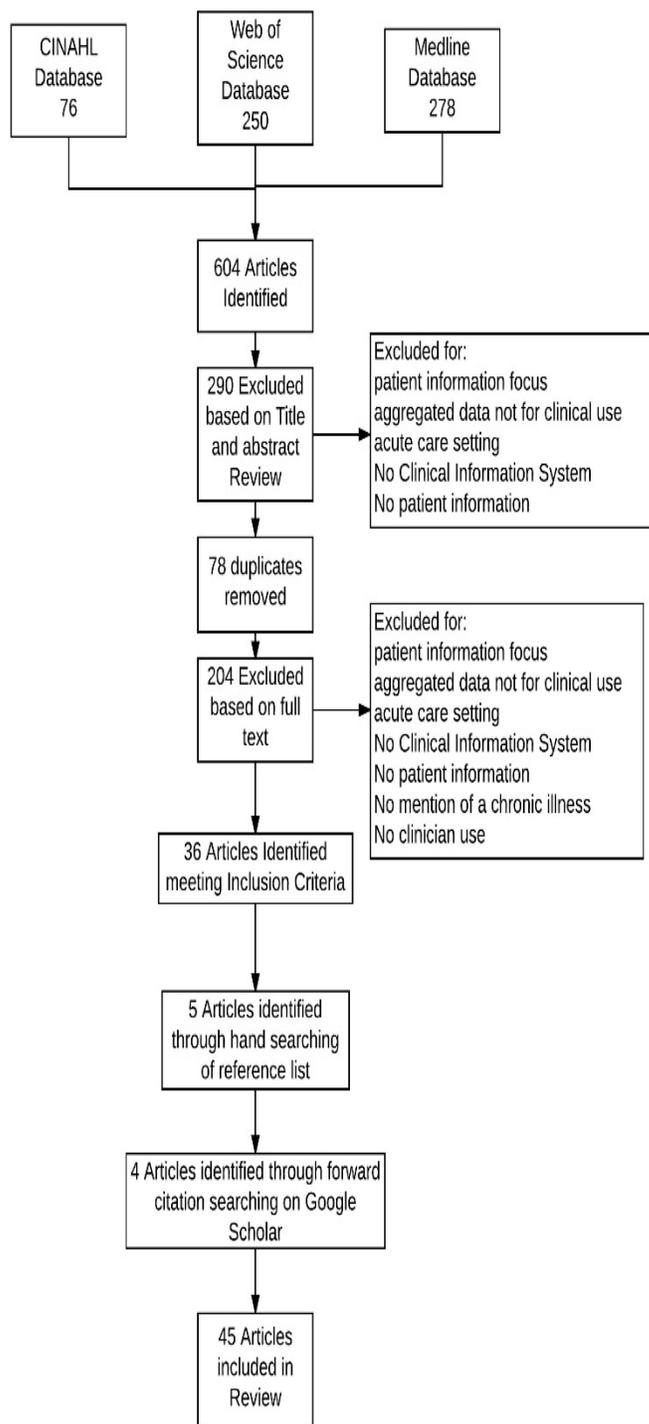


Figure 3. Article Selection and Flow Diagram

The dates of the articles ranged from 1983 to 2016 with eight of the articles from 2015. The majority of the articles were from the last 12 years ($n=37$). Of the 45 articles, 25 did not provide the country of origins. Of those that stated a country, the USA was the highest ($n=13$) the other countries are France, Germany, Greece, Uganda, and Japan. See Figure 4 for details.

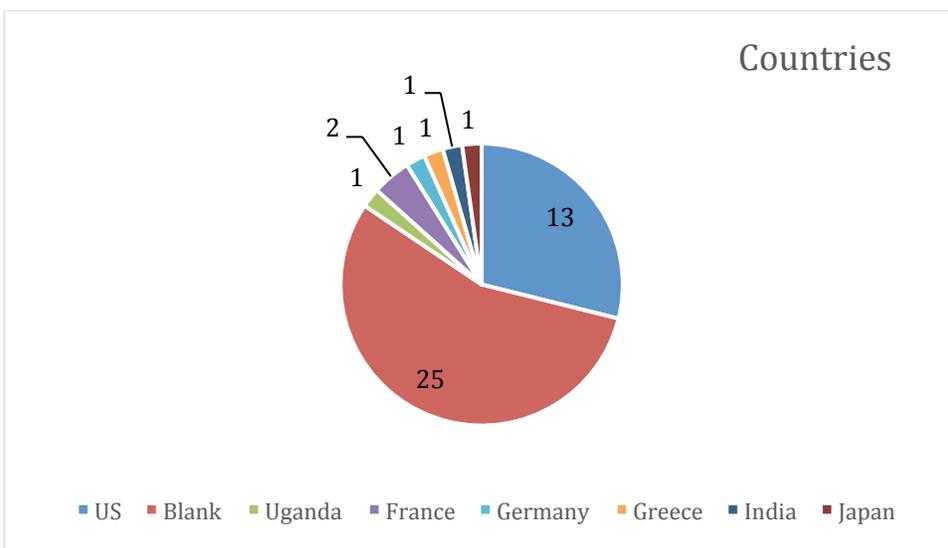


Figure 4. Countries in Articles

The implementation context, which included the number of systems and number of centres involved in the system implementation, varied within the articles. The majority were single CIS implemented in a single centre, ($n=18$) with a few implementing one system in two centres ($n=4$). The other scenarios that were described were one system in four centres and three systems in one centre. Many of the articles described CIS without describing the number of centres involved in the implementation (one system, 12 articles; two systems, 1 article; three systems, 3 articles). Of the remaining articles some were discussion papers on the topic of information needs or visualization that did not describe a system ($n=8$). See Figure 5 for details.

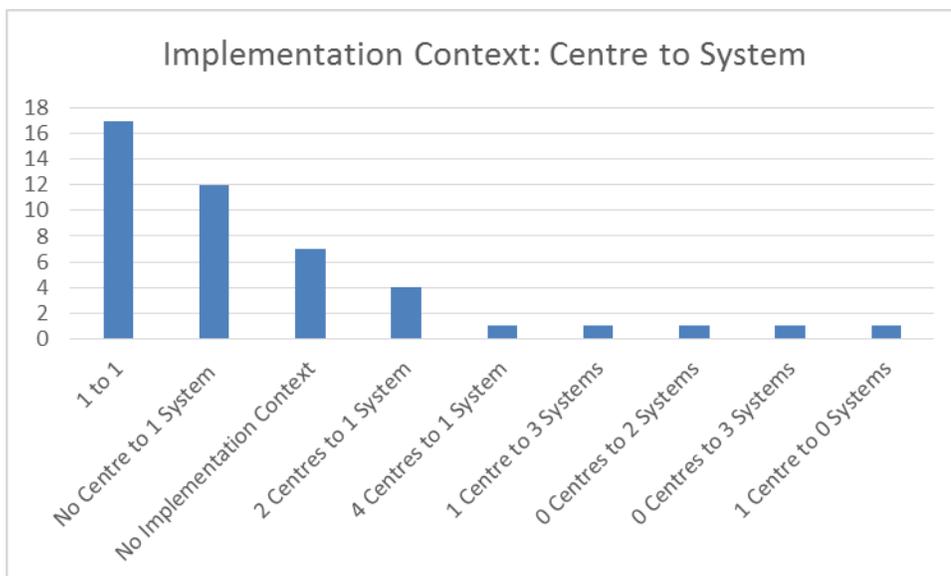


Figure 5. Implementation Context

There were several categories of article types. Types of articles included technical discussion papers, conference proceedings, research studies, technical articles with research, and a proposal paper. Technical papers included those that described the technical aspects of system design, and/or architecture and/or implementation. Discussion papers were articles that interpreted and described a topic but did not have a research or technical focus. Conference proceedings were articles that were published as conference proceedings and may not have provided the full details of the research and results. Broad ranges of methodological designs were employed within the articles that belong in the research categories. Most of the articles were concerned with one disease ($n = 39$), with diabetes ($n = 17$) and cancer ($n = 16$) as the primary disorders. See Figure 6 for a visual description.

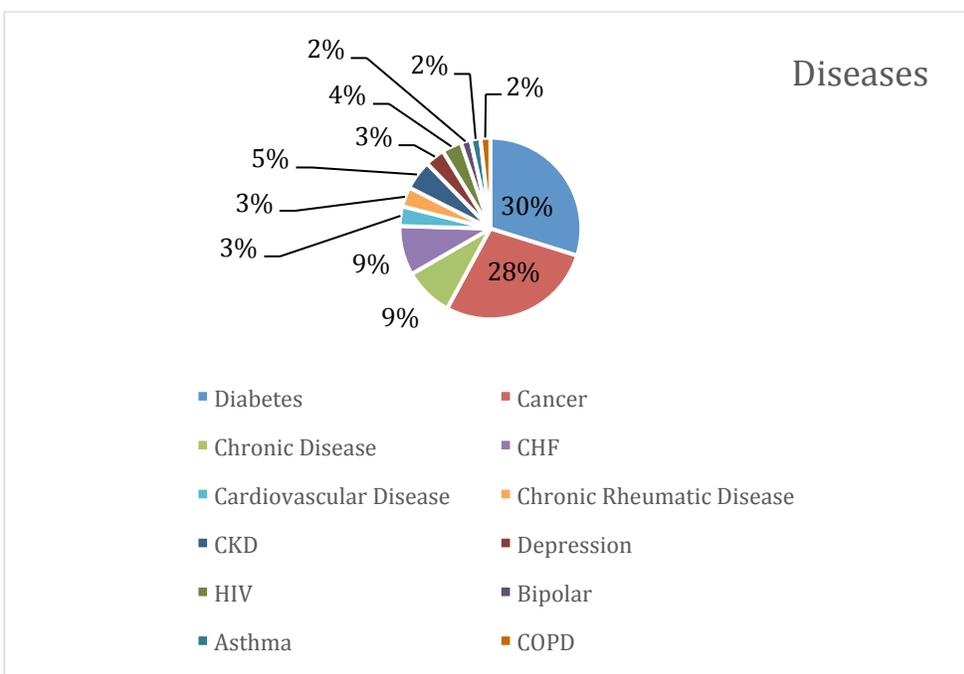


Figure 6. Diseases for Articles

The clinical settings and users varied. Two summary tables are provided in Tables 2 and 3. Table 2 contains the general characteristics of each article including the type of article, methodological design, clinical setting, chronic illness and user group. Table 3 provides information on the main focus of the article, the type of HIT and the stated purpose of the article. Foci of the articles were primarily descriptive rather than evaluative including: describing the system, describing how the system can support health care, describing features, and challenges, describing implementation, determining information needs, developing the system, developing a data model, developing a conceptual model, and evaluating the system, and finally reviewing research. The main focus of the articles was to describe the system and how it can support health care. Table 2 is organized by type of article. Table 3 is organized by the focus of the article.

Table 2*General Characteristics of Articles*

Reference	Type of Article	Research Design	Clinical Setting	Chronic Illness	User Group
Miller et al., 2003	Technical & Research	Observation & Survey	Department of Gynecology and Obstetrics	Diabetes	Physician, Midwife, Resident
Newman et al., 2015	Technical & Research	Comparative Evaluation & Survey	Rheumatology clinics	Rheumatoid Arthritis, Lupus and Systemic Ankylosing Spondylitis	Rheumatologists, Nurses
Senathirajah, Kaufman & Bakken	Technical & Research	Observation & Comparative	Hospital Outpatient Department	Diabetes and Renal Failure	Physicians
Warner et al., 2016	Technical & Research	Survey	None	Cancer	Physician
Were et al., 2010	Technical & Research	Survey and Comparative	HIV/AIDS clinic	HIV	Physicians
Bashyam et al., 2009	Technical	N/A	Neurooncology clinic	Cancer	Physicians
Blum & Lenhard, 1983	Technical	N/A	Oncology Centre	Cancer	Clinicians
Bui et al., 1998	Technical	N/A	Hospital Outpatient thoracic oncology	Cancer	Radiologists & Oncologists
Bui, Aberle & Kangerloo, 2007	Technical	N/A	None	Cancer	Physicians
Canfield et al., 1993	Technical	N/A	Ambulatory Care	Chronic Disease	Physicians

Hartzler et al., 2015	Technical	Usability & Survey & Action & Comparative	Urology and radiation oncology clinics	Prostate Cancer	Physicians, nurses, nursing assistants, patients
Hirsch et al., 2014	Technical	Usability & Comparative	Hospital Outpatient Department	Hypertension, Congestive Heart Failure (CHF) and Diabetes	Fellows, Residents Physicians
Hsu et al., 2012	Technical	N/A	Neurooncology clinic	Cancer	Physicians
Lowe et al., 1995	Technical	N/A	Ambulatory Care	Cancer	Physicians
Malaviya & Gogia, 2010	Technical	N/A	Private Clinic and Outpatient clinic in Spinal Injuries and Specialty Hospital	Rheumatoid Arthritis, Lupus and Systemic Ankylosing Spondylitis	Rheumatologists
Mane et al., 2012	Technical	N/A	None	Major Depressive Disorder	Clinicians
Massari et al., 2008	Technical	N/A	Hospital Outpatient Department	Congestive Heart Failure	Physician
Muller et al. 2016	Technical	N/A	Cancer Center	Cancer	Physician, Pathologist, Patient, Lab Tech
Schuler et al., 2006	Technical	N/A	None	Diabetes	None
Skevofilakas, 2007	Technical	N/A	None	Cancer	Physicians
Varma et al., 2009	Technical	N/A	None	Cancer	Oncologists and MOAs

Yamakazi et al., 1995	Technical	N/A	None	Diabetes	Physician
Teves, 2015	Research & Student Thesis	Experimental Single Cohort No Control	None	Diabetes	Clinicians,
Clarke et al.	Research	Observation & Comparative	None	Diabetes	Physicians
Denekamp, 2007	Research	Literature Review	None	COPD and Asthma	Physicians
Eminaga et al., 2010	Research	Qualitative & Comparative	Diagnostics	Prostate Cancer	Radiologists and Urologists
Feblowitz et al., 2011	Research	Literature Review	None	Diabetes	None
Foraker et al	Research	Experimental - Longitudinal, 2 cohorts with control	Outpatient Clinic	Cardiovascular Disease	Physicians
Foraker et al., 2015	Research	Experimental Single Cohort No Control	Outpatient Clinics	Cardiovascular Disease	Physicians, NPs, Pharmacists, Dietitians and Residents
Koopman et al., 2015	Research	Usability	Ambulatory Care	Diabetes, Hypertension, Hyperlipidemia and Depression	Physicians
Koopman et al., 2011	Research	Usability, Qualitative GT, and Experimental Single Cohort No control	None	Diabetes	Physicians
Ozery-Flato et al., 2015	Research	Observation & Case Study	Outpatient Clinic	Diabetes	Physician
Pivovarov & Elhadad, 2015	Research	Literature Review		Chronic Disease	

Vallez	Research	Comparative	Diagnostics	Cancer	Radiologists
Gong, Chandra & Wang, 2014	Research	Usability and Survey	Long Term Care	CHF, Chronic Disease	Geriatricians and Nurses
Thiessard et al., 2012	Project Proposal	N/A	None	Diabetes, Cancer	Clinicians
Miller, 1993	Discussion	N/A	None	Diabetes	
Powsner & Tufte, 1997	Discussion	N/A	None	Bipolar and Diabetes	Clinicians
Samal et al., 2015	Discussion	N/A	None	Chronic Kidney disease, cancer, CHF	Primary Care Provider
Smith & Newell, 2002	Discussion	N/A	Ambulatory Care	Diabetes	Physician
Toyoda & Niki, 2013	Discussion	N/A	None	Chronic Disease	Clinicians
Devarankonda et al., 2014	Conference Proceedings	N/A	None	Diabetes	None
Gotz & Wongsuphasawat, 2012)	Conference proceedings	N/A	None	CHF	Physicians
Gotz et al., 2011	Conference Proceedings	N/A	None	Cancer, Diabetes, CKD, HIV	Physicians
Matsumura, 2001	Conference Proceedings	N/A	Ambulatory Care and Hospital	Chronic Disease	Physicians

Table 3*Article Focus, Purpose and Type of HIT*

Reference	CIS Type	Focus	Purpose
Pivarov & Elhadad, 2015	EHR	Describe features, and challenges	In this review, we sample summarization applications to highlight different features including seminal work, different evaluation strategies, and various input/output data. We also examine current work and future directions for six challenges of EHR summarization: information redundancy, temporality, missing data, salience detection, rules and heuristics and deployment of summarization tools
Varma et al., 2009	EMR	Describe features, and challenges	Describes the system, architecture, and challenges
Gotz & Wongsuphasawat, 2012	CDI	Describe how system can support	To describe how text analytics can be applied to EMR data and this can be combined with interactive visualization tools to provide interactive intervention analysis
Mane et al., 2012	CDSS and EHR	Describe how system can support	The aim of this paper is to discuss the use of Visual Analytics for Comparative Effectiveness Research-based CDS using patient data from an EHR system.
Vallez, 2013	CDSS and EHR	Describe how system can support	comparison of CAD systems and integration with the EHR
Samal et al., 2015	CDSS, Display of EHR data, CPSS	Describe how system can support	To use clinical scenarios to explain how temporal data vies can aid providers in creating a mental timeline and recognizing trends. Define two types of temporal views visualization and diagnosis oriented summaries
Blum & Lenhard, 1983	CIS	Describe how system can support	To evaluate the display of clinical information to support medical decision making

Massari et al., 2008	EHR	Describe how system can support	The aim of this study is to describe and evaluate individual medical records sorted by typology of elements and by medical specialties based on terminological tools using CISMef super concepts
Miller, 1993	EHR	Describe how system can support	To describe the benefits and challenges of an EMR and the need for a national record
Thiessard et al., 2012	EHR	Describe how system can support	To improve an EHR so that it allows a clinician to effectively and efficiently locate relevant information in real time from structured and unstructured data and visualize them in synthetic and intuitive presentation models, using semantic indexing, information retrieval and data visualization
Devarakonda et al., 2014	EMR and CPSS	Describe how system can support	To help a physician care for a patient by providing a summarization of the electronic record
Canfield et al., 1993	EMR for specialty	Describe how system can support	To link a subsystem CIS to the Hospital Information System to support clinical management in a geriatric ambulatory care to support a research protocol
Toyoda & Niki, 2013	Viewers	Describe how system can support	To describe examples of visualization systems for chronic disease care
Smith & Newell, 2002	EMR	Describe implementation	To describe one physician's experience with choosing an EMR and support others in the process of choosing and implementing
Were et al., 2010	EMR and CPSS	Describe implementation	To provide patient specific EMR based clinical summaries for providers taking care of HIV positive adult patients in resource limited Uganda
Miller et al., 2003	EMR for specialty	Describe implementation	To describe the experience with implementing a problem list within a prenatal record system.
Gotz et al., 2011	CDI	Describe system	To describe an overview of the approach to clinical decision intelligence, describe the DICON visualization for cluster analysis of patients and provide feedback from two physicians on use of

			the system
Ozery-Flato et al., 2015	CDI	Describe system	To present a system that can evaluate a patient's clinical response in relation to a cohort of patients with similar conditions and a similar medication. The system allows visualization of the analysis and results of cohorts and individual patients
Skevofilakas et al., 2007	CDSS and EHR	Describe system	Our research's focus is twofold; our primary goal is to ensure consistency in clinical practice by importing clinical guidelines in an IT-driven decision support system (DSS). Furthermore, we seek to improve visualization of disease-specific clinical data, providing for its faster and more efficient use.
Hsu et al., 2012	Dashboard from EHR elements	Describe system	In this paper, we describe our efforts towards creating a context-based EHR, which employs biomedical ontologies and (graphical) disease models as sources of domain knowledge to identify relevant parts of the record to display.
Yamakazi et al., 1995	EMR	Describe system	To describe the model of two data dictionaries, the concept of a template function and a linkage of other systems in the HIS to this EMR
Bui et al., 1998	GUI and Multimedia Database	Describe system	To describe the oncology imaging timeline interface with a focus on automatic abstraction, capture and organization of pertinent patient information for the purpose of visualization and summarization
Bui, Aberle & Kangerloo, 2007	EHR	Describe system	describes the TimeLine display and its functionality, which serves to motivate the TimeLine architecture with details of the data mapping and clustering techniques, and the visualization framework that generates the display. Lastly, we conclude with a discussion of several open issues in TimeLine, and future directions for this project.
Clarke et al., 2014	EHR	Determine information needs	To determine the information needs of primary care physicians in an electronic visit note with particular emphasis on the importance of content within patient visit notes

Koopman et al., 2015	EHR	Determine information needs	How physicians reviewed notes, what the most important information was, and perceptions of how displays could be improved
Gong, Chandra & Wang, 2014	Health Data Display and EMR	Determine information needs and develop system	Identify key measurements among EMR, telemedicine and sensor data for health conditions and to develop an integrated health data display to monitor seniors health status. To prevent risk and identify deterioration at an early stage.
Powsner & Tufte, 1997	CPSS	Develop conceptual model	To propose a method of summarizing clinical data to serve patient care
Febowitz et al., 2011	hypothetical electronic summarizer	Develop conceptual model	To develop a conceptual model for describing and understanding clinical summarization in both computer-independent and computer-supported clinical tasks.
Eminaga et al., 2010	CIS	Develop data model	To develop a data model based on schematic diagrams for documentation and analysis of prostatectomy specimen reports
Matsumura, 2001	EMR Viewer	Develop data model	Develop a medical event information model flowsheet for the EMR to review a patient's history
Muller et al., 2016	CDSS and EHR	Develop system	To make the big amount of data understandable we developed a data driven GUI and visualization framework parameterized by the user role and experience and the outcome of the patient counseling and attributes of related medical events
Bashyam et al., 2009	Dashboard from EHR elements	Develop system	We developed our system with the goal of facilitating the clinician's ability to better understand a patient's clinical history and make optimal decisions about treatment.
Schuler et al., 2006	EHR	Develop system	To automatically generate a graphical user interface from openEHR archetypes expressed in ADL syntax

Lowe et al., 1995	EHR and image viewer	Develop system	To expand the image viewer and develop a portable solution for sharing, retrieving, storing images within the EHR
Malaviya & Gogia, 2010	EMR	Develop system	To develop an EMR specific to rheumatology that improves data entry for clinical evaluation in real time and saves time by displaying outcome measures in figures, and generates informative, well laid out reports as well as easily searchable and retrievable database
Newman et al., 2015	EMR for specialty	Develop system	To improve the quality of care for patients with chronic rheumatic diseases, developed a system for data capture, aggregation and display and documentation
Hartzler et al., 2015	Dashboar rd	Develop system and assess feasibility	Our objective was to design and assess the feasibility of integrating PRO dashboards into prostate cancer care.
Warner et al., 2016	CDSS and EHR	Evaluate System	To compare a patients diagnosis specific genomic mutation with a database of population level comparable data to be clinically used in real time
Foraker et al., 2015	CDSS and EHR	Evaluate System and Describe Implementation	To describe the implementation, provider satisfaction and patient outcomes one year after implementation of an EHR based CDS system for cardiovascular health
Foraker et al., 2016	CDSS and EHR	Evaluate system effect on patient outcomes	To determine the effect the CDS within the EHR on the CVH of women over 65
Teves, 2015	Dashboar rd Display	Evaluate system effect on performance	To evaluate dashboards showing blood glucose data of a hypothetical diabetic patient over time (daily and monthly) for both performance and preference of information visualization types
Koopman et al., 2011	Dashboar rd from EMR elements	Evaluate system effect on performance	To quantify time saved and reduce the mouse clicks

Senathirajah, Kaufman & Bakken, 2016	EHR and data display	Evaluate system in comparison	To compare medwise a novel EHR that supports user composable displays with a conventional EHR in terms of the number of repeat views of data elements for patient case appraisal
Hirsch et al., 2014	CPSS on top of EHR	Evaluate System, Describe system	To describe the system and perform a formative evaluation that assessed whether Harvest assisted physicians in reviewing patient data and gather feedback for an iterative design
Denekamp, 2007	CDSS and EHR	Review research to determine impact and status	To review the research and application of CDSS to determine impacts and status

Key Findings

A variety of terms were used to describe the tools in use: clinical summary, summarization tool, summarizer, patient summary dashboard, health data display, dashboard display, app, graphical user interface, viewer and dashboard. Other types of HIT were the EHR, Electronic Medical Record (EMR). These included EHRs and EMR designed for a specific disease or for general use. Finally, there were articles with tools that had the focus of clinical decision intelligence (CDI), and clinical decision support systems (CDSS), these were combined with the EHR and sometimes had a patient summary. CDI tools use data algorithms to identify and compare cohorts of patients within an EHR. Using the identified cohort's data, decision support specific to the patient and the cohort population can be generated (Gotz et al., 2011). CDSS is a computerized knowledge based system that provides clinical knowledge to support decision making to the user (Yang, Kang & Lee, 2016). Just like CDI, CDSS can be embedded within the EHR, paired with other HIT, such as CDI or stand on its own. The variety, differing levels of maturity of the types of CIS and as well as the differing purposes of the research, make

it difficult to evaluate the type of CIS in comparison with any of the key findings. The themes that have been derived are a comparison of all CIS types.

Three themes were derived from the design recommendations or system criteria provided in each article: (1) Patient information elements, (2) information visualization formats, techniques and organization methods and (3) information visualization formats for the patient information elements.

Patient information elements. The first category describes the type of information elements presented to clinicians using CIS for patients with chronic disease. In 43 of the articles, patient information elements were described. Three of the articles were focused on the information needs of HCP as a primary goal of the study (Clarke et al., 2014; Gong, Chandra & Wang, 2014; Koopman et al., 2015). Clarke et al., (2014) determined that in electronic clinical notes, physician's information needs varied between acute care tasks and chronic visit follow up. In chronic care, the plan was more important than the assessment. The history of present illness (HPI) was determined to be the third most important in both settings. Similarly, Koopman et al. (2015) examined information needs in the clinical notes, but used different methods. They found that Assessment, Plan, and HPI were the most important elements and were reviewed first. Review of systems did not meet the information needs because it contained repetitive information from the chart that was considered clutter. In contrast, Gong, Chandra & Wang (2014) used a dashboard to present sensor data about the vital signs of a theoretical CHF patient and his or her physical activity. The main findings of this study showed users were satisfied with the usability and believed it would help keep seniors with chronic illness independent. The rest of the articles described patient information elements within the system descriptions and did not assess information needs as a primary goal.

The elements mentioned in the articles were usually part of a system design description and varied according to type of CIS, users, chronic disease and tasks. Due to the lack of homogeneity of the diseases, implementation contexts and study design synthesis is difficult. Percentages were determined based on the frequency that they were mentioned across all 45 articles. Diagnostics (58%) and observations (56%) were the most frequently mentioned patient information elements across all the articles. The diagnostics category related to laboratory results, pathology results, imaging reports and diagnostic images. For some articles, diagnostic information was the main focus. See table 4 for details. Observations incorporated assessments, clinical findings, symptoms, complications, quality of life, vital signs, risk levels, review of systems, and behavioural health and functioning.

Clinical events, treatments, problem lists, medications and primary diagnosis or chief complaint were the next most frequent categories of patient information elements. The remaining categories of elements were mentioned less frequently. Communication and patient instructions were the least frequently mentioned categories in the system descriptions at 2% and 4% respectively. Table 4 provides a summary of the patient information elements frequency.

Table 4

<i>Patient Information Elements Frequency Per Category</i>		
Patient Information Element Category	% of Mention out of 45 Articles	References
Diagnostics	58%	Bashyam et al., 2009; Blum & Lenhard, 1983; Bui et al., 1998; Bui, Aberle & Kangerloo, 2007; Devarankonda et al., 2014; Eminaga et al., 2010; Hsu et al., 2012; Koopman et al., 2011; Koopman et al., 2015; Lowe et al., 1995; Malaviya & Gogia, 2010; Massari et al., 2008; Matsumura, 2001; Miller, 1993; Newman et al., 2015; Ozery-Flato et al., 2015; Senathirajah, Kaufman & Bakken, 2016; Skevofilakas, 2007; Smith & Newell, 2002; Teves, 2015; Toyoda & Niki, 2013; Vallez, 2013; Varma et al., 2009; Warner et al., 2016; Were et al., 2010; Yamakazi et al., 1995
Observations	56%	Bashyam et al., 2009; Blum & Lenhard, 1983; Bui, Aberle & Kangerloo, 2007; Canfield et al., 1993; Clarke et al., 2014; Devarankonda et al., 2014; Foraker et al., 2015; Foraker et al., 2016; Gong, Chandra & Wang, 2014; Hartzler et al., 2015; Hsu et al., 2012; Koopman et al., 2011; Koopman et al., 2015; Malaviya & Gogia, 2010; Matsumura, 2001; Miller, 1993; Muller et al. 2016; Newman et al., 2015; Powsner & Tufte, 1997; Skevofilakas, 2007; Smith & Newell, 2002; Vallez, 2013; Varma et al., 2009; Were et al., 2010; Yamakazi et al., 1995
Problem List	33%	Bashyam et al., 2009; Bui et al., 1998; Bui, Aberle & Kangerloo, 2007; Canfield et al., 1993; Devarankonda et al., 2014; Gong, Chandra & Wang, 2014; Hirsch et al., 2014; Koopman et al., 2011; Mane et al., 2012; Matsumura, 2001; Miller et al., 2003; Newman et al., 2015; Smith & Newell, 2002; Thiessard et al., 2012; Were et al., 2010
Medications	31%	Blum & Lenhard, 1983; Bui, Aberle & Kangerloo, 2007; Devarankonda et al., 2014; Hsu et al., 2012; Koopman et al., 2011; Koopman et al., 2015; Malaviya & Gogia, 2010; Mane et al., 2012; Newman et al., 2015; Ozery-Flato et al., 2015; Powsner & Tufte, 1997; Smith & Newell, 2002; Toyoda & Niki, 2013; Were et al., 2010
Clinical Events	31%	Bui et al., 1998; Canfield et al., 1993; Hirsch et al., 2014; Hsu et al., 2012; Malaviya & Gogia, 2010; Mane et al., 2012; Massari et al., 2008; Matsumura, 2001; Miller, 1993;

		Muller et al. 2016; Newman et al., 2015; Powsner & Tufte, 1997; Smith & Newell, 2002; Toyoda & Niki, 2013; Were et al., 2010
Chief Complaint & Primary Diagnosis	29%	Blum & Lenhard, 1983; Bui, Aberle & Kangerloo, 2007; Canfield et al., 1993; Gong, Chandra & Wang, 2014; Koopman et al., 2011; Malaviya & Gogia, 2010; Massari et al., 2008; Muller et al. 2016; Skevofilakas, 2007; Smith & Newell, 2002; Varma et al., 2009; Warner et al., 2016; Were et al., 2010; Yamakazi et al., 1995
Treatments	29%	Blum & Lenhard, 1983; Bui et al., 1998; Bui, Aberle & Kangerloo, 2007; Canfield et al., 1993; Devarankonda et al., 2014; Gong, Chandra & Wang, 2014; Gotz & Wongsuphasawat, 2012; Hsu et al., 2012; Massari et al., 2008; Muller et al. 2016; Skevofilakas, 2007; Thiessard et al., 2012; Were et al., 2010
Outcomes & Comparisons	22%	Gotz et al., 2011; Gotz & Wongsuphasawat, 2012; Hartzler et al., 2015; Koopman et al., 2011; Mane et al., 2012; Miller et al., 2003; Newman et al., 2015; Ozery-Flato et al., 2015; Smith & Newell, 2002; Warner et al., 2016
Guidelines	22%	Blum & Lenhard, 1983; Denekamp, 2007; Foraker et al., 2015; Foraker et al., 2016; Gotz & Wongsuphasawat, 2012; Koopman et al., 2011; Muller et al. 2016; Samal et al., 2015; Skevofilakas, 2007; Varma et al., 2009
Patient Demographics	20%	Bui, Aberle & Kangerloo, 2007; Canfield et al., 1993; Mane et al., 2012; Matsumura, 2001; Newman et al., 2015; Powsner & Tufte, 1997; Smith & Newell, 2002; Warner et al., 2016; Were et al., 2010
Clinical Notes	20%	Bashyam et al., 2009; Bui et al., 1998; Bui, Aberle & Kangerloo, 2007; Devarankonda et al., 2014; Hirsch et al., 2014; Matsumura, 2001; Miller, 1993; Powsner & Tufte, 1997; Senathirajah, Kaufman & Bakken, 2016
History	20%	Bui, Aberle & Kangerloo, 2007; Clarke et al., 2014; Gong, Chandra & Wang, 2014; Koopman et al., 2015; Miller et al., 2003; Newman et al., 2015; Powsner & Tufte, 1997; Varma et al., 2009; Were et al., 2010
Care Plan	16%	Blum & Lenhard, 1983; Clarke et al., 2014; Koopman et al., 2015; Miller et al., 2003; Newman et al., 2015; Smith & Newell, 2002; Toyoda & Niki, 2013

Orders	13%	Blum & Lenhard, 1983; Canfield et al., 1993; Matsumura, 2001; Miller, 1993; Toyoda & Niki, 2013; Yamakazi et al., 1995
Allergies	7%	Koopman et al., 2011; Koopman et al., 2015; Were et al., 2010
Patient Instructions	4%	Malaviya & Gogia, 2010; Miller, 1993
Clinician to Clinician Communication	2%	Bui et al., 1998

Visualization formats, techniques and organization. Three subthemes emerged in the visualization theme: (1) format of representation, (2) detail management techniques and, (3) organization of the data. The format of representation referred to the way that the data was displayed in the user interface for visualization. Detail management techniques were user interface features that allowed the user to either increase or decrease the amount of data available to the user in the user interface. The organization theme referred to how the data was grouped together and how relationships between data were determined.

Forty-two out of 45 articles mentioned a format of representation for the data. Text was the most frequent representation of data mentioned in 27 articles. Text included narrative summaries, narrative documentation, templates, lists, and numbers. Timelines (n= 11) and graphs (n=15) and colour coding (n=12) were the next most frequent formats described. The other formats including images, sparklines, tables, bar charts & graphs, shapes, icons, flowsheets, scatterplots, highlighting, pictographs, pathways, information bubbles, pie charts, glyphs, were mentioned less frequently. See table 5 for details.

Detail management techniques were mentioned in 26 of the 45 articles. These techniques were used to either limit or expand the detail about the patient information available to the HCP.

More than one technique was mentioned in 8 of the 27 articles. Nine of these articles mentioned filtering, and eight described expanding & collapsing and multiple views as detail management techniques. Five of the articles mentioned hover or mouse over and pop-up windows. The least frequently mentioned was zooming ($n=2$)

There were a variety of data organization models and methods that emerged within the theme of data organization in 43 out of 45 of the articles. Organization based on the disease including elements with relationships to the disease was the primary method described in 15 of the articles. Time, and users and tasks were the next most frequently used method ($n=9$). The remaining organization methods included anatomy, source, guidelines, analytics, terminology indexing, concepts, archetypes, health status, customization, and research protocol. See table 5 for a summary of the representation formats, detail management techniques, and organization methods per article.

Table 5*Visualization Formats, Techniques and Organization*

Reference	Format of Representation	Detail Management Techniques	Organization
(Bashyam et al., 2009)	Images, Summary Sentences, Colour Coding, Timeline Grid, Infobuttons, Text	Pop Up Windows	Hierarchic Tree by Disease, findings, anatomy, time, and causality, Sort by location, concept or keyword
(Blum & Lenhard, 1983)	Flowsheet, Scatterplots	Multiple Views	User & Task
(Bui et al., 1998)	Timeline, Image Column, Icons, Graph, Bar Chart	Zoom, Hover Over	Rows for Tumours & Images, Organ System for documents
(Bui, Aberle & Kangerloo, 2007)	Timeline, icons, Tables, Images, Graph, Highlighting	Expand & Collapse, Filtering	Anatomy & Disease
(Canfield et al., 1993)	Text	Multiple Views, Pop up windows	Disease, Date or Protocol
(Denekamp, 2007)	Text	None	Hierarchy of Information
(Devarankonda et al., 2014)	None	None	None
(Eminaga et al., 2010)	Timeline, Highlighting, Colour Coding	Expand & Collapse, Filtering based on date, Pop up Window	Clinical Relationships to disease, User Specialty
(Febowitz et al., 2011)	Images, Numbers, Pictographs, Highlighting	Pop up Windows	Tumour
(Foraker et al., 2015)	Graphs, Images, Text, Highlighting	None	User & Task
(Gong, Chandra & Wang, 2014)	None	None	Guidelines

(Gotz & Wongsuphasawat, 2012)	Colour Coding, Numbers, Panels	Multiple Views	Guidelines
(Gotz et al., 2011)	Graphs, Colour coding, Histograms, Text, Pathways	Mouse Over	Analytics for Clusters
(Hartzler et al., 2015)	icons, clustes, histograms, colour coding, timeline, scatterplot	Filtering by disease, eliminate overlap	Analytics for Clusters
(Hirsch et al., 2014)	Table, graphs, bar chart, pictograph	hover over	Analytics for Clusters
(Hsu et al., 2012)	Timeline, Information Bubbles, panels, Word Graphics, Text	Filtering by disease	Weight of Problem based on # of mentions
(Koopman et al., 2011)	Timeline, Colour Coding, Text Descriptions	Hover Over, Filteringby selection	Disease & Improvement Status, Source & Date
(Koopman et al., 2015)	Text	None	Important at the Top
(Lowe et al., 1995)	Sparkline, Word Graphics, Icons, Table,	None	Disease
(Malaviya & Gogia, 2010)	Images and Videos	None	Terminology indexing
(Massari et al., 2008)	Tables, Numbers, Text	Multiple Views	User
(Matsumura, 2001)	Colour coding, graphs, Numbers, shapes, Timeline, Highlight	Multiple Views	Analytics for Clusters
(Miller et al., 2003)	Text	Expand & Collapse	Terminology indexing
(Miller, 1993)	Flowsheet, Shapes, Text	Multiple Views, Pop up windows, Filter by problem	Problem and Date & Time
(Muller et al. 2016)	Text	None	Date & Time, Event
(Newman et al., 2015)	Text	Hide resolved	User & Task & Disease
(Ozery-Flato et al., 2015)	Glyphs, Colour Coding, Narrative Summary	None	User & Task
(Pivovarov & Elhadad, 2015)	Table, graphs, colour coding, narrative summary	None	Disease

(Powsner & Tufte, 1997)	Numbers, Text, Graphs, Colour Coding, Timeline	Nesting, Expand & Collapse	Analytics for Clusters
(Samal et al., 2015)	Text & Graph	None	Concepts
(Schuler et al., 2006)	Timeline, shapes, bar charts, graphs, numbers, Text descriptions,	None	User & Task
(Skevofilakas, 2007)	Graphs, sparklines, stacked timelines, narrative summary	None	Disease
(Teves, 2015) (Thiessard et al., 2012)	Text & Numbers Columns, timeline, template, colour coding	None Spatial Arrangement, Expand and collapse	Archetypes Customizable,
(Toyoda & Niki, 2013)	Text, Numbers	None	User & Task & Disease
(Varma et al., 2009)	Template, Graphs	Filtering, Sorting	Customizable
(Warner et al., 2016)	Infographics, Graphs, Tables	None	None
(Were et al., 2010)	Text	None	Terminology indexing
(Yamakazi et al., 1995)	Buttons, Icons, Tables	None	Disease & Date & Time
(Clarke et al., 2014)	Images, Buttons, Numbers	Zoom	User & Task
(Foraker et al., 2016)	Icons, Timelinenarrative summary, Images, Text Descriptions	mouse over, expand & collapse	Disease & Date & Time
(Mane et al., 2012)	Pie Charts, Narrative Summary, Bar Graph, Colour Coding	Multiple Views	Analytics for Clusters
(Senathirajah, Kaufman & Bakken, 2016)	Text & Numbers	None	Disease & Date & Time
(Smith & Newell, 2002)	Template, Graph, Images, Numbers	Multiple Views	Disease
(Vallez, 2013)	Colour Coding, Text	Expand & Collapse	Health Status

Visualization of patient information elements. The theme above showed the frequency and types of visualization formats, detail management techniques and organization methods. The format of representation was mentioned for each of the patient information element categories listed in the first theme. Analysis revealed a wide variety of formats used for each of the patient information elements. However, there were some consistencies. It must be noted that not all descriptions of patient information elements within the CIS were accompanied with a description of the format of representation. Only one of the articles explored which format was optimal for a particular patient information element and it was limited to one laboratory result. Teves (2015) compared graphs, tables and infographics and identified that for tasks requiring a clinician to get an overall picture of a problem, tables and graphs were the most effective. Graphs were superior for monthly and trending tasks. Tables were effective for extracting discrete data and predicting data values. Infographics were the most preferred of the three formats, but least effective for assisting with either trending or extracting tasks.

Within the review articles, timelines were the most frequently mentioned representation format for clinical events (n=6). Text was the only format mentioned universally across all patient information element categories, with the exception of outcomes and comparisons. These were presented in colour coded and/or graph format. Text was also mentioned most frequently for the observations category of patient information elements. It was the only format mentioned for the patient information categories of: communication, patient instructions, demographics and care plan. Images were only mentioned for diagnostics. Graphs were used most frequently to represent diagnostics (n=5). All other patient information categories were represented by more than one format. See Table 5 for the full details. In the content column the number in brackets refers to the count of how articles mentioned that element. The numbers in the format columns

represent a count of how many times that format was mentioned for that patient information element category.

Table 6*Visualization Formats of Patient Information Elements*

Category/Format	Text	Timeline	Graph	Colour Coded	Table	Images	Icons	Bar Chart	Flowsheet	Shapes	Pictograph	Highlight	Bar Graph	Information Bubbles	Sparkline	Pie Chart	Glyphs	Scatterplot	Pathways	
Allergies (3)	2				1															
Care Plan (7)	5																			
Clinical Events (16)	5	6	2	2	1			1	1	3				1			1			
Clinical Notes (8)	7						3													
Communication (1)	1																			
Demographics (7)	6																			
Diagnosis (14)	11	1																		
Diagnostics (26)	10	3	5	1	2	9	1		2		1	2			1			1		
Guidelines (10)	6	1	1				2								1					
History (9)	5										1									
Medications (14)	4	3	2	1	3		1	3		1		2								
Observations (25)	14	2	3	4				2	1	1	2									
Orders (6)	4								1											
Outcomes & Comparisons (10)		2	4	5	2		1	1			1		2	1		1				1
Patient Instructions (2)	2																			
Problem Lists (13)	8	1		1	1				1											
Treatment (12)	8	1	2																	
Totals	97	20	19	14	10	9	8	7	6	5	5	4	2	2	2	1	1	1	1	1

Scoping Review Gaps

In order to answer the research questions below a scoping review was conducted:

1. What recommendations have been made in the literature about how to identify and present relevant information in a clinical information system to support HCP performance in community based chronic illness care?
2. What methodologies are used to identify HCP information needs and information presentation in clinical information systems for chronic illness care?

The analysis of the data extracted from the articles revealed three main themes to answer the first research question above. These included which patient information element categories were described, what visualization formats, techniques, and organization methods have been used, and which of the visualization formats have been described in relation to the patient information element categories. There were no recommendations in the literature that discussed how to identify and present relevant information to HCP. Therefore the system descriptions were used. These descriptions were not specifically recommendations of how to identify and present relevant information to HCP in community based chronic illness care to support performance. However, these results do provide a thorough analysis of what has been described and used within the literature. The results of the literature review were also insufficient to draw conclusions about the relevant information for any one discipline and therefore the aggregated information needs of all HCP are presented. These results lay the foundation for further research into recommendations for a framework for CIS design. The next chapter describes the pilot study that was conducted to determine feasibility for gathering the required information elements and the visualization formats and organization methods from a key user group of nurse case managers.

Chapter 4

Pilot Study

The scoping review results in the previous chapter revealed a wide variety of patient information elements, visualization formats, detail management techniques and organization methods. More knowledge is needed to inform CIS design including; which patient information elements are required for each of the clinical professions, what patient information elements are important for each of the chronic diseases, what specific elements within the patient information categories are required, and how HCP would need to see the information presented and organized.

A pilot study was conducted to determine the feasibility of using an exploratory survey and follow up interview method to gather the required patient information elements for a patient with multiple chronic illnesses in a community setting. Exploring the information needs and associated design requirements for all professions and all chronic illnesses in every patient scenario is a large research endeavour. Therefore, nurse case managers were chosen as the users because of the key role they play in chronic illness care. An outpatient clinic setting was chosen because this is where a large portion of chronic illness care occurs with these nurses. Finally, Chronic Kidney Disease (CKD) and diabetes were chosen as the chronic illnesses to narrow the scope of the study. The results of the scoping review also revealed a wide variety of methodologies and a scarcity of empirical evidence on this topic. It cannot be determined from the scoping review results, which methodology is the most appropriate for answering these types of research questions. Therefore, a pilot study was conducted in order to determine the most feasible methodology for answering these types of research questions.

Pilot Study Objectives

A pilot study was conducted that intended to explore what information nurse case managers require in an electronic clinical patient summary screen (CPSS), as well as how to display the information, to support management of patients with multiple chronic diseases in an outpatient setting. The research questions included:

1. What information do nurse case managers require from a clinical patient summary screen used for community-based chronic disease management?
2. Which of the required information in a CPSS should be communicated to other members of the interprofessional health care team?
3. How should the information be displayed in a CPSS?

Pilot Study Design

This research study used a two-phase exploratory questionnaire and follow up interview design. Each phase informed the next. The two phases to the research included:

1. Phase 1 – to brainstorm and capture the data elements.
2. Phase 2 – to validate and prioritize the data elements, explore the relationships between data elements, and explore the representation of the data elements.

Phase 1. The goal of the first phase was to capture the information needs or data elements required when summarizing a patient's health information for a follow-up clinic visit as well as capture which information elements are required to follow clinical guidelines. Satisfying this goal answers research question 1. During this phase, the participants were provided with a case study of a patient with diabetes, chronic kidney disease and hypertension within an electronic questionnaire. See Appendix C for the case study. The initial questionnaire asked participants to indicate what information was needed prior to or during seeing this patient for a routine clinic visit. This was presented to participants using a pick list of elements that was derived from

provincial clinical guidelines and assessment forms. There were also free text options to add, omit or comment on any elements. In order to answer research question 2, questions were also asked identify which elements were required for communication with the interprofessional team. See Appendix D for the initial questionnaire. The results from Phase 1 were used to inform Phase 2.

Phase 2. The goal of the second phase was to prioritize and validate the primary set of information needs, elicit the relationships between the data elements, and explore the ideal presentation of the data. Satisfying this goal answers research question 3. During this phase, there was semi-structured follow up interview. Questionnaire responses from the first phase were given to the participant to review prior to the interview. The participant was asked to validate his or her original responses in relation to other participant responses, as well as indicate what information should be presented together. These questions provide answers to research question 3. The participant was also asked what format to present the information in and how to highlight important information such as standards of care and evidence-based guidelines. See Appendix E for the follow-up interview guide. The interview was transcribed by the researcher and analyzed using content analysis for theme identification.

Recruitment and participants. The initial recruitment method was purposive sampling. Participants were recruited from Chronic Kidney Disease and Diabetes clinics in BC. Three of the five health authorities were included in the recruitment of the sample. An adequate sample size was determined to be 12-18 participants. This is an appropriate sample size for a pilot study like this research study. Hertzog (2008) suggests that a sample of 10 to 15 participants will allow decisions to be made about research methods and instruments (as referenced in LoBiondo-Wood & Haber, 2013). Following ethical and operational approval, managers of nurse case managers

provided email addresses to the researcher of appropriate staff or distributed the invitation to participate to their staff directly. A snowball technique was suggested to each participant within the invitation script, but no additional participants were recruited using snowball techniques.

Inclusion criteria was registered nurses working in a diabetic or chronic kidney disease clinic in British Columbia; working with adult patients; having direct patient interaction; and having an email account and internet access. Invitations were sent to thirty three potential participants with weekly reminder emails. Participants had the option to stop receiving the reminders and decline the questionnaire. Two potential participants chose the option to stop receiving reminders. Four participants were recruited for the initial questionnaire and one participant completed the follow up interview.

Additional recruitment techniques included using InspireNet, a network of nurse researchers, practitioners, policy makers, educators, and students in British Columbia. The newsletter, website postings for research, blog, and emails to InspireNet subscribers posted and distributed an advertisement with an invitation to participate in the pilot study.

Data collection. All data collection for phase one was completed before phase two was initiated.

1. Phase 1: an electronic questionnaire was administered through the web using the questionnaire tool FluidSurveys © 2016. The data was exported to an excel spreadsheet.
2. Phase 2: two a semi-structured interview was performed over Skype © (Version 7.35.0.102, 2017) by the researcher using an interview guide and the participant's initial questionnaire responses. The interview was recorded using Callnote © (Version 4.4.0, 2017). The interview was then manually transcribed by the researcher.

Questionnaire. In order to test the face validity of the questionnaire and anticipate any

procedural or technical difficulties the draft questionnaire was administered to five content experts not participating in the study. This was done after ethical approval, but before operational approval. These participants were recruited from nursing faculty at the Universities of Victoria and Northern BC, as well as professional contacts of the researcher. The participants did not overlap with the study participants. The invitation script for content experts is provided in appendix K. The purpose of the distribution of the questionnaire to content experts was to improve comprehension and attempt to anticipate any procedural or technical difficulties within the initial questionnaire. Face validity is defined as the extent to which a test is viewed to cover the concept being measured (LoBiondo-Wood & Haber, 2013). Minor revisions were made to the wording and format of some questions based on feedback from the participants. The content expert answers indicated that there was face validity to the questionnaire. Issues were identified with the password and fixed.

Semi-structured interview guide. The semi-structured interview guide was developed based on follow up questions that had originally been intended to be administered in a follow up questionnaire. The questions were revised to be open-ended and provided in an interview format rather than in a questionnaire format.

Data analysis. The results from the questionnaire were collected and analyzed prior to the data collection for phase two. The initial questionnaire data was summarized using nonparametric statistics for percent of agreement. The free text responses to the open-ended questions were coded and categorized using descriptive content analysis. Qualitative content analysis can be defined “as a research method for the subjective interpretation of the content of text data through a systematic classification process of coding and identifying themes or patterns” (Hsieh & Shannon, 2005, p.1278). As the amount of data was small; this was done in

Microsoft Excel. This was done in three phases. An initial reading was to familiarize the researcher with the content. In the second reading, key terms and phrases were extracted. These key terms and phrases were compiled into themes. A final reading of the responses was done and the codes associated with the themes were applied to the responses.

The interview was hand-coded using content analysis using the same approach as with the open-ended questions. Themes were difficult to generate because they were only based on one participant's responses. Responses to questions about patient information elements that had changed from the initial questionnaire were updated to reflect final consensus in the percent of agreement results. For example, when the participant changed a response to yes, the percent of agreement results were updated to reflect this change.

Ethical considerations. Ethical approval was obtained from a Harmonized Human Research Ethics Board which included the ethics boards of Island Health, University of British Columbia representing Vancouver Coastal Health, Northern Health, Interior Health and the University of Victoria IH REB file #2015-16-006-H. No patient information was collected and participants were free to do the questionnaire on their own time. Interior Health was the board of record because this health authority had the majority of clinics for recruitment. Fraser Health, and Providence Health Authority were excluded from the study during the ethics process because they required extra permission and affiliations, which would have postponed the date that the research could commence.

After ethical approval was granted, operational approval was sought from the research departments and managers of the clinics within each health authority included in the ethical review. Recruitment began after operation approval was requested. Interior Health (IH) denied operational approval for all but one clinic and therefore only one clinic was included in the

recruitment. Invitations to participate included the name of the study, the researcher's contact information and a brief explanation of the research. See Appendix F and G. The link to the questionnaire and the participant information letter (See Appendix H) was emailed to participants who agreed to participate. To ensure the questionnaire's security, password access was given after agreement to participate. The participant's letter of information clearly stated that completing the questionnaire implied consent. Invitations to participate in the follow up interview were only sent via email to those that had completed the initial questionnaire, Appendix I. Two ethics revisions were submitted to the IH board of record for ethics to obtain approval for changes made to the study methods due to inadequate recruitment. The first change revised the method from three questionnaires to one questionnaire and a follow-up interview. The second change added a recruitment method through a social media site called InspireNet, which included an advertisement to participate (See Appendix J) and a revision to the invitation to participate. These were approved by the IH board of record for the ethics protocol for this study.

Pilot Study Results

The next discussion in this chapter is a review of the pilot study results.

Participants. Four participants were recruited for the first phase. Only one participant participated in the follow up interview for an attrition rate of 75%. It was difficult to calculate the response rate because the total sample with the snowball recruitment was unknown. Thirty-three potential participants were identified using managers of case managers as a third party contact. Four participants were recruited for the initial questionnaire and one completed the follow up interview. The InspireNet recruitment method did not yield any new participants.

Required information. Consensus rates were calculated to answer the first research question about which information nurse case managers require from a CPSS used for community based chronic disease management. The consensus rates were calculated from the results of both the questionnaire and the follow up interview. The consensus rates were 100% or four out of four, 75% or three out of four, 50% or two out of four and 25% or one out of four. There were 11 elements that had 100% agreement among participants: Assessments, self-management barriers, patient goals, medications, edema, blood pressure, chest x-ray, low density lipoprotein (LDL), potassium, glomerular filtration rate (GFR), and glycated hemoglobin (HgbA1c).

There was a consensus rate of 75% for 19 of the patient information elements: hemoglobin, white blood cells (WBC), creatinine, albumin, blood urea nitrogen (BUN), phosphorus, (HDL), triglycerides, urine-ACR, weight, skin integrity, health problems, alerts, patient demographics, clinical notes, history, last visit date and reminders.

There was 50% consensus for two of the missing elements identified and that was calcium and brain natriuretic peptide (BNP). The three other data elements participants felt were missing from the original pick list in the initial questionnaire were only mentioned once for a consensus rate of 25%. These elements included dialysis access status, advanced care planning, and modality choice. The full details of the percent of agreement for data elements after the follow up interview are presented in Figure 7

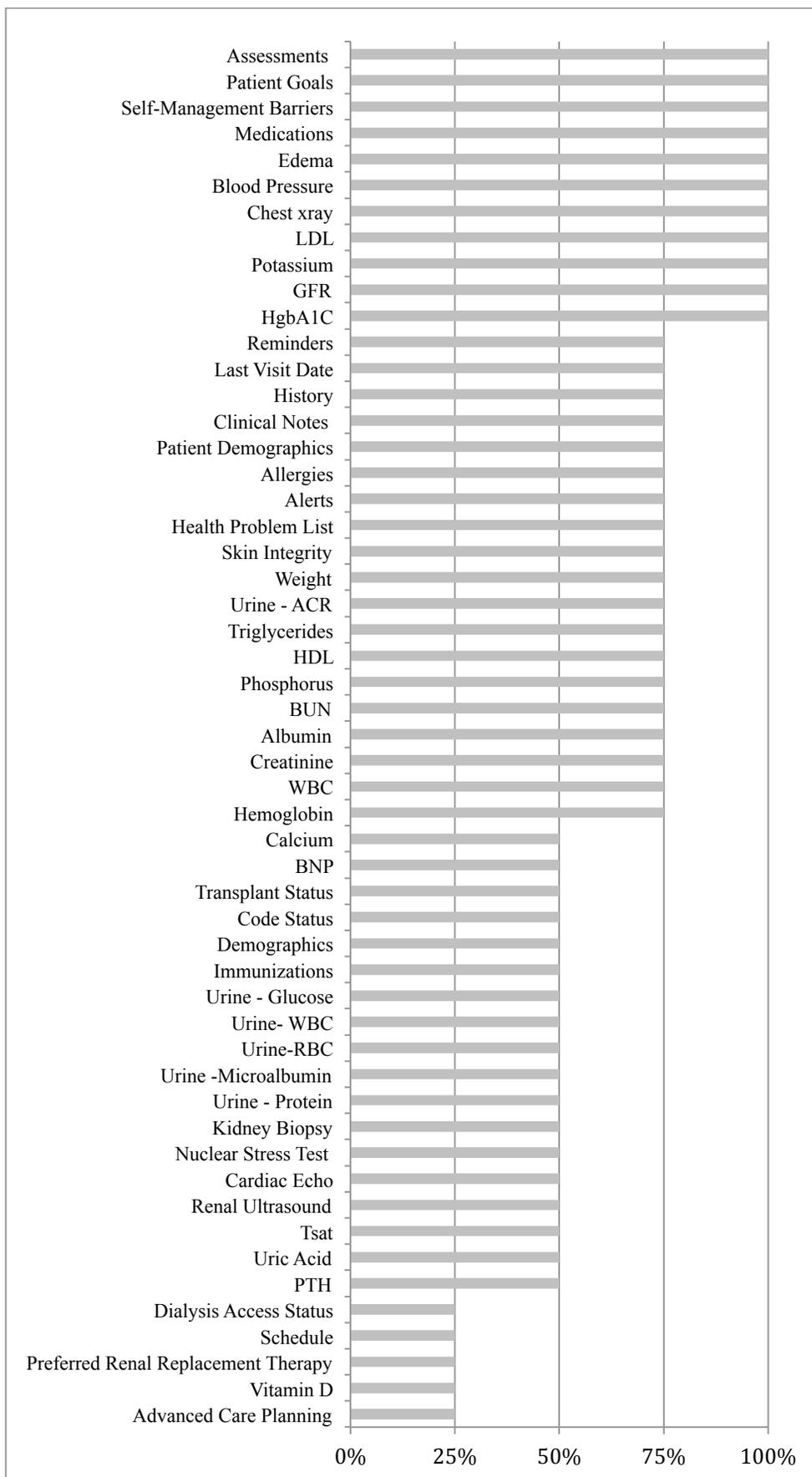


Figure 7. Percent of agreement between participants for patient information elements

Required information. There were two themes that related to research question 1 that were derived from the follow up interview. The first theme was that required information could change due to changes in clinical guidelines and these changes are important. For example the participant mentioned:

[B]ut one thing that we probably should consider now because we're just doing some training now and we have now been mandated to um incorporate this into all our patient encounters um is advanced care planning.

Another theme was that certain information was used for different purposes, such as patient involvement and predicting disease trajectories. This may reflect the need to change patient information elements available in a CPSS when guidelines change. The participant indicated that the patient information element of advanced care planning would facilitate a discussion with the patient:

... [W]e're going to be handing the patients the voice and then advising them that this is what they need to complete. So basically um advanced care planning discussion is really what it will be maybe be as involved as we will get in the CKD population and then documenting yes or no if it has been completed by the patient.

Some information was determined to be more important because it was necessary for monitoring the disease trajectory and predicting prognosis. "It's part of our ongoing assessment. So we want to monitor any changes to those items as part of the disease trajectory in predicting health care goals or I guess end points. Dialysis things like that". Other elements could be included, but may not be useful. "I'll say yes because it's not going to hurt to have them. I don't know how useful that is but yes ok". Other elements were explicitly indicated to be important by the participant including GFR, any recent lab results, vaccinations that were due, medications, in

particular Aranesp, and allergies. Because the importance was only collected with one participant ranking of importance could not be done.

Information required for communication to the interprofessional team. Research question two asked which of the required information in a CPSS should be communicated to other members of the interprofessional health care team. In order to answer this question, the free text responses on the initial questionnaire for one question were analyzed. Two themes emerged from the free text responses on the initial questionnaire for this information. This first theme was that information required for communication with the interprofessional team was related to HCP concerns. For example, "Any that are not within normal limits" and "I would discuss my concerns with the multidisciplinary team and I would report all my findings back to the primary care physician who is most responsible for the patient".

The second theme addressing this research question two was that the required information varied depending on the discipline of the clinician reviewing it. "Ok so when I'm commenting on what I think should be in the chart is this what I'm thinking from my nurse's perspective or am I thinking for all disciplines? Right because that makes a difference too".

Presentation of information. The third research question addressed how to present this information to nurse case managers. There were themes derived from the interview around how to organize the information and what format to present the information in.

Organization. The theme of how to organize the information was that certain types of information should be grouped together. These groupings were perceived to facilitate the ease of following the information. "... [J]ust for ease, just for ease um of following however this will look..." See the list below for the groupings identified:

- Serum Results
- Urine Results

- Imaging
- Assessments
- Health Problems
- Medications
- Immunizations
- Clinical Notes
- Care Plan
- Demographics
- Allergies
- Alerts

Visualization formats. The types of visualization formats mentioned were check boxes on a flowsheet called ‘ticky boxes’, graphs, and colour coding. These formats were based on what the participant had already seen and used in both electronic and paper format. “Um I guess as ticky boxes. Does that make sense? I can’t visualize how that will be. I’m just thinking on our assessment on our CKD record we use ticky boxes format right as a summary”. These types of visualization formats were perceived to facilitate a quicker assessment. “I’m just thinking it would make my assessment quicker”. Graphs and colour coding were mentioned in relation to lab results and target values. “... [S]o what types of results? So anything colour code anything that’s outside of normal target limits I would think. So lab so any results that are out of target”.

Difficult to visualize without seeing or trying the CIS. Another theme within the presentation of information was that it was difficult for the participant to visualize how to present the information and know if the organization would work without a visual aid or trying it for a period of time.

...I mean we when we redesign our clinic record which we have done several times over the past sometimes it takes working with it for a while to realize this was really a stupid place to put this ticky box. It just doesn’t flow so it’s sort of hard for me to just kind of imagine how this would flow without actually seeing it”.

The pilot study was conducted to determine the feasibility of collecting HCP information needs for required patient information elements, the presentation formats and the organization of these elements using an exploratory survey and follow up interview. The scope was limited to nurse case managers as users and two chronic illnesses to limit the resources and analysis required. Nurse case managers were chosen due to a gap in the literature for the role of the CNS. Two chronic illnesses were provided in the case study due to a gap in the literature for system use for multiple chronic illnesses. The results of this pilot study need to be discussed in relation to the CCM and eCCM and the scoping review results to suggest recommendations for further research, including methodologies and recommendations for a design framework for CIS's for community based chronic illness care.

Chapter 5

Discussion

This chapter will integrate the results of the pilot with the results of the review and theoretical models of the CCM and eCCM. The first part of this chapter will compare the designs of the scoping review and the pilot study. The second part of the chapter will address the answers to the research questions for the review and what gaps the pilot study was designed to cover. The third part of the chapter will review the consistencies and inconsistencies, between the review, the pilot study, the CCM and the eCCM for the patient information elements, visualization formats, techniques and organization methods. There are three main challenges in CIS for chronic illness care: information overload, including information identification and presentation, interprofessional team based care, including the role of the nurse case manager and the differing information needs, and multiple chronic illnesses. This chapter will also discuss how the scoping review and the pilot study contributed to the state of the knowledge on these challenges.

Comparison of Review and Pilot Study

It is difficult to directly compare the pilot study results to the review results because of the differing purposes, users, and settings (see Table 7 for details). The pilot study attempted to address some of the gaps in the literature by exploring the information required by nurse case managers and how to display that information. The focus of the pilot was specifically an electronic clinical patient summary for nurse case managers for facilitating a clinic visit with a unique scenario. It was the intention of the scoping review to examine recommendations and methodologies for identification and presentation of information within CIS to support HCP performance in chronic illness care. The review's focus was much broader and examined all types of CIS, users, and a variety of settings that may have involved multiple scenarios.

Table 7*Comparison of Pilot Study Design vs. Review Design*

Design	Pilot	Review
Research Questions	<ol style="list-style-type: none"> 1. What information do nurse case managers require from a clinical patient summary screen used for community-based chronic disease management? 2. Which of the required information in a CPSS should be communicated to other members of the multidisciplinary health care team? 3. How should the information be displayed in a CPSS? 	<ol style="list-style-type: none"> 1. What recommendations have been made in the literature about how to identify and present relevant information in a clinical information system to support HCP performance in community based chronic illness care? 2. What methodologies are used to identify HCP information needs and information presentation in clinical information systems for chronic illness care?
Purpose	To explore what information nurse case managers require in an electronic clinical patient summary screen (CPSS), as well as how to display the information, in order to manage patients with multiple chronic diseases in an outpatient setting.	The purpose of this study is to determine what is known from the literature about the use of HIT to support the information needs of individual health care providers and the interprofessional team, including the nurse case manager, providing chronic illness care in the community setting.
Users	Nurse Case Managers	All Health Care Providers
Settings	Diabetic or CKD Clinic	Community-based Settings
Scenario	Unique Case Study for a clinic visit	No specific scenario.

Methodologies used for determining design of CIS. The research question of which research methodologies to use to identify HCP information needs in a CIS to support HCP performance in community based chronic illness care was only present in the review. When the

research methodologies were extracted from the articles 18 of the 45 articles in the scoping review were research studies. These studies employed a wide variety of methodologies employed in these articles (Table 1) including experimental, usability, survey, observation, participatory action, grounded theory and case study methodologies. Furthermore, only four of the 18 articles had an experimental design and only one of the four had a control group. Therefore, the amount of empirical evidence on using CIS for chronic illness care identified through this scoping review is relatively sparse and no conclusions can be drawn to answer research question two of the review. The pilot study intended to add to the evidence base by contributing new research evidence to the field of knowledge through an exploratory survey and follow-up interview methodology.

Measurements of success of CIS design and reducing information overload. When attempting to determine recommendations for designing CIS, it is important to know if the design used within a study or a group of studies had a beneficial effect on HCP performance or patient outcomes. If there is a beneficial effect, then it is likely that the challenges of information overload and information identification have been addressed. This is difficult to determine from the research articles included in the scoping review due to the measurements used in the reported designs. For example, only six of the 45 articles evaluated the system design for effect on performance and these studies used measurements such as HCP preference, reduced mouse clicks, reduced time for task, or reduced repeat data views to determine success (Foraker et al., 2015; Hartzler, 2015; Koopman et al., 2011; Schuler et al., 2006; Smith & Newell, 2002; Teves, 2002; Warner et al., 2016). Additionally, these studies do not provide evidence on the completeness of the information, or the accuracy of the decisions made. For example, only one of these articles addressed patient outcomes in relation to the use of the system (Foraker et al.,

2016). Although this study found positive effects of the CIS on patient outcomes, more evidence is needed to form conclusions about the design of CIS for effective chronic illness care. It was beyond the scope of the pilot study to address this gap in the literature. That is to say, the pilot study did not address the effect of the information visualization formats and techniques on the performance of those nurse case managers or the effects on patient outcomes. None of the articles examined both the information needed by the HCP in chronic illness care and how to present that information to improve performance. This gap in the literature must be addressed. This gap may be due to the fact that this area of research appears to be relatively new with the majority of the articles published in 2007 or later. The pilot study showed that preferences of information presentation could be investigated using survey and interview methods, but that performance must be addressed using different methods. Experimental methodologies must be used to evaluate performance and patient outcomes.

Interprofessional team and the role of the CNS nurse case manager. It is known from the literature that different users have different tasks and information needs. Studying system use from the perspective of the appropriate user base is important to determine if the system design recommendations apply to the intended audience of the information. Only a few of the articles studied how the system was used by the HCP (Hartzler et al., 2015; Hirsch et al., 2014; Koopman et al., 2015; Newman et al., 2015; Ozery-Flato et al., 2015; Teves, 2015; Were et al., 2010). Nursing and allied health were underrepresented within this literature. Of these seven articles, two included nurses as users with physicians (Hartzler et al., 2015 & Newman et al., 2015), one mentioned general clinicians (Teves, 2015), who may or may not include nurses, and the rest studied physician use only (Hirsch et al., 2014; Koopman et al., 2011; Ozery-Flato et al., 2015; Were et al., 2010). None of the articles focused on nurses or nurse case managers as the

primary user group and only one other article from the scoping review had nurses as a user group (Gong, Chandra & Wang, 2014). Furthermore, two articles mentioned above focused on physicians as the primary user group with nurses providing some of the documentation. This may mean that the results of the review are biased toward the patient information elements, presentation and organization necessary to support physician information needs in chronic illness care. This represents a significant gap in the literature that needs to be addressed.

Case managers in chronic illness care are integral roles within interprofessional teams providing chronic illness care. The role of a case manager can be performed by any discipline; however, a nurse usually fulfills it. This role is found to be crucial to interprofessional collaboration and patient outcomes (Van Dongen et al., 2016). As illustrated in the introduction of this paper, the CNS role of the nurse case manager enables the components of the CCM and eCCM. The participant in the follow up interview enforced the idea that the discipline of the audience of a CIS matters when determining which patient information should be included. Therefore, more research is needed that examines the information needed by the HCP, in particular the nurse case manager, to support effective chronic illness care. The pilot study attempted to address this gap by selecting nurse case managers as the population for the study. However, future studies would need to determine the patient information needs of all members of the interprofessional team. Comparisons could then be done for every discipline and a common set of patient information elements could be derived. This would inform which patient information needs were specific to nurse case managers and inform the CIS design. Ideally future studies would derive this information from analysis of the use of the CIS within a HCP every day work or in laboratory settings with case studies based on real scenarios. In addition to the users, the chronic illness or combinations of chronic illnesses of the person being cared for

impact the information required.

Multiple chronic illnesses. Comorbidity is a key challenge in chronic illness care (Andolsek et al., 2013). The design recommendations or decisions from a system that only focuses on one disease will likely not be generalizable to other chronic conditions. Although it has not been explicitly stated, it can be inferred that the more conditions that a system has been designed for the more generalizable the design decisions or recommendations to other chronic diseases. Designing for multiple conditions is difficult and therefore it is not surprising that the majority (n=35) of the articles focused on specific diseases e.g. diabetes, cancer, CHF. Only a small subset (n=10) mentioned more than one disease and of these half only mentioned two diseases. Therefore, the results of the review may be more heavily weighted to the design of CIS for single disease and not address the need for information needs for patients with multiple comorbidities.

The case study for the pilot, attempted to address the challenge of multiple chronic illnesses by describing a patient with two chronic illnesses, diabetes and CKD, as well as the complication of hypertension. Nurse case managers were recruited from both diabetic and CKD clinics to ensure that perspectives for both specialties were included. However, the results of the pilot study may be heavily weighted to CKD because 3 of the 4 participants were nurse case managers from CKD clinics. In summary, the pilot study attempted to address the gaps in the literature surrounding nurse case managers as users, multiple chronic illnesses and the challenge of identifying and presenting relevant patient information within the context in a community setting. The following discussion integrates the results of the two studies and incorporates the theoretical underpinnings of the CCM and eCCM.

Integration of pilot study and review results for patient information elements.

The following discussion presents the integration of results of the pilot and the review. The first section examines the results with agreement in both review and the pilot study results. The second section discusses areas with disagreement in both the results of the review and those of the pilot study. The third section discusses review results that were not present in the pilot study results. The final section discusses results that were not represented in either the review or the pilot study results.

Results agreement between pilot and review for patient information element relevance.

The pilot study examined patient information elements in more granularity in terms of specific elements while the review focused on categories. Although this made it difficult to compare patient information elements between the two studies, nevertheless, there were some consistencies between the two (see Table 8). There were 17 categories in the review overall and the pilot study elements align with nine of those categories. The reason there are categories from the review with no patient information elements in the pilot study is a result of the limited scope of the pilot that focused on a patient summary and the generation of a pick list of elements from existing clinical guidelines, assessments, and a literature review of patient summaries. Agreement was determined if there was a high percent of agreement (100% or 75%) in the pilot study and a high frequency of mention in the system descriptions (22% and above) within the review or a low percent of agreement (50% and 25%) in the pilot study and a low frequency (below 22%) in the review results. The frequency percent cut off for high and low at 22% was determined based on the median frequency. Agreement and disagreement categories were not mutually exclusive. A category in the review could have some elements that were in agreement and some elements that were in disagreement including: diagnostics, medications, clinical events, and care plan. The review categories that were consistent with the pilot study for high

agreement and high frequency included diagnostics, observations, medications, problem list, clinical events, and guidelines.

Table 8

Comparison of Scoping Review Categories and Pilot Study Patient Information Elements

Review Categories	Pilot Information Elements
Diagnostics (58%)	100% Chest X-ray, LDL, Potassium, GFR, HgbA1C 75% Urine-ACR, Triglycerides, HDL, Phosphorus, BUN, Albumin, Creatinine, WBC, Hemoglobin 50% Calcium, BNP, Urine-Glucose, Urine-RBC, Urine-Microalbumin, Urine-Protein, Kidney Biopsy, Nuclear Stress Test, Cardiac Echo, Renal Ultrasound, Tsat, Uric Acid, PTH 25% Vitamin D
Observations (56%)	100 % Edema, Blood Pressure, Assessment 75% Skin Integrity, Weight
Problem List (33%)	75% Health Problem List
Medications (31%)	100% Medications 50% Immunizations
Clinical Events (31%)	75% Last Visit Date 25% Schedule
Treatments (29%)	50% Transplant status 25% Dialysis access status
Guidelines (22%)	75% Alerts, Reminders
Patient Demographics (22%)	50% Patient Demographics
Clinical Notes (20%)	75% Clinical Notes
History (20%)	75% History
Care Plan (16%)	100% Patient Goals, Self-Management Barriers 50% Code Status 25% Advanced Care Planning, Preferred Renal Replacement Therapy
Allergies (7%)	Allergies (75%)
Chief Complaint & Primary Diagnosis (29%)	Not in the pilot study

Outcomes & Comparisons (22%)	Not in the pilot study
Guidelines (22%)	Not in the pilot study
Orders (13%)	Not in the pilot study
Patient Instructions (4%)	Not in the pilot study
Clinician to Clinician Communication (2%)	Not in the pilot study

Diagnostics was most frequently mentioned category with the review. Within the pilot study five of the 11 elements that had 100% agreement and nine of the 20 elements with 75% agreement from participants were diagnostics. Observations was the next most frequent review category and 3 of the pilot study elements with 100% agreement and two of the 20 elements with 75% agreement fell into the category of observations. Medications were mentioned in 31% of the scoping review articles and had 100% agreement from the participants in the pilot study. Clinical events had a frequency of 31% in the scoping review and one of the two patient information elements, last visit date, had a 75% agreement with pilot participants. Guidelines had a 22% frequency in the review results and both patient information elements that relate to guidelines, alerts and reminders had a 75% agreement with participants. These categories with the identified patient information elements should be examined closely when designing a CIS for chronic illness care and could represent a minimum data set from which to start the design.

The patient information elements that were consistent with the pilot study for low agreement and low frequency only included the care plan. Two of the patient information elements (advanced care planning and preferred renal replacement therapy) from the pilot had 25% agreement from the participants and the frequency of the review result was 16%. The care plan category was also an area of disagreement between the review and the pilot study results, which will be discussed below.

Result agreement for patient information element presentation format. Another area of

consistency between the results for both studies was the presentation format of graphs and colour coding for diagnostic results. The pilot study participant identifying graphs and colour coding as a preferred method for displaying laboratory results in the follow up interview. This is consistent with the review results as both of these formats were mentioned in relation to diagnostic results. Although graphs were not the most frequently mentioned presentation format for diagnostics and neither was colour coding. One article within the review, supported this finding by determining that graphs were a superior method for monthly or trending tasks (Teves, 2015). Reviewing laboratory results for a nurse case manager usually occur on a monthly basis and would focus on identifying trends therefore it is not surprising that graphs were mentioned as the primary format for presenting laboratory results. Only three visualization formats, flowsheets, graphs, and colour coding, were mentioned in the pilot study and all of these formats were also mentioned in the review. This small number of formats identified by the pilot participant may be due to the fact there was only one participant. More participants may have identified more formats. Furthermore, the participant indicated in the follow up interview that it was difficult to imagine what the summary would look like and that only by using it would she know if it would be useable. It may be that as HCP are presented with more formats of representation that they will start to request these to represent required patient information.

Disagreement between pilot study and review. There were several areas of disagreement between the categories of patient information in the review and the patient information elements in the pilot study including: diagnostics, clinical events, treatments, medications, patient demographics, clinical notes, history and care plan. Diagnostics, which had a frequency of 58% only had one patient information element that was not in agreement, Vitamin D levels (at 25% agreement). The participant indicated in the follow up interview that this may be an element that

was necessary before but is no longer needed. This may mean that the necessary diagnostic results for chronic illness care change over time.

Differences in the results may be due to the scenario in the pilot study or the type of CIS as a patient summary in the pilot. For example, patient demographics had 50% agreement with participants in the pilot study and the review results had a frequency of 22%. It may be that for the unique scenario or within an electronic patient summary this is unnecessary information but it would be necessary with a different scenario or different types of CIS.

One primary area of difference between pilot study, the review and the CCM and eCCM was the care plan category. The care plan is expressed as one of the most important elements in the literature (Barr et al., 2003; Gee et al., 2015; MacColl Centre for Health Innovation, 2017). Additionally, it is also part of the self-management support component of the CCM with the actions of goal setting and action planning as presented in the model elements on the improvingchronicillnesscare.org website (MacColl Center for Healthcare Innovation, 2017). As a case in point, the participants in the identified studies from the review that focused on information needs of physicians providing chronic illness care validated the importance of the plan portion of the care plan (Clarke et al., 2014 & Koopman et al., 2015). Two of the 11 elements with 100% agreement in the pilot study were in the care plan category. This was incongruent with the review results as only 16% of the total review articles mentioned the care plan. This may be due to the difference in users in the review and the pilot study. The review had physicians as the primary users and the pilot study had nurse case managers. Care plans have been written and used by nurses throughout history (McCloskey, 1975). However the use of care plans by physicians is low despite the endorsement of use in clinical guidelines (Merport et al., 2012). Therefore it is not surprising that the care plan category is under represented in the review

results while being represented in the pilot study results.

This under-representation of the care plan could be due to the prevalence of unstructured narrative documentation in CIS. One factor may be that the plan is still embedded within clinical notes (Clarke et al., 2014 & Koopman et al., 2015). Structured documentation is still not used consistently within CIS for HCP documentation and needs to be implemented with caution to avoid over-structuring clinical notes and losing the meaning in the narrative (Kuhn et al., 2015). Unstructured narratives embedded within note documents are still a frequently used method of documentation in CIS (Neri et al., 2014). A CIS that is organizing or summarizing information from within an EHR would only have unstructured clinical notes with the plan embedded from which to pull data. Free text and unstructured data makes it difficult to use technical solutions to present and organize this information. Although this would then suggest that clinical notes should then be a frequently mentioned category in the review and they were not. Clinical notes were however an agreed upon patient information element within the pilot study.

Another area of disagreement was the presentation and organization of the information. Organization of information within a CIS can also be discussed as the view type for the information. There are three types of views identified in the literature: source, time, and concept. Zeng and Cimino (2001) indicate that source-oriented views, where data is organized by where the data was collected, and time-oriented views, where data is organized by when it was collected, are the most common views within CIS. Concept-oriented, where data is organized around clinical concepts such as strategies, goals, or diagnoses, views are less common. Samal et al. (2011) illustrate how concept-oriented views can support assist HCP in reviewing information. Although concept-oriented views are known to be helpful they are however, difficult to design.

The primary organization method mentioned in the review literature was based on the disease and the elements related to the disease, which is a type of concept-oriented view. This indicates an attempt within the literature to address how to build and implement concept-oriented views within CIS. This differs from the results of the pilot study. The pilot study purposefully chose information related to the disease based on clinical guidelines as options in the pick list of the questionnaire, but the pick list was not organized by relationships to the disease. The groupings on the questionnaire were primarily by source. The participant response in the follow up interview indicated a preference for organizing elements based on the type of information, which is a source-oriented view. For example, all laboratory items were grouped together and not grouped with the assessment. If a concept-oriented list was presented to the participants the responses may have favored this organization. The participant may have indicated this organization because this is what was presented in the questionnaire. The choice of a source-oriented view may be due to what is familiar to the participant. She indicated that the reference for the organization method was based on paper and her current EHR, both of which are primarily organized by source. If more CIS start to use concept-oriented views users may start to prefer them, but this choice of design should be based on research that indicates that these views improve HCP performance.

The visualization formats identified in the pilot study were also an area of inconsistency with the review results. Text was the primary format for representation of patient information identified within the review. This is consistent with the literature, which has identified that narrative summaries have been found to be helpful in reviewing patient information (Van Vleck et al., 2007, Hunter et al., 2008). There was no mention of narrative summaries or text as a method of presentation method within the pilot study results. While text was not mentioned by

the participant in the pilot, it may have been assumed that this would accompany what the participant referred to as ‘ticky’ boxes on the summary that were requested by the participant or that certain types of information are only presented in text such as clinical notes.

Review results not present in the pilot. The CCM and eCCM illustrate that decision support and measurable goals and outcomes as important components of effective chronic illness care (Barr et al., 2003; Gee et al., 2015; MacColl Centre for Health Innovation, 2017). These were under represented in the results of the review and missing from the results of the pilot study. For example, the patient information elements of guidelines and outcomes and comparisons were mentioned less frequently than the majority of the other patient information elements in the articles identified for the review. This was consistent with the results from the pilot study. Participants from the pilot study identified that some elements were required to follow clinical guidelines, particularly lab results. However, participants mentioned neither the guidelines nor the outcomes and comparisons to other patient populations as necessary information element within a CPSS. This may have been due to the fact that guideline and outcome and comparison elements were neither options on the initial questionnaire picklist nor the focus of a question with the follow up interview. If outcomes and comparison elements had been presented on the pick list, or a specific question within the interview the results may have varied.

Although the chronic care literature (Barr et al., 2003; Gee et al., 2015; MacColl Centre for Health Innovation, 2017) emphasized care coordination and productive patient interactions, as key factors for effective chronic illness care, the related patient information elements were missing from the results. Only one article mentioned communication between providers (Bui et al., 1998) as an information element. None of the pilot participants mentioned communication

between providers as a necessary element. The pilot study did attempt to address, which elements were needed for communication and while there was no consensus, a theme emerged that the participants would communicate any information of concern. If the questionnaire had asked specifically if the participant required the communications between providers in the summary the results may have differed.

Patient information elements missing from both the review and the pilot. Neither the review nor the pilot study mentioned communication between the patient and the HCP. The literature states that productive patient interactions and the feedback loop are integral components in the CCM and eCCM (Barr et al., 2003; Gee et al., 2015; MacColl Centre for Health Innovation, 2017). However, both the review and the pilot have minimal results that relate to facilitating patient interactions. For instance, only one article in the review focused on patient involvement and the use of the information to facilitate interactions (Gotz & Wongsuphasawat, 2012). Furthermore, this article does not describe which elements are necessary for these interactions. This may be due to the search terms and the exclusion criteria of patient information. Using different search terms or including patient information needs in the study may have identified elements that were necessary for patient and provider communication.

The lack of representation of patient-provider communication is consistent with the pilot results. An illustration of this was the advanced care planning element was identified as required to facilitate a patient interaction, but no other elements were identified as required for patient interactions. Additionally, the other participants did not mention this element at all and no other participants mentioned that any information was necessary for productive patient interactions. Communication between providers and patients would be part of productive patient and provider interactions within the CCM and eCCM. If the questionnaire or interview questions were

designed to address which elements were necessary to facilitate patient interactions within the questionnaire and follow up interview, different results may have been produced. This area of the literature needs further research to identify which patient information elements are necessary to support productive patient provider interactions and how to present this information to both the patients and the providers.

Throughout the literature on chronic illness, interprofessional teams are noted as vital for efficiency (Zwarenstein et al., 2009; Van Royen et al., 2014, Vyt, 2008; Rocco et al., 2011). One article mentioned clinician-to-clinician communication as a necessary patient information element (Bui et al., 1998). None of the articles described how team information needs could be satisfied or how their interaction could be supported. This may have been due to the search terms and if terms related to care coordination and team-based care were included the results may have differed. The pilot study did identify that some of the necessary information should be communicated to the interprofessional team, if it was of concern to the nurse case manager. It was not possible to determine from the responses whether this was for the purposes of care coordination or if the actual communications were necessary elements in the summary. More in depth questions around the use and communication or source of the information may have provided different results. More research is needed to determine which information is necessary in the CIS to support team based care.

Limitations

There were several limitations with this scoping review. The first limitation was that this review was performed by one reviewer, which limits the reliability of the search. This was mitigated with specific inclusion and exclusion criteria, but cannot be eliminated entirely. The

first part of the search was rerun and results were spot checked to determine if the reviewer was being consistent. No discrepancies were identified.

There were some limitations with the data analysis. For instance, the analysis of the articles was done by one reviewer which introduces the possibility of bias in the themes and categories for patient information elements, visualization and organization techniques. However, the reviewer did use strategies such journaling and challenging of assumptions and biases throughout the data collection and analysis phases of the review to reduce bias. Different insights may have been gleaned from the data analysis with the inclusion of other researchers. Furthermore a framework for analysis may have identified different themes within the results. Another data analysis limitation was that the results primarily came from descriptions of the systems, which may not have been complete and may have missed important details.

There were limitations due to the search strategy. For example, the search limitations that were put in place due to time and resource constraints which may have introduced bias. A language bias may have been introduced as a result of the fact that the search was limited to the English language. Although this is unlikely because adding the English language filter only removed 14 articles from the search results. It is also possible that articles were missed due to the fact that only three electronic databases were searched. Grey literature exclusion could have contributed to a publication bias. A final limitation was the lack of assessment of the quality of the evidence identifying patient information elements and/or the visualization themes. Due to time and resources only the frequency of reporting in the literature was examined. Therefore this limits the ability to draw conclusions on the results.

The pilot study had several limitations. The main limitations were an inadequate response rate and a high attrition rate. The recruitment strategy had several issues, which likely

contributed to the inadequate response rate. The first was the need for operational approval from all of the individual managers at each health authority that operated those clinics. This was not known in advance. Recruitment relied heavily on those operational managers identifying the appropriate audience and forwarding on the invites or providing the names of eligible participants. Furthermore, the researcher was expected to know the organizational structure of each health authority and identify the managers. This was an unexpected burden. Professional practice offices were also engaged to distribute the survey invitations and post them on internal websites, but the organizational rules prevented this from occurring without operational approval as well, so this did not negate the need for directly contacting each operational manager. This recruitment strategy was used to allow for the accurate identification of the participants. These managers determined if the study was important or worth the time of the staff. After discussions with some managers, they mentioned that a provincial CIS provided summaries of patients and they did not see the need for another. Explanations of the purpose to expand beyond just a registry with specific disease information usually convinced them that the study had value, but this only worked for those that participated in the discussions. These conversations only occurred with three managers. A revision to the recruitment strategy should include prior contact with managers in a meeting before ethical approval is attempted to determine feasibility and prepare managers for the request.

Altering the recruitment strategy to social media and the CNA mailing lists for CNS that had completed specializations related to chronic disease would have eliminated the need for operational approval and may have increased the sample size, but it would mean more effort during the screening portion to ensure participants meet the criteria before or during the questionnaire. Another improvement to the recruitment strategy would be to expand to other

provinces that use a similar model for chronic illness care such as Alberta or Ontario. This would have increased the sample size. However, this would have meant partnering with other Universities to gain out of province ethical approval. In retrospect, the most successful recruitment strategy may have been social media, CNA mailing lists and a Canada-wide recruitment. This would have increased the time and effort up front for ethical approval, but would have reduced the time and effort that was required for operational approval and amendments to the recruitment strategy to increase participation.

Inaccurate assumptions may also have contributed to the low response rate. An assumption was made that the term nurse case manager would be understood and accepted by nurses within the clinics. It may be that these CNS working in the chronic disease clinics do not identify as nurse case managers and therefore did not respond to the study invitation. Assessing the language and identification of what nurses fulfilling this role in Canada identify as prior to developing the study invitation may also increase the response rate. Another assumption was that nurse case managers would be employed at every clinic. After discussions with managers some clinics had dieticians filling the role of a coordinator or case manager. This means that the sample size was actually lower.

The high attrition rate may have been due to the length of time between the initial questionnaire and the request for the follow up interview. To prevent this attrition in other studies, the timing of the follow up should be as close to the initial questionnaire as possible. Another possible design to prevention attrition be back to back focus groups in webinar format where the information required is gathered in the first focus group and the follow up focus group identifies the presentation formats and organization of the required information. A prototype

could then be developed in which a final focus group or questionnaire could gather participant feedback on the design and use of the prototype.

Another limitation of the pilot study was the possibility of a response bias introduced by providing a pick list for the questionnaire. Other designs such as cognitive task analysis with think aloud protocols may be more effective identifying patient information elements required and presentation and organization formats that enhance HCP and nurse case manager performance without introducing response bias. However, these methods require the researcher or an affiliate to be present at the site, which was not possible with this study. The limitations of the pilot study mean that no conclusions can be drawn from the results. The lessons learned also identifies that significant changes should be made to the recruitment strategy and possibly the research design. The next chapter discusses recommendations about research design that address these lessons learned as well as recommendations for the patient information element categories and their visualization formats, detail management techniques, and an organization method for the design of a CIS to support effective chronic illness care in a community based setting.

Chapter 6

Recommendations

The recommendations based on the review findings, pilot study findings, the CCM and the eCCM are presented below. Recommendations are provided for the proposed patient information elements, the presentation formats for those elements, and the organization method and detail management techniques that should be utilized in CIS design to support chronic illness care. Recommendations are also provided for research methods to determine the relevance and presentation of patient information elements for HCP, in particular the nurse case manager, in community based chronic illness care settings in future studies informed by the lessons learned from the pilot study. These recommendations can be used to inform nurse informatics specialists, and guide CIS design and research in chronic illness care.

Proposed Patient Information Elements

The proposed categories for inclusion in a CIS design for community based chronic illness care are those that had agreement between the review and the pilot study. Additional categories are also proposed that are necessary to support the role of the nurse case manager and facilitate the components of the CCM and eCCM. The specific elements are not proposed due to limited results of the pilot study. The proposed categories as a result of agreement between the review and pilot study results are diagnostics, observations, medications, problem list, clinical events and guidelines. The additional categories proposed to support the role of the nurse case manager and the CCM and eCCM are care plan, outcomes and comparisons, clinician to clinician communication, and patient to clinician and clinician to patient communication.

The care plan category is integral to improving patient centred care and care coordination. The nurse case managers in the pilot study and the literature on the CCM and

eCCM emphasize the need for the inclusion of the care plan category. This category is therefore necessary to support the patient information needs of the nurse case manager and improve patient self-management and patient centred care and is therefore recommended for inclusion in CIS design. The care plan category should include representation of the patient's preferences and values to truly support patient centered care planning. The monitoring of guideline adherence or decision support features within a CIS will also have to allow guidelines and decision support to be overridden by entries of patient preferences and/or values. This is also a key area where the nurse case manager as a CNS can advocate for changes in CIS design and clinical documentation standards to support the ability to capture and act upon patient preferences and values with the support of a CIS

Two additional categories are proposed to support interprofessional teams, inclusive of the patient. At this point, the results of the review and the pilot do not provide support for the inclusion of the elements: clinician to clinician communication, patient to clinician and clinician to patient communication within the CIS. However, support for the team's interactions, as well as the patient-provider interactions, within the healthcare system is recognized as necessary for optimizing health and wellness (Epping-Jordan, Bengoa, & Wagner, 2004; Gee et al., 2015; World Health Organization, 2013). Therefore, these elements are recommended for inclusion in CIS design to enhance the utilization of CIS for chronic illness care. The nurse case manager should advocate for this type of information sharing between patients and providers, which is best supported by giving patients access to their own health care information through technical solutions such as patient health records or portals. These tools are not widely used in Canada today therefore this advocacy is crucial to supporting the inclusion of the communication categories and supporting the complete feedback loop within the CCM and eCCM. These

categories will likely also require other technical solutions such as interoperability with patient health records and secure messaging portals (Gee et al., 2015) in order to facilitate efficient workflows.

The results of both studies do not support the inclusion of the category outcomes and comparisons. However, the inclusion of the category outcomes and comparisons is also recommended to support the nurse case manager role to implement guidelines into clinical practice. This also supports the components of the chronic care model, decision support, delivery system design and the health system. This category promotes the ability of nurse case manager to fully enact the chronic care model through facilitating access the nurse case managers access to data on outcomes and comparisons at a patient, as well as an aggregate level. At a patient level access to this data through the CIS design allows the nurse case manager to educate the client on trajectories and facilitate self-management support through direct care. At an aggregate level outcomes and comparisons allow the nurse case manage to participate in quality improvement initiatives that are essential to the delivery system component of the CCM and eCCM. This data is also essential for the nurse case manager to collaborate on improvement to clinical guidelines based on data from the patient population they are supporting. Revisions to guidelines can then be incorporated into the decision support features of the CIS.

Health care and technology are not static entities. New evidence and priorities emerge in both technology and healthcare frequently. Nurse Informatics Specialists must be prepared to provide appropriate guidance with the support of health information technology (McCormick et al., 2007). Therefore it is also recommended that there is a method within the CIS design to quickly and easily adjust categories and update the included elements within the categories based on the new findings in the literature, policy changes, and changes in clinical guidelines and

standards of care. The nurse case manager also has a role in advocating and monitoring that these updates to the CIS to happen in time to support changes in practice.

Finally the inclusion of any of the patient information element categories in CIS design are only useful if the documentation that provides the data within the categories is accurate and timely. Therefore the nurse case manager also has a role in influencing documentation policies to enforce the use of the CIS by HCPs. The CIS is a tool similar to a blood pressure cuff or an IV pump and the CNS has a vital role in creating the standards around the use and design of the tool.

Proposed Visualization Techniques and Formats

The recommended presentation formats for the proposed patient information elements are based primarily on the review findings with the exception of the recommendation for diagnostics, which is derived from the results from both the review and the pilot study. In order to support nurse case manager information needs within CIS design, this recommendation is the first and primary recommendation for visualization formats. The proposed presentation formats for the patient information elements are:

1. Graphs and colour coding as the presentation format for diagnostics and outcomes and comparisons.
2. Text as the presentation format for observations, medications, problem lists, care plan, guidelines, clinician to clinician communication, patient to clinician and clinician to patient communication.
3. Timelines as the presentation format for representing clinical events.

A concept-oriented view is the proposed organization method for the patient information elements. The concept-oriented views in the literature were focused on organization by diagnosis which is not surprising given the primary user group was physicians and this view supports the

biomedical model and physician information needs. In contrast, these views should be customizable by user role depending on the role in the team a user is fulfilling. For example, additional concept-oriented views should be explored that facilitate the workflow of the nurse case manager such as organizing elements by the nursing process or the care plan. In order to manage details in this view the recommended detail management technique for CIS design is a combination of filtering, expanding and collapsing, and multiple views.

Recommendations for Research Design

The researcher's experience with the pilot study resulted in lessons learned that have been translated into recommendations for future research study design in the area of patient information elements identification and presentation for HCP, including the nurse case manager. . The primary lesson learned was that feasibility and context needs to be investigated to inform research design. The recommendations include conducting an environmental scan, utilizing a variety of recruitment strategies, aligning data collection with clinical workflow, using of an experimental design to measure impact to quality of patient care, and providing visual representations and interaction to participants.

A primary recommendation for future research in this area would be to perform an environmental scan of the research approval procedures and the service delivery model within each health authority. This should include interviews with other researchers that have done similar province wide research, with the population of nurse case managers on the topic of CIS, as well as, interviews with operational managers and the research departments in each health authority. This preparation prior to undertaking the research process would validate assumptions and increase utility and relevance of research to the practice area of nurse case managers. Coyne, Grafton & Reid (2016) recently identified strategies for improving recruitment and engagement

of clinical nurses as research participants. These strategies included securing key nursing staff engagement, understanding work constraints and establishing rapport with participants.

Discussions with operational managers would allow the researcher to explain the importance and applicability of the research to operational managers who have the authority to approve or deny research in their programs and discuss strategies for reducing participant burden to acceptable limits within work constraints. The information gathered in the environmental scan could also identify other avenues for recruitment and engagement.

Another recommendation aimed at improving recruitment and participation would be to use a variety of recruitment strategies. Recruitment strategies that have been shown to improve response rates include incentives, enlisting champions or leaders, multiple contact attempts, and information letters or posters to increase awareness before data collection (Bonevski, 2014). These strategies should not all require operational approval within the health authorities. Operational managers may act as gatekeepers that prevent interested participants from being identified. A national registry of nurses that identifies the role each nurse would solve this problem. However, in the absence of a national registry of nurses other avenues must be used to identify participants. The use of social media is an acceptable, low cost and effective method for recruitment if the demographics of the desired population fit with those using social media (Child et al., 2014). The use of social media may introduce a participant bias, but this bias could be mitigated by not using a variety of recruitment methods. Even with successful recruitment there are still other barriers that must be addressed to increase engagement of nurses and HCP's as research participants. These recruitment strategies are necessary to ensure that the nursing profession has representation in CIS research if nurses can find the time to participate.

One identified barrier to participation in research by HCP is lack of time (Bonevski, 2014). Therefore research designs should also utilize data collection methods that align with clinical workflow and do not require extra time or effort on the part of the HCP. Another option would be to request protected time within the HCP work hours. However this is unlikely without a drastic change to the culture in health care organizations and the practice of those HCP (Bonevski, 2014). This is another area where the environmental scan and enlisting operational managers as champions could improve participation and inform research design.

In order to provide recommendations for CIS design that are supported by empirical evidence, it is necessary for studies to use well designed evaluation studies (Ammenwerth, 2015). Health care leadership requires evidence that justifies the costs and risks associated with CIS implementation (Chaudry et al., 2006). In addition, software designers require this evidence to justify the effort and risk associated in changing the CIS design. The strongest evidence comes from experimental designs (LoBiondo-Wood & Haber, 2013). However, experimental designs are often unattainable for graduate student theses due to their cost, research skills required, stringent ethics and operational approval requirements, and long timelines. Therefore, a balance must be struck between the need for experimental designs and other research methodologies that fit within budgets, skills, and time of the researcher and still answer the research questions. This may mean performing experimental evaluation studies within one institution or one health authority rather than provincial or national studies. These results could then be aggregated with others to strengthen the evidence. The aggregated findings of the single institution or health authority studies could then be utilized by Nursing Informatics Specialists in advocating for evidence informed decision making about CIS design and procurement supported by evidence.

While many types of evaluation studies will generate evidence that improves or justifies CIS use, there is a gap in empirical evidence on the impact on the quality of patient care. Only 15.5% of studies in a HIT research database evaluated the impact on quality of care (Ammenwerth, 2015). This is consistent with the review findings where only one study measured patient outcomes (Foraker et al., 2016). The metrics for future studies evaluating the impact of CIS design should be focused on quality of patient care including patient outcomes and HCP, in particular the nurse case managers, performance. These metrics should also evaluate the CIS design for improved team performance. CIS procurement and implementation is expensive and often fails (Unertl et al., 2012). There is a consensus that nurses must participate in developing information systems that improve the quality of patient care (McCormick et al., 2007) Therefore it is necessary to research the necessary patient information elements and visualization formats, techniques and views that improve both the nurse case managers, and interprofessional team performance and patient outcomes in order to inform the CIS design. Nursing Informatics Specialists will play key roles in translating this evidence into the CIS design.

A final recommendation based on the pilot study participant's responses is to provide visual representation of options to participants early in the research phases. The participant indicated that the summary was difficult to visualize and if she saw the patient summary she would have more feedback. She also indicated that her choices were based on what was familiar both from the paper record and the current EHR. This aligns with human-centered design principles and usability research principles that emphasize that is necessary to involve users early in the design and to test the use with real world scenarios (Kushniruk et al., 2013). This indicates that prototypes and visual examples must be presented to research participants. It also indicates

that it is necessary for HCP to use the CIS with different information elements and presentation formats and this use must be evaluated. The recommendations above provide a starting point for CIS design and inform future research that can be utilized and expanded on by Nursing Informatics Specialists.

In Summary

Research into the pertinent information required for HCP providing community-based chronic illness care is relatively new. Furthermore, research into the pertinent information required by the role of the nurse case manager is nonexistent. To the researcher's knowledge this is the first scoping review that has examined information needs and presentation in CIS for the HCP within the context of community chronic illness care. The pilot study is the only study to the researcher's knowledge that examines the patient information nurse case managers require for community-based chronic illness care and how to present this information. This review and the accompanying pilot study did not allow for definitive conclusions on which patient information elements are necessary for the purpose of chronic illness care or how to represent that information within a CIS. However there is a possible starting point for a framework of guidelines for CIS design including: diagnostics, and outcomes and observations represented as graphs and colour coded, observations, medications, problem lists, guidelines, the care plan, clinician to clinician communication, patient to clinician and clinician to patient communication, represented as text, and clinical events represented in a timeline. All of these categories should be organized in a concept view that is customizable by the role including a view that supports the nurse case manager's workflow. This view must also be able to change when there are updates to the required information such as changes to clinical guidelines or standards of care. The nurse

case manager has a vital role in advocating for the changes to the CIS design, as well as promoting the use of the CIS by other HCPs.

Gaps in the literature identified more research is required on what information is needed and how to present this information in a way that supports HCP, in particular the nurse case manager's and the interprofessional team's performance, as well as, patient outcomes within chronic illness care. This research should focus on the information needs that are common across multiple diseases and therefore can be utilized for patients with comorbidities. Evaluations will also be needed of the organization and presentation of this information. There was also a gap in the literature and within the CCM and eCCM concerning patient involvement and how CIS and CDSS can facilitate the self-management component of the CCM and eCCM. Therefore, future research should also include explorations of the required information to support patient based decision support. Additionally, more research on determining information relevance, visualization, and organization techniques that facilitate patient involvement in patient centred care planning is necessary. This will assist nursing informatics specialists to advocate for functionality in personal health records, patient portals, and interoperability processes and standards that will support patient involvement in patient centered care planning. In order to align with the theoretical models of the CCM and eCCM evaluated processes should focus on those that are necessary for effective chronic illness care including fostering productive patient interactions, attaining measurable outcomes, interprofessional team interactions, and patient self-management including patient centered care planning.

An increasing number of CIS are being developed to provide the right information at the right time in the right way to health care providers. These CIS should be designed based on a framework that is supported by empirical evidence. Within this framework, a set of guidelines is

required for development of these CIS that identifies the required data elements, visualization formats and techniques, format and organization methods. These guidelines should be developed with the needs of CNS role of the nurse case manager prioritized. The design guidelines should also be supported by the theoretical framework of the CCM and eCCM. The recommendations within this paper provide a starting point for the development of this framework. This framework can be utilized by Nurse Informatics Specialists to guide the future of CIS design to support chronic illness care in community settings.

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Appendix A

Search Terms

Database	Limits	Query	Results	Excluded Based on Abstract and Title Review
Medline	English	(MH "Health Information System OR MH "Electronic Health Record (UT)" OR "Clinical Information System" [All Fields] OR (EMR OR EHR [All Fields]) OR "Computerized Patient Record* [All Fields] OR "Electronic Medical Record*" [All Fields]) AND (MH "Data Display" OR MH "Medical Record, Problem-Oriented" OR "Clinical Summarization" [All Fields] OR Visualization [All Fields] OR "Concept Oriented View*" [All Fields] OR "Problem Oriented View*" [All Fields])	278	136
CINAHL	English, Excluded Magazines	(MH "Electronic Health Records" OR MH "Patient Records Systems" OR "Clinical Information System*" [All Fields] OR EMR [All Fields] OR "Electronic Medical Record* [All Fields] OR "Computerized Patient Record* [All Fields] OR EHR [All Fields]) AND (MH "Data Display" OR "Concept Oriented View" [ALL Fields] OR MH "Problem Oriented Records" OR "Problem Oriented View" [All Fields] OR Visualization [All Fields] OR "Clinical Summarization" [All Fields])	76	38
Web Of Science	English, Excluded Book Chapters and Editorials	("Concept Oriented View*" OR "Problem Oriented Medical Record*" OR "Problem Oriented View*" OR "Data Display*" OR "Information Visualization" OR "Visualization" OR "Clinical Summarization" [All in Topic]) AND (EHR OR EMR OR "electronic health record*" OR "Clinical Information System*" OR "electronic medical record*" OR "computerized patient record*" [All in Topic]) * No MeSH Headings were used as the database did not have this option	250	112

Appendix B**Data Extraction Form**

Title:

Author:

Date:

Article Type:

Methodology:

Purpose:

Theory:

Setting:

Participants:

Sample Size:

Health Information Technology Type:

Design Recommendations:

Research Recommendations:

Results:

Chronic Illness:

Prototype

Article Category:

Appendix C

Case Study

A 59-year-old lady is coming to the clinic for a routine visit. She has a history of hypertension, diabetes mellitus type 2, and chronic renal insufficiency of more than 10 years duration. She lives on an island in Northern BC. She works as an animal rescuer for wild animals. This requires frequent and unexpected travel in which she is required to eat at truck stops and sometimes miss meals. Each bus trip to the clinic takes 2 days of travel each way plus the day of the appointment and costs \$75. Her husband passed away this year and she now lives alone. She has two adult children who live 8 and 10 hours away. She reports fatigue, decreased appetite, and lower extremity edema for the last few months. The patient's current medications include atenolol 50 mg daily, Hydrochlorothiazide 25 mg daily, and metformin 1,000 mg twice daily. She smokes one pack of cigarettes daily. Examination: Weight—60 kg, pulse—78, and BP—176/96 mmHg. She has no periorbital edema. She denies shortness of breath at rest but experiences dyspnea with exercise. Her lower extremities show diminished peripheral pulses and trace pedal edema. Current labs are normal except for a serum creatinine of 220µmol/L, GFR 35ml/min and a HgA1C of 8.5.

Modified from: Lerma, E. & Rosner, M (2013). Chronic kidney disease: Definition and general approach. In *Clinical Decisions in Nephrology, Hypertension and Kidney Transplantation*. Springer Science + Business Media, New York, n.p. Retrieved from http://link.springer.com.ezproxy.library.uvic.ca/chapter/10.1007/978-1-4614-4454-1_23/fulltext.html on February 23, 2015.

Appendix D

First Round Questionnaire

Note: This questionnaire appeared different in the electronic version. The free text boxes were next to each element and expandable which will allow for as many comments as the participant desired to make.

After reviewing the case study above please answer the following questions:

1. What patient information would you review before or during a clinic visit for the case study above? Please check all that apply

Diagnostics

Blood

- HgbA1C
- Hemoglobin
- WBC
- Creatinine
- GFR
- Albumin
- BUN
- PTH
- Uric Acid
- Vit D
- Tsat
- Potassium
- Phosphorus
- HDL
- LDL
- Triglycerides

Imaging

- Chest xray
- Renal Ultrasound
- Cardiac Echo
- Nuclear Stress Test
- Kidney Biopsy

Urine

- Protein
- microalbumin
- RBC
- WBC
- ACR

Measurements

- Weight
- BP
- Edema
- Skin integrity

- Medications
- Vaccines

- Demographics
- Code Status
- Transplant Status
- Preferred Renal Replacement Therapy

- Problem List
- Alerts
- Allergies
- Patient Demographics

- Self-Management Barriers
- Patient Goals
- Clinical Notes - Please list all types
- Assessments- Please list all types
- History
- Schedule
- Last visit date
- Reminders

2. Was there any patient information missing from the list above? If so please identify and explain.

3. What, if any, of the patient information above would you communicate to or receive from another member of the multidisciplinary team for this patient that you would include in the summary?

4. Which of the patient information is needed in the summary for you to follow clinical or best practice guidelines? Please Identify and explain.

Appendix E

Semi-Structured Interview Guide

1. I have sent you your responses, the original case study and how your responses compared to the other participants. Have you had a chance to review this? If not we can review it now.
2. Do you have any comments about your responses? Are there any clarifications needed about these items?
3. These are the items that you believed should be included and the other participants did not. Do you still agree with these items being included? Probing question: Is there anything else you think should be included looking at this list now?
4. These are the items the others believed should be included and you did not? Do you still believe these items should not be included? Probing question: Any other changes you would like to make?
5. These are the items that you were in agreement with the other participants. Would you like to make any changes to these items? Probing question: Anything else?
6. Which of the items that you believe should be included are the most important? Probing question: Any others?
7. What makes this/these items the most important? Probing question: Anything else that makes this/them important?
8. How would you like to see the information that you believe should be included in the summary presented? Prompts of options include: 1. Text 2. Directional Arrows (ex. ↗ for increase) 3. Graph 4. Number 5. Colour Coded 5. Other
9. How would showing the information in this way help you? Probing question Is there any other reasons or ways it would help?
10. Which of the items that you believe should be included in the patient summary should be grouped together in the display?
11. Why do you think that they should be grouped in this way? Probing question: How would this help you or other nurses?
12. Any other comments?
13. Thank you for your time and participation. Depending on the results of the analysis of the interviews the third survey may still be sent out in the next few weeks

Appendix F

Original Study Script Invitation

You are being invited to participate in a study entitled “Development of a Clinical Patient Summary Screen for Case Management Nurses Working in Chronic Disease Management”, conducted by Vanessa Kinch a Masters Student at the University of Victoria. Your participation must be free and voluntary. You can contact her at [REDACTED] or by email at vmkinch@uvic.ca. This research is part of a Master’s Thesis conducted under the supervision of Dr. James Ronan and Dr. Karen Courtney, who can be contacted at [REDACTED] – or by email at jronan@uvic.ca and [REDACTED] – or by email at court009@uvic.ca respectively.

The objective of this research is to explore what patient information is desired in an electronic patient summary by case management nurses working with patients with multiple chronic diseases. Additionally objectives include explore how the information should be presented in the summary and what functionality it should contain. A key component of this research is obtaining the opinions of a panel of experts in the field on the information and functionality requirements in order to develop a prototype of a clinical patient summary screen designed for use in chronic disease management clinics. In order to choose and prioritize the patient data a clinical patient summary screen for use in chronic disease management clinics should be composed of your opinions would be of great value.

If you should agree to participate an initial open-ended online questionnaire will be administered to identify a comprehensive list of patient data types to be included in the summary. A second questionnaire will follow a few weeks later to validate and prioritize the data types as well as determine what format to present the data in. A third questionnaire with a prototype clinical patient summary screen will be administered to assess the perceived usefulness and quality of the prototype developed based on the responses from the first two questionnaires.

The questionnaires will be delivered online through a web survey tool FluidSurveys which has been purchased by a U.S. Company. Please be advised that this research study includes data storage in the U.S.A. As such, there is a possibility that information about you that is gathered for this research study may be accessed without your knowledge or consent by the U.S. government in compliance with the U.S. Patriot Act. A period of approximately 3 weeks to one month is anticipated between questionnaires and it is anticipated that they will take 15-30 minutes to complete. Should you agree to participate an access code will be emailed to you. All participants are anonymous to each other. Your data will be combined with the other participants in the analysis and only the summarized results will be presented in the second questionnaire. No individual responses will be reported. Your confidentiality will be protected and your answers will be anonymous.

The data in each phase’s questionnaire will be used to inform the next phase’s questionnaire and the prototype clinical patient summary screen. The results of this study will be shared with committee members. The results will be used in the researcher’s Master’s Thesis and will be published in an online directory through the University of Victoria. The results may also be published in journal articles and presented at research conferences.

All data will be stored in encrypted files on a password protected computer in the researcher's home. This is a personal desktop. Individual access codes will be given to each participant to access their own questionnaires. Electronic data will use participant codes as identifiers not participant information. Any files containing a link between participant codes and participant information that can identify a participant will be stored separately in a separate encrypted file from the electronic data. This file will be stored on a separate password protected segment of the hard drive. Upon thesis completion and graduation the survey and all participant surveys will be erased by the researcher from the Fluid Survey servers. The data will be stored for five years on a password protected personal computer in encrypted files. After five years the files will be erased.

Your participation in this research is completely voluntary and you may drop out of the study at any time. If you drop out after the first questionnaire, your individual survey will be removed. However if this is after the closing date of the initial survey your data will already have been used in the data analysis to inform the next round and it will be too difficult to remove individual data. Therefore it will be used to inform the second and third questionnaires. Withdrawal will mean that no further reminders or access codes will be sent to you; however data already given will remain in the study. All data will be stored and analyzed on the researcher's personal computer in password-protected files. Results will not include any personal identifiers. Only the researcher and the supervisors will be aware of participant identities. All data will be erased and destroyed upon the researcher's graduation.

The results of this study will be valuable to clinical informatics specialists and information technology vendors and designers in designing useful clinical patient summary screens for the purpose of coordinating and providing care to patients with multiple chronic diseases.

The results of this study will be shared with committee members. The results will be used in the researcher's Master's Thesis and will be published in an online directory through the University of Victoria. The results may also be published in journal articles and presented at research conferences.

At the conclusion of this study participants will be sent the abstract of the study and results as well as a link to access the online thesis.

You may verify the ethics approval of this study or raise any concerns with the Human Research Ethics Office at the University of Victoria (250) 472-4545 or ethics@uvic.ca

You may also contact the Chair of the Interior Health Research Ethics Board at 250-870-4602 or via email to researchethics@interiorhealth.ca

You may also contact Health Research Ethics Office of Island Health 250 370-8620 or researchethics@viha.ca.

Appendix G

Revised Study Script Invitation

You are being invited to participate in a study entitled “Development of a Clinical Patient Summary Screen for Case Management Nurses Working in Chronic Disease Management”, conducted by Vanessa Kinch a Masters Student at the University of Victoria. Your participation must be free and voluntary. **You can contact her at [REDACTED] or by email at vmkinch@uvic.ca.** This research is part of a Master’s Thesis conducted under the supervision of Dr. James Ronan and Dr. Karen Courtney, who can be contacted at [REDACTED] – or by email at jronan@uvic.ca and [REDACTED] – or by email at court009@uvic.ca respectively.

The objective of this research is to explore what patient information is desired in an electronic patient summary by case management nurses working with patients with multiple chronic diseases. Additional objectives include exploring the format the information should be presented in and how the user can manipulate the display of information. A key component of this research is obtaining the opinions of a panel of experts in the field on the information and functionality requirements in order to develop a prototype of a clinical patient summary screen designed for use in chronic disease management clinics. Your opinions would be of great value in informing the research and developing the prototype.

If you should agree to participate an initial open-ended online questionnaire will be administered to identify a comprehensive list of patient data types to be included in the summary. A follow-up interview will follow a few weeks later to validate and prioritize the data types as well as determine what format to present the data in. A final questionnaire with a prototype clinical patient summary screen may be administered to assess the perceived usefulness and quality of the prototype developed based on the responses from the first questionnaire and the follow up interviews. If you do not have approval to participate during work hours it is requested that you participate during personal time.

The questionnaires will be delivered online through a web survey tool FluidSurveys which has been purchased by a U.S. Company. Please be advised that this research study includes data storage in the U.S.A. As such, there is a possibility that information about you that is gathered for this research study may be accessed without your knowledge or consent by the U.S. government in compliance with the U.S. Patriot Act. A period of approximately 3 weeks to one month is anticipated between questionnaires and it is anticipated that they will take 15-30 minutes to complete. Should you agree to participate an access code will be emailed to you. All participants are anonymous to each other. Your data will be combined with the other participants in the analysis and only the summarized results will be presented in the second questionnaire. No individual responses will be reported. Your confidentiality will be protected and your answers will be anonymous.

The data in the first questionnaire will be used to inform the follow up interview. Furthermore the data from both the interviews and the questionnaires will be used to inform the prototype clinical patient summary screen. The results of this study will be shared with committee members. The results will be used in the researcher’s Master’s Thesis and will be published in an

online directory through the University of Victoria. The results may also be published in journal articles and presented at research conferences.

All data will be stored in encrypted files on a password protected computer in the researcher's home. This is a personal desktop. Individual access codes will be given to each participant to access their own questionnaires. Electronic data will use participant codes as identifiers not participant information. Any files containing a link between participant codes and participant information that can identify a participant will be stored separately in a separate encrypted file from the electronic data. This file will be stored on a separate password protected segment of the hard drive. Upon thesis completion and graduation the survey and all participant surveys will be erased by the researcher from the Fluid Survey servers. The data will be stored for five years on a password protected personal computer in encrypted files. After five years the files will be erased.

Your participation in this research is completely voluntary and you may drop out of the study at any time. If you drop out after the first questionnaire, your individual survey will be removed. However if this is after the closing date of the initial survey your data will already have been used in the data analysis to inform the next round and it will be too difficult to remove individual data. Therefore it will be used to inform the follow up interviews and final questionnaires. Withdrawal will mean that no further reminders or access codes will be sent to you; however data already given will remain in the study. All data will be stored and analyzed on the researcher's personal computer in password-protected files. Results will not include any personal identifiers. Only the researcher and the supervisors will be aware of participant identities. All data will be erased and destroyed upon the researcher's graduation.

The results of this study will be valuable to clinical informatics specialists and information technology vendors and designers in designing useful clinical patient summary screens for the purpose of coordinating and providing care to patients with multiple chronic diseases.

The results of this study will be shared with committee members. The results will be used in the researcher's Master's Thesis and will be published in an online directory through the University of Victoria. The results may also be published in journal articles and presented at research conferences.

At the conclusion of this study participants will be sent the abstract of the study and results as well as a link to access the online thesis.

You may verify the ethics approval of this study or raise any concerns with the Human Research Ethics Office at the University of Victoria (250) 472-4545 or ethics@uvic.ca

You may also contact the Chair of the Interior Health Research Ethics Board at 250-870-4602 or via email to researchethics@interiorhealth.ca

You may also contact Health Research Ethics Office of Island Health 250 370-8620 or researchethics@viha.ca.

Appendix H

Original Participant Information Letter

Project Title: Development of a Clinical Patient Summary Screen for Chronic Disease Management

Researcher(s): VANESSA KINCH, Graduate Student, Departments of Nursing and Health Information Science, UNIVERSITY OF VICTORIA, [REDACTED], vmkinch@uvic.ca

Supervisor: Dr. James Ronan, Department of Nursing, [REDACTED], jronan@uvic.ca and Dr. Karen Courtney, Department of Health Information Science, [REDACTED], court009@uvic.ca

Purpose(s) and Objective(s) of the Research:

- The purpose of this study will be to explore what information nurses require in an Clinical Patient Summary Screen (CPSS) in order to manage a patient with multiple chronic diseases.
- Additionally it will explore how the information should be displayed, what features and functionality the user interface should include, and the perceived usefulness of the tool.
- The objective is to design a prototype CPSS that could be adapted and implement in CDM clinics that utilize case management nurses as part of the multidisciplinary team.

This Research is Important because:

- *In the field of chronic disease management a multi-pronged strategy is believed to be the most effective way to improve the care of patients. Health information technology (HIT) tools have been identified as a major component in that strategy. Designing effective HIT tools that assist clinicians in identifying pertinent patient information within the EHR that requires action or decision-making, such as the one this study intends to develop, has the ability to improve care. Currently there are no guidelines on what information to include or how to present it to clinicians. This study will provide guidance in the absence of these guidelines.*

Participation:

- You have been selected to participate because you are a registered nurse working in either a diabetic clinic or a chronic kidney disease clinic in BC and therefore meet the requirements to participate in the study.
- Participation in this project is entirely voluntary.
- You will not be compensated for your participation in the study.
- Whether you choose to participate or not will have no effect on your position [e.g. employment, class standing] or how you will be treated.

Procedures:

- Three online questionnaires will be administered over a period of six weeks. With each questionnaire you will be mailed a hyperlink and an access code. The results of each questionnaire inform the next. The final questionnaire will contain a prototype clinical patient summary screen based on the results from the first two questionnaires.

- **Duration: 15-30 minutes per questionnaire**
 - **Location: Online**
 - **Inconvenience:** *This is a three-part study that happens over a period of several weeks so the time commitment is higher than just a one time interview or questionnaire.*
5. **Sample Question:** Which of the patient information is needed in the summary for you to follow clinical or best practice guidelines? Please Identify and explain.

Benefits:

- This study will assist in developing the knowledge base for clinical informatics specialists, vendors and clinicians with the development of chronic disease management patient summaries designed to support case management nurse's information needs.
- Summary screens have been shown to be useful in identifying relevant information, filtering out extraneous data, and finding a particular piece of patient information. They have also been shown to be satisfying to clinicians and may improve patient care. This study will result in a prototype summary screen that can be adapted for use in chronic disease management settings.

Risks:

- There are no known or anticipated risks to you by participating in this research

Researcher's Relationship with Participants:

- The researcher may have a relationship to you as a previous coworker

Withdrawal of Participation:

- You may withdraw at any time without explanation or consequence.
- Should you withdraw before the second round, your data will no longer be used and will be removed from the analysis. Your first survey will be removed. If you withdraw after the second round your data will already have been analyzed and used to inform the next rounds.

Continued or On-going Consent:

- Your consent is implied by your voluntary participation in the surveys.

Anonymity and Confidentiality:

- All participants are anonymous to each other. All of your answers will be kept confidential. The questionnaire and the data will be password protected. Each participant will have a unique access code. The results of the data are analyzed without identifying information. Direct identifiers are removed and replaced with a code. The principal investigator will retain a list but it will be kept in a separate encrypted file on a password protected separate segment of the computer's hard drive.
- Only summary statistics will be provided to indicate group opinions. Individual opinions will not be provided to other participants. All narrative responses will be coded and categorized. No individual responses or identify language will be used.
- No names or identifying information will be used in data analysis or in the reporting of research results.

- Please be advised that this research study includes data storage in the U.S.A. As such, there is a possibility that information about you that is gathered for this research study may be accessed without your knowledge or consent by the U.S. government in compliance with the U.S. Patriot Act.

Research Results will [may] be Used/Disseminated in the Following Ways:

- Research results will be disseminated online in a electronic version of the researcher's thesis. The may also be published in journal articles and in conference presentations if deemed appropriate by the researcher and her supervisor's.
- A link to the thesis and an executive summary will be sent to participants

Disposal of Data

- All data will be stored in encrypted files on a password protected computer in the researcher's home. This is a personal desktop. Individual access codes will be given to each participant to access their own questionnaires. Electronic data will use participant codes as identifiers not participant information. Any files containing a link between participant codes and participant information that can identify a participant will be stored separately in a separate encrypted file from the electronic data. This file will be stored on a separate password protected segment of the hard drive. Upon thesis completion and graduation the survey and all participant surveys will be erased by the researcher from the Fluid Survey servers. The data will be stored for five years on a password protected personal computer in encrypted files. After five years the files will be erased.

Questions or Concerns:

- Contact the researcher(s) using the information at the top of page 1;
- Contact the Human Research Ethics Office, University of Victoria, (250) 472-4545 ethics@uvic.ca
- You may also contact the Chair of the Interior Health Research Ethics Board at 250-870-4602 or via email to researchethis@interiorhealth.ca
- If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the University of British Columbia Office of Research Ethics by e-mail at RSIL@ors.ubc.ca or by phone at 604-822-8598 (Toll Free: 1-877-822-8598).
- You may also contact the Health Research Ethics Office of Island Health 250 370-8620 or researchethics@viha.ca.

Consent:

By completing and submitting the questionnaires, **YOUR FREE AND INFORMED CONSENT IS IMPLIED** and 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, and that you consent to participate in this research project. By consenting, you have not waived any rights to legal recourse in the event of research-related harm

Appendix I

Revised Participant Information Letter

Project Title: Development of a Clinical Patient Summary Screen for Chronic Disease Management

Researcher(s): VANESSA KINCH, Graduate Student, Departments of Nursing and Health Information Science, UNIVERSITY OF VICTORIA, [REDACTED], vmkinch@uvic.ca

Supervisor: Dr. James Ronan, Department of Nursing, [REDACTED], jronan@uvic.ca and Dr. Karen Courtney, Department of Health Information Science, [REDACTED], court009@uvic.ca

Purpose(s) and Objective(s) of the Research:

- The purpose of this study will be to explore what information nurses require in an Clinical Patient Summary Screen (CPSS) in order to manage a patient with multiple chronic diseases.
- Additionally it will explore how the information should be displayed, what features and functionality the user interface should include, and the perceived usefulness of the tool.
- The objective is to design a prototype CPSS that could be adapted and implement in CDM clinics that utilize case management nurses as part of the multidisciplinary team.

This Research is Important because:

- *In the field of chronic disease management a multi-pronged strategy is believed to be the most effective way to improve the care of patients. Health information technology (HIT) tools have been identified as a major component in that strategy. Designing effective HIT tools that assist clinicians in identifying pertinent patient information within the EHR that requires action or decision-making, such as the one this study intends to develop, has the ability to improve care. Currently there are no guidelines on what information to include or how to present it to clinicians. This study will provide guidance in the absence of these guidelines.*

Participation:

- You have been selected to participate because you are a registered nurse working in either a diabetic clinic or a chronic kidney disease clinic in BC and therefore meet the requirements to participate in the study.
- Participation in this project is entirely voluntary.
- You will not be compensated for your participation in the study.
- Whether you choose to participate or not will have no effect on your position [e.g. employment, class standing] or how you will be treated.

Procedures:

- A phone interview will be conducted instead of the second questionnaire. This interview will be audio recorded and transcribed. There may still be a final questionnaire administered in the next few weeks that is informed by the results of all the participants

interview responses. The final questionnaire will contain a prototype clinical patient summary screen based on the results from the first two questionnaires.

- **Duration: 30-45 minutes for the interview and 15-30 minutes for the final questionnaire**
 - **Location: Telephone and Online**
 - **Inconvenience:** *This is a three-part study that happens over a period of several weeks so the time commitment is higher than just a one time interview or questionnaire.*
6. **Sample Question:** Which of the patient information is needed in the summary for you to follow clinical or best practice guidelines? Please Identify and explain.

Benefits:

- This study will assist in developing the knowledge base for clinical informatics specialists, vendors and clinicians with the development of chronic disease management patient summaries designed to support case management nurse's information needs.
- Summary screens have been shown to be useful in identifying relevant information, filtering out extraneous data, and finding a particular piece of patient information. They have also been shown to be satisfying to clinicians and may improve patient care. This study will result in a prototype summary screen that can be adapted for use in chronic disease management settings.

Risks:

- There are no known or anticipated risks to you by participating in this research

Researcher's Relationship with Participants:

- The researcher may have a relationship to you as a previous coworker

Withdrawal of Participation:

- You may withdraw at any time without explanation or consequence.
- Should you withdraw before the second round, your data will no longer be used and will be removed from the analysis. Your first survey will be removed. If you withdraw after the second round your data will already have been analyzed and used to inform the next rounds.

Continued or On-going Consent:

- Your consent is required to participate in the interview and your ongoing consent is implied if you complete the final questionnaire

Anonymity and Confidentiality:

- All participants are anonymous to each other. All of your answers will be kept confidential. The questionnaire and the data will be password protected. Each participant will have a unique access code. The results of the data are analyzed without identifying information. Direct identifiers are removed and replaced with a code. The principal investigator will retain a list but it will be kept in a separate encrypted file on a password protected separate segment of the computer's hard drive.

- Only summary statistics will be provided to indicate group opinions. Individual opinions will not be provided to other participants. All narrative responses will be coded and categorized. No individual responses or identify language will be used.
- No names or identifying information will be used in data analysis or in the reporting of research results.
- Please be advised that this research study includes data storage in the U.S.A. As such, there is a possibility that information about you that is gathered for this research study may be accessed without your knowledge or consent by the U.S. government in compliance with the U.S. Patriot Act.

Research Results will [may] be Used/Disseminated in the Following Ways:

- Research results will be disseminated online in an electronic version of the researcher's thesis. The may also be published in journal articles and in conference presentations if deemed appropriate by the researcher and her supervisor's.
- A link to the thesis and an executive summary will be sent to participants

Disposal of Data

- All data will be stored in encrypted files on a password protected computer in the researcher's home. This is a personal desktop. Individual access codes will be given to each participant to access their own questionnaires. Electronic data will use participant codes as identifiers not participant information. Any files containing a link between participant codes and participant information that can identify a participant will be stored separately in a separate encrypted file from the electronic data. This file will be stored on a separate password protected segment of the hard drive. Upon thesis completion and graduation the survey and all participant surveys will be erased by the researcher from the Fluid Survey servers. The data will be stored for five years on a password protected personal computer in encrypted files. After five years the files will be erased.

Questions or Concerns:

- Contact the researcher(s) using the information at the top of page 1;
- Contact the Human Research Ethics Office, University of Victoria, (250) 472-4545 ethics@uvic.ca
- You may also contact the Chair of the Interior Health Research Ethics Board at 250-870-4602 or via email to researchethics@interiorhealth.ca
- If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the University of British Columbia Office of Research Ethics by e-mail at RSIL@ors.ubc.ca or by phone at 604-822-8598 (Toll Free: 1-877-822-8598).
- You may also contact the Health Research Ethics Office of Island Health 250 370-8620 or researchethics@viha.ca.

Consent:

Type of recording

I agree to the use of ___ audiotapes

Consent by adults

I agree to participate in the described research. The nature of the project was explained to me and I have read the above information and know that I have the opportunity to discuss in full the nature of this project, and to question the principal investigator Vanessa Kinch

Signature

Date

Printed name

By completing and submitting the final questionnaire, **YOUR FREE AND INFORMED CONSENT IS IMPLIED** and 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, and that you consent to participate in this research project. By consenting, you have not waived any rights to legal recourse in the event of research-related harm

Appendix J

Advertisement for Invitation to Participate Development of a Clinical Patient Summary Screen

A Masters of Nursing and Health Information Science student is looking for nurses working in chronic disease management clinics for chronic kidney disease and/or diabetes. **If you are a registered nurse working within a clinic that provides chronic disease management to patients with either diabetes and/or chronic kidney disease you are invited to participate in a three part study aimed at designing an electronic patient summary screen for nurses managing patients with multiple chronic diseases.** The first part is an online questionnaire that will take 15-30min to complete. The second part is a follow up interview based on your responses to the questionnaire that will take 30-45min to complete. The final part is another online questionnaire that will validate the design of an electronic summary screen designed from the results of the questionnaires and interviews of participants. Please contact ymkinch@uvic.ca to participate.

Details: Will include link to full Invitation to Participate and Participant Information Letter

Appendix K

Invitation Script for Experts not Part of Sample

You are being invited to participate in a pilot study entitled “Development of a Clinical Patient Summary Screen for Case Management Nurses Working in Chronic Disease Management”, conducted by Vanessa Kinch a Masters Student at the University of Victoria. Your participation must be free and voluntary. You can contact her at [REDACTED] or by email at vmkinch@uvic.ca. This research is part of a Master’s Thesis conducted under the supervision of Dr. James Ronan and Dr. Karen Courtney, who can be contacted at [REDACTED] – or by email at jronan@uvic.ca and [REDACTED] – or by email at court009@uvic.ca respectively.

The objective of this pilot study is to test the adequacy and clarity of the initial survey instrument that is to be distributed to the actual study participants as well as the distribution method. The initial survey will be revised based upon your feedback and responses. The purposes of the actual study is to explore what patient information is desired in an electronic patient summary by case management nurses working with patients with multiple chronic diseases. Additionally objectives include explore how the information should be presented in the summary and what functionality it should contain. A key component of this research is obtaining the opinions of a panel of experts in the field on the information and functionality requirements in order to develop a prototype of a clinical patient summary screen designed for use in chronic disease management clinics. In order to choose and prioritize the patient data a clinical patient summary screen for use in chronic disease management clinics should be composed of your opinions would be of great value.

If you should agree to participate an initial open-ended online questionnaire will be administered to identify a comprehensive list of patient data types to be included in the summary. This is the initial questionnaire in the study. Your answers will be used to revise and clarify the questions that will be administered to study participants.

The questionnaires will be delivered online through a web survey tool Fluid Surveys which has been purchased by a U.S. Company. Please be advised that this research study includes data storage in the U.S.A. As such, there is a possibility that information about you that is gathered for this research study may be accessed without your knowledge or consent by the U.S. government in compliance with the U.S. Patriot Act. Should you agree to participate an access code will be emailed to you. All participants are anonymous to each other. Your data will not be included in the data analysis. Your data will only be used to revise and improve the initial questionnaire. No individual responses will be reported. Your confidentiality will be protected and your answers will be anonymous.

In the pilot study the data will be used to revise the original survey and resolve any issues in the distribution method. For the actual study, the data in each phase’s questionnaire will be used to inform the next phase’s questionnaire and the prototype clinical patient summary screen. The results of this study will be shared with committee members. The results will be used in the researcher’s Master’s Thesis and will be published in an online directory through the University of Victoria. The results may also be published in journal articles and presented at research conferences.

All data for both the pilot and the actual study will be stored in encrypted files on a password protected computer in the researcher's home. This is a personal desktop. Individual access codes will be given to each participant to access their own questionnaires. Electronic data will use participant codes as identifiers not participant information. Any files containing a link between participant codes and participant information that can identify a participant will be stored separately in a separate encrypted file from the electronic data. This file will be stored on a separate password protected segment of the hard drive. Upon thesis completion and graduation the survey and all participant surveys will be erased by the researcher from the Fluid Survey servers. The data will be stored for five years on a password protected personal computer in encrypted files. After five years the files will be erased.

Your participation in this pilot research is completely voluntary and you may refuse to participate. Results will not include any personal identifiers. Only the researcher and the supervisors will be aware of participant identities. All data will be erased and destroyed upon the researcher's graduation.

The results of this study will be valuable to clinical informatics specialists and information technology vendors and designers in designing useful clinical patient summary screens for the purpose of coordinating and providing care to patients with multiple chronic diseases.

The results of this study will be shared with committee members.

You may verify the ethics approval of this study or raise any concerns with the Human Research Ethics Office at the University of Victoria (250) 472-4545 or ethics@uvic.ca

You may also contact the Chair of the Interior Health Research Ethics Board at 250-870-4602 or via email to researchethics@interiorhealth.ca

You may also contact Health Research Ethics Office of Island Health 250 370-8620 or researchethics@viha.ca.

Appendix L

Certificate of Ethical Approval

**Board of Record
Interior Health**

220 - 1815 Kirschner Road
Kelowna, BC V1W 4N7



**Certificate of Ethical Approval for Harmonized
Minimal Risk Behavioural Study**

Also reviewed and approved by:

Island Health
Northern Health
UBC-BREB
University of Victoria

Principal Investigator: **Vanessa Kinch** Primary Appointment: **University of Victoria** Board of Record Approval Reference #: **2015-16-006-H**

Study Title: **Development of a Clinical Patient Summary Screen for Case Management Nurses in Chronic Disease Management**

Study Approved: **Jun-19-2015**

Expiry Date: **Jun-19-2016**

Research Team Members: Dr. James Ronan
Dr. Karen Courtney

Sponsoring Agencies: unfunded

Documents Included in this Approval:		
Development of a CDM DPSS Thesis Proposal		v3, June 18, 2015
University of Victoria HREB Application for Research Ethics Approval		v3, June 18, 2015
Harmonized Report of Review _Response		v3, June 18, 2015
Study Invitation Script		v3, June 18, 2015
Pilot Invitation Script		v3, June 18, 2015
Participant Information Letter		v3, June 18, 2015
Case Study		v3, June 18, 2015
1st Round Questionnaire		v3, June 18, 2015
2nd Round Questionnaire		v3, June 18, 2015
3rd Round Questionnaire		v3, June 18, 2015

This ethics approval applies to research ethics issues only and does not include provision for any administrative approvals required from individual institutions before research activities can commence.

The Board of Record (as noted above) has reviewed and approved this study in accordance with the requirements of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2, 2014).

The "Board of Record" is the Research Ethics Board designated on behalf of the participating REBs involved in a harmonized study to facilitate the ethics review and approval process. In the event that there are any changes or amendments to this approved protocol, please notify the Board of Record.

In respect of the identified study, I certify, as representative of this Research Ethics Board that:

[Remove / modify / add statements as required]

1. The membership of this Research Ethics Board complies with the membership requirements for Research Ethics Boards defined in Part C Division 5 of the Food and Drug Regulations.
2. This Research Ethics Board carries out its functions in a manner consistent with Good Clinical Practices.
3. This Research Ethics Board has reviewed and approved the clinical trial protocol and informed consent form for the trial which is to be conducted by the qualified investigator named above at the specified clinical trial site. This approval and the views of this Research Ethics Board have been documented in writing.

Board of Record Research Ethics Board Representative

Name: Wendy Petillion

Title: Chair, Interior Health REB

Signature: 

Date: Jun-19-2015

Appendix M

Certificate of Ethics Amendment Approval March 2016



Research Ethics Board
220 - 1815 Kirschner Road
Kelowna, B.C. V1Y 4N7

***Certificate of Research Ethics Board Delegated Approval -
Amendment***

Principal Investigator: Vanessa Kinch	Institution of Primary Association University of Victoria	IH Research File Identifier 2015-16-006-H
Study Title: Development of a Clinical Patient Summary Screen for Case Management Nurses in Chronic Disease Management		
IH Administrative Contact Patricia Park		Co-Investigators Dr. James Ronan, Dr. Karen Courtney
Sponsoring/Funding Agencies unfunded		IH Departments Involved in Research Study IH Outpatient Kidney and Diabetes clinics
Documents Covered by this Approval University of Victoria Request for Modification of an Approved Protocol received February 26, 2016 Appendix C, Sample Second Round Interview Appendix F, Participant Information Form v 4 dated March 3, 2016		
Certification It is the assessment of IH that this research study poses minimal risk to human participants and therefore qualifies for delegated review. The above named documents have been reviewed according to Interior Health Research Ethics Board policy and the procedures were found to be acceptable on ethical grounds for research involving human participants. This Certificate of Approval is valid for the term specified below provided there are no changes in the study procedures. <i>The Interior Health Research Ethics Board is in compliance with the ethical principles presented in the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans</i>		
Conditions for Approval It is the responsibility of the Principal Investigator to inform the IH Research Ethics Board if there are changes to consents or other materials used with human participants. Changes must be submitted to the IH Research Ethics Office for review and approval prior to implementation. It is the responsibility of the Principal Investigator to inform the IH Research Ethics Office if human participants experience serious or unexpected events.		
Approval Date March 3, 2016		Approval Term For remainder of current term
IH Authorized Signature 		<i>March 3, 2016</i> Date
Wendy Petillion, Chair / Interior Health Research Ethics Board		

Appendix N

Certificate of Ethics Amendment Approval May 2016



Research Ethics Board
220 - 1815 Kirschner Road
Kelowna, B.C. V1Y 4N7

**Certificate of Research Ethics Board Delegated Approval -
Amendment**

Principal Investigator: Vanessa Kinch	Institution of Primary Association University of Victoria	IH Research File Identifier 2015-16-006-H
Study Title: Development of a Clinical Patient Summary Screen for Case Management Nurses in Chronic Disease Management		
IH Administrative Contact Patricia Park	Co-Investigators Dr. James Ronan, Dr. Karen Courtney	
Sponsoring/Funding Agencies unfunded	IH Departments Involved in Research Study IH Outpatient Kidney and Diabetes clinics	
Documents Covered by this Approval IH REB Application for Amendment of an Approved project dated May 5, 2016 Instructions and Invitation Amendment version 2, dated May 9, 2016 PI Response to IH REB Report of Review received May 9, 2016		
Certification It is the assessment of IH that this research study poses minimal risk to human participants and therefore qualifies for delegated review. The above named documents have been reviewed according to Interior Health Research Ethics Board policy and the procedures were found to be acceptable on ethical grounds for research involving human participants. This Certificate of Approval is valid for the term specified below provided there are no changes in the study procedures. <i>The Interior Health Research Ethics Board is in compliance with the ethical principles presented in the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans</i>		
Conditions for Approval It is the responsibility of the Principal Investigator to inform the IH Research Ethics Board if there are changes to consents or other materials used with human participants. Changes must be submitted to the IH Research Ethics Office for review and approval prior to implementation. It is the responsibility of the Principal Investigator to inform the IH Research Ethics Office if human participants experience serious or unexpected events.		
Approval Date May 11, 2016	Approval Term For remainder of current term	
IH Authorized Signature 		<i>May 11, 2016</i> Date
Wendy Petillion, Chair, Interior Health Research Ethics Board		