

**Developing a set of criteria for defining the roles and responsibilities of the different types  
of heart failure disease management programs in Ontario:**

**A mixed methods study**

by

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## **AUTHORS DECLARATION**

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

## ABSTRACT

Heart failure is a complex, progressive cardiac condition, which is characterized as an inability to pump blood at a rate sufficient to meet the metabolic demands of the body. The heart failure syndrome is chronic with periods of stability punctuated by instability during which the patient can experience acute episodes of declining health and hospitalizations. Heart failure most commonly develops after the age of 65 and the risk of developing heart failure rises exponentially with age. Roughly 50,000 Canadians are diagnosed with heart failure annually and the absolute number of heart failure cases is expected to double by the year 2056 due to the aging population. Heart failure is the leading cause of hospitalizations for the elderly, accounting for 20,000 hospitalizations annually. The hospitalizations result in a decrease in the health of heart failure patients and place an undue burden on the acute care system. As such, outpatient heart failure clinics, defined as a “clinic that consists *at a minimum* of a physician (family physician/internist/cardiologist) and a nurse, one of whom has specialized training or interest in heart failure” were established in order to properly manage the condition. A 2013 study conducted by the Toronto Economics and Technology Assessment (THETA) Collaborative found that these outpatient clinics are only used by 10% of heart failure patients and there are significant differences in the resources, staffing, infrastructure and funding between the outpatient clinics. It is therefore crucial to establish a robust definition of the roles and responsibilities of the different types of outpatient heart failure disease management programs in Ontario.

The Cardiac Care Network Heart Failure Working Group generated a report outlining a strategy that would improve the integration of outpatient heart failure management in Ontario. One of the main recommendations outlined in this report was to establish a “hub and spoke”

organization of care. The “hub and spoke” organization of care is represented as a continuum of care that heart failure patients transition through as their heart failure condition changes. The outpatient heart failure clinics within this continuum are either defined as a “hub” of heart failure expertise or as a “spoke” in need of capacity building and access to mentors knowledgeable in managing the condition. The “hubs” and “spokes” represent the different types of outpatient heart failure disease management programs within Ontario. The wide variation in the operation of different outpatient heart failure clinics indicates that the roles and responsibilities of these different types of outpatient heart failure disease management programs are incompletely defined. The lack of robust criteria presents difficulties with establishing proper management protocols for patients with heart failure and will ultimately make the “hub and spoke” organization of care unsustainable in Ontario. The overall research aim of this study was to develop a set of criteria for defining the roles and responsibilities of the different types of outpatient heart failure disease management programs in Ontario and to create a list of recommendations to assist with the optimization of the quality and role of these different types of outpatient heart failure disease management programs. This was completed in two phases. The first phase observed two outpatient heart failure clinics, which represented two of the different types of outpatient heart failure disease management programs. The findings from this clinical observation were used to restructure a heart failure disease management scoring system developed by Reigel et al (2010) in order to develop a preliminary set of criteria. During the second phase of the study the preliminary set of criteria was used to score different types of outpatient heart failure disease management programs based responses from previously collected survey data. The care providers of these four outpatient heart failure disease management programs were then invited to participate in focus groups. The focus groups served to finalize

the set of criteria, as well as to identify barriers and facilitators to adopting the roles and responsibilities of the different types of outpatient heart failure disease management programs as described by the finalized set of criteria. Finally, the information gathered from the second phase of the study was used to construct a list of recommendations to assist with the optimization of the quality and role of the different types of outpatient heart failure disease management programs in Ontario.

There were four primary research objectives for this study:

1. To use the findings from our clinical observation to restructure a heart failure disease management scoring system developed by Reigel et al (2010) in order to develop a preliminary set of criteria to be used in the second phase of the study.
2. To use responses from an environmental scan survey to classify four outpatient heart failure disease management programs according to the preliminary set of criteria established during the first phase of this study
3. To use input from focus groups with physicians, clinical care coordinators, nurse practitioners, registered nurses and allied health professionals at the four outpatient heart failure disease management programs to:
  - a. Build upon and finalize the set of criteria for defining the roles and responsibilities of the different types of outpatient heart failure disease management programs.
  - b. Determine factors that facilitate or hinder outpatient heart failure disease management programs from adopting the finalized set of criteria
4. To triangulate the data from the second and third objectives in order to construct a list of recommendations to assist the Cardiac Care Network with the optimization of the quality

and role of the different types of outpatient heart failure disease management programs in Ontario according to the “hub and spoke” organization of care.

A mixed methods design, that combined both the quantitative and qualitative research methods, was used to address the research aim and objectives for the second phase of the study. The quantitative component explored the first research objective by using secondary data analysis to score four outpatient heart failure disease management programs in Ontario according to the preliminary set of criteria established during the first phase of the study. This served as a confirmation of the outpatient heart failure disease management program’s classification, as well as identified any issues with using the preliminary set of criteria. According to the first phase of the study there are three types of outpatient heart failure disease management programs in Ontario. With this knowledge we were able to pre-classify the four outpatient heart failure disease management programs as one of these three types. Since the preliminary set of criteria served to describe the roles and responsibilities for each type of outpatient heart failure disease management program, we were able to use this to score our programs and confirm our classification.

The qualitative component addressed the second research objective by using an ontological approach, which is a philosophical assumption whereby the researcher questions the nature of reality as seen through multiple views. The qualitative component served to finalize the set of criteria by understanding how the domains in the preliminary set of criteria were applicable to the different types of outpatient heart failure disease management programs in Ontario. The focus groups also determined factors that facilitated or hindered outpatient heart failure disease management programs from adopting the roles and responsibilities of their type of outpatient heart failure disease management program.

Finally, the data from the quantitative and qualitative components were methodologically triangulated in order to inform the third research objective. The triangulation process combined the information collected from the analysis of the survey and the focus group responses to create a list of recommendations to assist the Cardiac Care Network with the optimization of the quality and role of the different types of outpatient heart failure disease management programs in Ontario. The use of data triangulation complemented the quantitative and qualitative components of the study, which in turn increased the validity of the recommendations.

The quantitative component found that there was agreement between the preliminary set of criteria and the environmental scan survey regarding the classification of all four outpatient heart failure disease management programs. With respect to the qualitative component, the preliminary set of criteria were modified and finalized based on the feedback from focus group participants. Some of the domains were renamed and additional information was added to either avoid future confusion or assist care providers with identifying the roles and responsibilities that needed to be adopted in their type of outpatient heart failure disease management program. Further, the preliminary set of criteria was modified to include only two types of outpatient heart failure disease management programs, since focus groups with community care heart failure disease management programs did not take place. The scoring system was removed and replaced with a checklist of characteristics under each domain to improve ease of use. The qualitative component also addressed barriers and facilitators to adopting the finalized set of criteria. There were significantly more barriers identified than facilitators. All four of the outpatient heart failure disease management programs felt that they had adopted the roles and responsibilities of their type of outpatient heart failure disease management program. Thus, the facilitators are of key importance to future use of the finalized set of criteria for adopting the

roles and responsibilities for other outpatient heart failure disease management programs in Ontario.

In total nine barriers and four facilitators were identified. The nine barriers included: lack of education/knowledge/training in managing heart failure; provider comfort/ability in managing heart failure; difficulty discharging patients; poor communication across the continuum of care; nurse's scope of practice; nature of the disease; administrative barriers; resource availability; and rural issues with managing heart failure. Additionally, the four facilitators included: positive patient outcomes; mentorship from established programs; previous success in managing other chronic diseases; and support and relationships with other care settings. Finally, the results of the data triangulation identified four recommendations for optimizing the quality and role of outpatient heart failure disease management programs. These included: developing a guideline and/or education program on how to use the finalized set of criteria for defining the roles and responsibilities of the different types of outpatient heart failure disease management programs; encouraging the practice of having registered nurses with medical directives in outpatient heart failure disease management programs; increasing access to care in primary care heart failure disease management programs; and establishing and encouraging mandates for building relationships across the continuum of care.

In conclusion, the development of a set of criteria for defining the roles and responsibilities of the different types of outpatient heart failure disease management programs, as well as establishing a list of recommendations for optimizing the quality and role of outpatient heart failure disease management programs were important steps towards establishing a heart failure disease management strategy in Ontario. Further research is required in order to represent and reflect the full scope of heart failure disease management in the finalized set of criteria and

recommendations prior to implementing them in practice. However, acknowledgment of the findings on a small scale should show that the adoption of the finalized set of criteria and the implementation of the recommendations will improve the quality of heart failure disease management, thereby improving the health outcomes for heart failure patients in Ontario.

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## **LIST OF ABBREVIATIONS**

HF – Heart Failure

PCP – Primary Care Practice

FHT – Family Health Team

FHG – Family Health Group

CCAC – Community Care Access Centres

CCN – Cardiac Care Network

OHA – Ontario Hospital Association

THETA – Toronto Health Economics and Technology Assessment

## CHAPTER 1: INTRODUCTION AND OVERVIEW

Heart failure is a complex, progressive cardiac condition, which is characterized as an inability to pump blood at a rate sufficient to meet the metabolic demands of the body (Arnold et al., 2006). Often patients experience weakness, severe shortness of breath, fatigue, poor exercise tolerance and reductions in quality of life and survival (Arnold et al., 2006; Goodlin, 2009). The heart failure syndrome is chronic, consisting of alternating periods of stability and instability during which the patient can experience acute episodes of declining health and hospitalizations (Goodlin, 2009; Howlett et al., 2010). Roughly 50,000 Canadians are diagnosed with heart failure annually (Dai et al., 2012) and the absolute number of heart failure cases is expected to double by the year 2056 due to the aging population (CCN, 2014). Heart failure most commonly develops after the age of 65 and the risk of developing heart failure rises exponentially with age, reaching 20% in those over the age of 80 (Harkness et al., 2012). The 10 year mortality rate is 99% from the time of diagnosis; however, due to the clinical instability of the condition, over half of the patients with heart failure die within two years of being diagnosed (Chun et al., 2012). Heart failure is the leading cause of hospitalizations for the elderly, accounting for 20,000 hospitalizations annually (Dai et al., 2012), and is most often due to the ineffective management of the condition (McKelvie et al., 2013). The hospitalizations result in a decrease in the health of heart failure patients and place an undue burden on the acute care system (Dai et al., 2012). These hospitalizations and associated negative outcomes are potentially avoidable if a proper system for managing heart failure is established in Ontario.

A solution to the ineffective management of heart failure patients was the introduction of outpatient heart failure clinics in hospitals and some primary care clinics in Ontario. An outpatient heart failure clinic is defined as a “clinic that consists *at a minimum* of a physician

(family physician/internist/cardiologist) and a nurse, one of whom has specialized training or interest in heart failure” (Wijeysundera et al., 2011, pp.6). The clinics are described as outpatient because the heart failure patients that are generally seen in the clinic are not hospitalized (Krumholz et al., 2006). The Toronto Health Economics and Technology Assessment (THETA) identified 34 outpatient heart failure clinics in Ontario but noted that only 10% of all heart failure patients are seen in these outpatient heart failure clinics (Wijeysundera et al., 2011). The Cardiac Care Network suggested a number of reasons for this. Firstly, many primary care providers are not aware of the existence of outpatient heart failure clinics and therefore, rarely refer their patients to these services (CCN, 2014). This is worsened by the fact that there are currently no mechanisms in place that aim to integrate outpatient heart failure clinics with primary care providers (CCN, 2014). Secondly, there are no uniform criteria for accepting heart failure patients at the outpatient heart failure clinics (CCN, 2014). Finally, Ontario has not developed a standard care model for managing heart failure, which results in significant differences in the resources, staffing, infrastructure and funding in outpatient heart failure clinics as was described in the THETA report (CCN, 2014; Wijeysundera et al., 2011). In an attempt to develop a standard care model for managing heart failure and to improve the integration of care for heart failure patients, the Cardiac Care Network of Ontario suggested the adoption of a “hub and spoke” organization of care.

### **1.1 Cardiac Care Network Hub and Spoke Organization of Care**

The “hub and spoke” organization of care was developed by the Cardiac Care Network’s Heart Failure Working Group as a standard model of care in order to improve the integration of the outpatient management of heart failure in Ontario. According to this model, an ideal system for managing heart failure is one that centres on the primary care sector and includes integration

between community care programs, such as home care and palliative care, as well as specialty services (CCN 2014). Studies have found that long-term follow-up in primary care is appropriate for patients who are managed for heart failure (Luttik et al, 2014). Luttik et al (2014) described a study in which they compared patients with mild to moderate heart failure who were managed in primary care by a general practitioner vs. those who were managed in a hospital-based outpatient heart failure clinic. They found that long-term follow-up in a hospital-based outpatient heart failure clinic did not offer more benefits than follow-up in primary care for clinically stable heart failure patients (Luttik et al., 2014). Further, it was shown that patients can be referred for follow-up in primary care, once they are clinically stable, without an increased risk of mortality or hospital readmissions (Luttik et al., 2014). It is important to stress, however that according to the “hub and spoke” organization of care, follow-up in primary care is only successful if the care is integrated with community programs and specialty services (CCN, 2014; Luttik et al., 2014).

An integrated system for the outpatient management of heart failure creates a regional network of heart failure care, which offers the ability to co-manage heart failure patients across multiple sectors of care as well as the opportunity to establish mentorship programs (CCN, 2014). The establishment of mentorship programs fosters the growth in clinical competency and heart failure knowledge among providers at the primary care and community level, thereby increasing the quality of heart failure management at these levels (CCN, 2014). Further, integration across multiple sectors of care requires that care providers create professional relationships across the continuum of care, which allows heart failure patients the opportunity to make seamless transitions between care settings as their heart failure becomes less stable and/or more complex (CCN, 2014). It is vital that heart failure patients are afforded the opportunity to

make seamless and timely transitions across multiple sectors of care in order to ensure that limited, vital resources are appropriately provided to heart failure patients in the appropriate setting and within the appropriate timeframe (CCN, 2014). Therefore, the Cardiac Care Network of Ontario has recommended that outpatient heart failure management be based on a highly collaborative clinical practice model that facilitates communication and collaboration between primary care, specialty care and community care; thereby fostering the development of integrated care for heart failure patients in Ontario (CCN, 2014).

The integration of community care, primary care and specialty care in the “hub and spoke” organization of care is represented as a continuum of care that heart failure patients progress and regress through as their heart failure worsens or stabilizes, respectfully (CCN, 2014). The “hubs” and “spokes” represent the three different types of outpatient heart failure disease management programs within Ontario. A “spoke” represents a community care heart failure disease management program, which are described as either an independent provider clinic such as a specialist clinic; as a family health team; or as a community program such as CCAC. A “primary hub” represents a primary care heart failure disease management program, which can usually be described as an outpatient heart failure clinic within a family health team. Finally, a “tertiary care hub” and “quaternary care hub” represent specialty care heart failure disease management programs, which are generally described as outpatient heart failure clinics within a hospital and a hospital site that has a transplant program, respectfully. The outpatient heart failure clinics were described previously in this chapter. These “hubs and spokes” are defined as either a “hub” of heart failure expertise or as a “spoke” in need of capacity building and access to mentors knowledgeable in managing the condition according to Figure 1 (CCN, 2014).

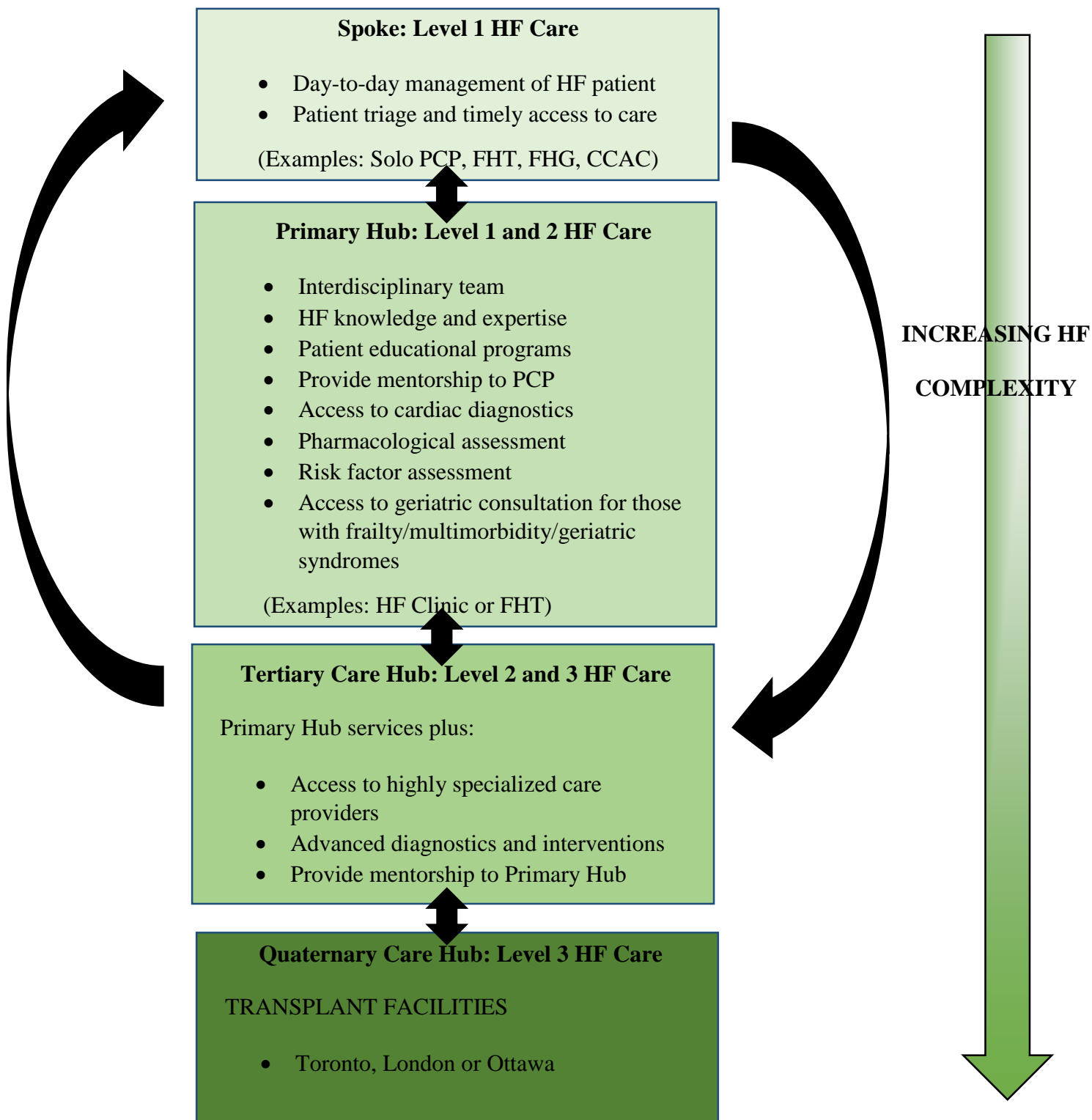


Figure 1. Hub and Spoke Organization of Care. Adapted from the CCN Strategy for Community Management of Heart Failure in Ontario Report, 2014

As depicted in Figure 1. “hubs” and “spokes” are responsible for different levels of heart failure (HF) care. Within this, heart failure patients can be identified according to the level of heart failure care that they require, which ensures that the appropriate care is provided in the correct care environment and in a timely fashion (CCN, 2014). For reference, level 1 HF care can be provided in a “spoke or primary hub”; level 2 HF care can be provided in a “primary hub or tertiary care hub” and level 3 HF care can be provided in a “tertiary care hub or quaternary care hub.” In the initial development of the “hub and spoke” organization of care each level of heart failure care was defined by a heart failure patient’s complexity according to the New York Heart Association (NYHA) classification and the type of care provision provided by the care environment at that level (CCN, 2014). The NYHA classification for each level of heart failure care and the respective care provision at that level is provided in Table 1.

Table 1. NYHA Classification and Care Provision According to the Level of HF Care. Adapted from the CCN Strategy for Community Management of Heart Failure in Ontario Report, 2014

<b>Level of HF Care</b>	<b>Type of Care Environment</b>	<b>Patient Status</b>	<b>Care Provision</b>
<b>1</b>	“Spoke” OR “Primary Hub”	Low complexity NYHA I-II	Optimal prescription of pharmacological and non-pharmacological therapy  Patient and caregiver self-care education and support
<b>2</b>	“Primary Hub” OR “Tertiary Care Hub”	Intermediate complexity NYHA II-III Unable to stabilize at Level 1	Consultation by Level 2 HF team  Patient stabilization  Review of therapies and recommendations for changes  Discharge to Level 1 when stable
<b>3</b>	“Tertiary Care Hub” OR “Quaternary Care Hub”	High complexity NYHA III-IV Unable to stabilize at Level 2	Consultation with and involvement of Level 3 specialized team until patient stabilizes sufficiently for transfer to Level 2 care  Ability to refer patients to appropriate transplant facilities

Regardless of the effort to define the characteristics of different types of outpatient heart failure disease management programs, there is still wide variation in the outpatient management of heart failure among similar types of outpatient heart failure disease management programs. An environmental scan survey conducted by the Cardiac Care Network found that, “primary hubs” were vastly different in terms of the resources, staffing, infrastructure and/or funding (Kingsbury, 2014). Similar findings were seen among the “tertiary care hubs” (Kingsbury, 2014).

Fragmented care within outpatient heart failure disease management programs poses a threat to the timeliness and quality of care heart failure patients receive both within and across jurisdictions. Within a jurisdiction improper funding, staffing, infrastructure and/or resources within one type of outpatient heart failure disease management program (i.e., the “primary hub”) prevents proper transitions and care integration with another type of outpatient heart failure disease management program (i.e., the “tertiary care hub”) (CCN, 2014). This creates a backlog in the system and prevents heart failure patients from being seen in the correct care environment in a timely manner (CCN, 2014). For example, if a heart failure patient is stabilized and can be discharged from the “tertiary care hub” but there is not a proper “primary hub” to discharge to; the heart failure patient will be inappropriately followed in the “tertiary care hub” and a more complex, unstable heart failure patient may not be able to be seen in the “tertiary care hub” in a timely manner. The inability to offer the more complex, unstable heart failure patient the appropriate care in a timely manner increases the patient’s risk of hospitalizations and poor health outcomes (Dai et al., 2012; Krumholz et al., 2006; McKelvie et al., 2013). Similarly if two “primary hubs” operated differently across jurisdictions, the quality and timeliness of care in one jurisdiction will supersede that in another jurisdiction (CCN, 2014). This unequal management increases the risk of the aforementioned consequences in the latter jurisdiction, which causes an unequal distribution of hospitalizations and health outcomes across the province (CCN, 2014). This unequal distribution strains the acute care system and inhibits providers from offering high quality heart failure care (Dai et al., 2012). Therefore, it is clear that the roles and responsibilities of these different types of heart failure disease management programs are incompletely defined and need to be further refined in order of the “hub and spoke” organization of care to meet the needs of the heart failure patients in Ontario. The first phase in developing this set of criteria,

was to use the literature to summarize and build upon work that has been previously completed in this field.

## **CHAPTER 2: LITERATURE REVIEW**

Heart failure is a complex condition that places a significant demand on the healthcare system (Dai et al., 2012) resulting from the need for heart failure patients to have frequent follow-up visits with care providers (CCN, 2014). If a heart failure patient experiences delays in seeking the appropriate care from their designated care provider, e.g., a family care physician or a heart failure specialist; the patient experiences a worsening of their heart failure symptoms and is at an increased risk of experiencing a hospitalization or negative health outcome associated with the condition (Dai et al., 2012; Krumholz et al., 2006; McKelvie et al., 2013). Therefore, it is essential to establish an approach to the optimal management of heart failure that optimizes the efficiency of care delivery, thereby improving the health outcomes for heart failure patients.

One such approach to managing heart failure is with the implementation of disease management programs. Disease management programs are defined as “a systematic process of managing the care of patients with specific chronic diseases or conditions across the spectrum of outpatient, inpatient and ancillary services” (Riegel et al., 2010, pp. 324). These programs have been put in place in recent decades in an effort to improve the health outcomes and quality of life of patients as well as to reduce healthcare costs associated with managing chronic disease (Krumholz et al., 2006). Since the ineffective management of heart failure is associated with poor patient outcomes and skyrocketing healthcare costs, it is no surprise that disease management programs specifically designed to optimize the outpatient management of heart failure have been designed and implemented in Ontario.

### **2.1 Heart Failure Disease Management Programs**

Heart failure disease management programs are designed to manage heart failure and prevent adverse outcomes by providing treatment adherence and monitoring the progression of

patient symptoms (Riegel et al., 2010). Heart failure disease management programs are characterized as programs that incorporate patient education, an integrated approach to patient care and the collection of patient outcome data into their daily practice (Reigel et al., 2010). These management programs are generally incorporated into hospital outpatient services and/or family health teams at the primary care level as outpatient heart failure clinics. The outpatient heart failure clinics were described in an earlier chapter as “clinic that consists *at a minimum* of a physician (family physician/internist/cardiologist) and a nurse, one of whom has specialized training or interest in heart failure” (Wijeysundera et al., 2011, pp.6). The outpatient heart failure clinic is strategically placed in the hospital or family health team environment so that patients within these settings have the ability to be easily referred to providers with a high capacity for heart failure knowledge in a timely manner (CCN, 2014). Once referred to clinic, heart failure patients are provided with thorough education on how to properly manage the condition, which includes the importance of symptom recognition and treatment adherence (Krumholz et al., 2006). Patients are typically seen quite frequently (every two to four weeks) during the initial stages of their care, which includes optimizing and up-titrating heart failure medications (CCN, 2014; Krumholz et al., 2006). During this time patients are also afforded the opportunity to have consistent and timely telephone support with the nursing staff (CCN, 2014; Krumholz et al., 2006). The telephone support allows heart failure patients to contact the clinic between appointments if questions concerning their medications or symptoms should arise or urgent care is required so that a crisis can be avoided (Krumholz et al., 2006). Once stabilized, heart patients enter a maintenance phase during which they are followed in the clinic less frequently but still have access to telephone support when required (CCN., 2014a).

Overall, heart failure disease management programs, specifically the outpatient heart failure clinics described previously, have been shown to have a number of benefits. These include a significant decrease in the hospitalization rates of heart failure patients, thereby reducing healthcare costs; and an improvement in the clinical outcomes for heart failure patients (CCN, 2014; Krumholz et al., 2006). The Cardiac Care Network identified a number of factors that are responsible for these beneficial outcomes. First, educating heart failure patients on symptom recognition ensures that the patients are able to recognize when an issue arises and can contact the clinic in a timely fashion, thereby avoiding a potential hospitalization (CCN, 2014). Second, the use of a multi-disciplinary team with specialized heart failure knowledge ensures the adherence of guideline supported medication management, which improves the clinical outcomes for patients (CCN, 2014). Finally, and arguably most importantly, the frequent follow-up of heart failure patients in addition to telephone support is essential to minimizing healthcare costs and improving the clinical outcomes for heart failure patients (CCN, 2014). Heart failure patients develop an important relationship with the outpatient heart failure clinic, whereby the patient understands that calling the clinic when a problem arises will provide an immediate and pro-active solution to the issue (CCN, 2014).

A well-established outpatient heart failure disease management program may be able to provide the benefits listed above but many of these programs lack a generalized framework concerning their roles and responsibilities (Krumholz et al., 2006; Reigel et al., 2010). This makes the outpatient management of heart failure fraught with inconsistency and variability across Ontario, which sets the stage for developing a set of criteria that would outline the roles and responsibilities of outpatient heart failure disease management programs. Previous work has been completed in an attempt to create a set of criteria for defining the roles and responsibilities

of outpatient heart failure disease management programs. Two such initiatives including, works by Krumholz et al in 2006 and Riegel in 2010, are described in the following sections.

### 2.1.1 A Taxonomy for Disease Management

Krumholz et al (2006) set out to develop taxonomy for classifying a diverse range of disease management programs. The authors recognized that certain disease management programs are more comprehensive than others and therefore defined a broad based disease management taxonomy to be used as a common language for assessing disease management programs (Krumholz et al., 2006). The taxonomy was developed using the results of a literature search for disease management programs and includes eight different domains. The taxonomy is highlighted in Figure 2.

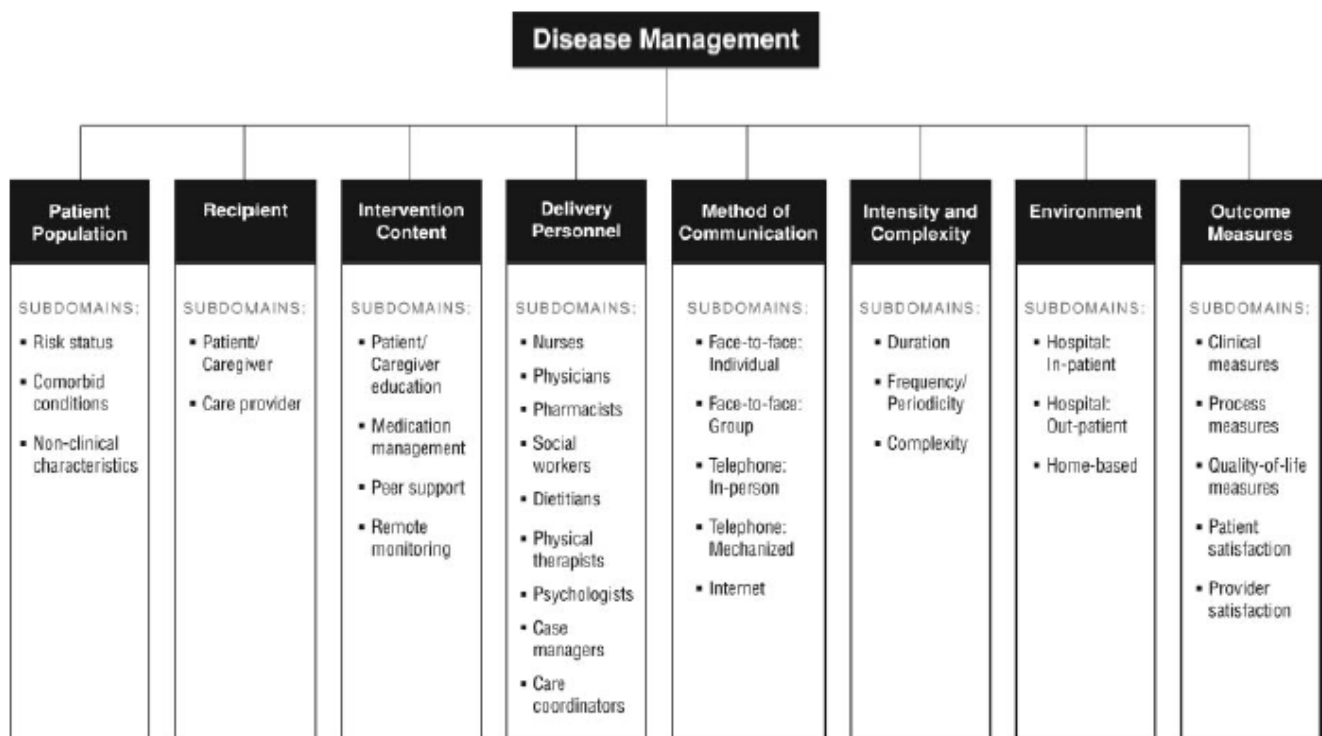


Figure 2. Krumholz's Disease Management Taxonomy (Krumholz et al., 2006)

As shown in Figure 4, the eight different domains include: patient population, recipient, intervention content, delivery personnel, method of communication, intensity and complexity, environment and outcome measures (Krumholz et al., 2006). The taxonomy suggests that programs that have commonalities in each of the eight domains would be classified as similar types of disease management programs (Krumholz et al., 2006). The taxonomy is therefore useful for comparing two types of outpatient heart failure disease management programs and ultimately serves as a first step towards classifying these programs based on common elements across the eight domains (Krumholz et al., 2006).

While Krumholz's work serves as a strong first stepping stone towards classifying outpatient heart failure disease management programs, there are a number of issues to using the taxonomy as a set of criteria for defining the roles and responsibilities of different outpatient heart failure disease management programs. First, the taxonomy was developed for disease management programs in general and therefore does not specifically relate to outpatient heart failure disease management programs. It is therefore unclear how many of the domains would be relevant in classifying different outpatient heart failure disease management programs. Second, Krumholz's work did not indicate whether the taxonomy was applicable across multiple health care systems. Similar to the first issue, it is unclear whether any of the domains would be applicable to outpatient heart failure disease management programs operating within the context of the Canadian healthcare system. For example, due to the differences in funding and infrastructure between different healthcare systems; the availability of delivery personnel or heart failure disease management program components may significantly differ, thereby resulting in the inapplicability of a domain. Similarly, Canadian outpatient heart failure disease management programs may use another domain to classify their programs that has not been

previously identified. Finally, the “hub and spoke” organization of care, which was described in the previous chapter, suggests that there are three types of outpatient heart failure disease management programs. While Krumholz’s taxonomy provides clear definitions of each of the domains; it does not explain how the domains would differentiate between different types of heart failure disease management programs. Therefore, further research is required to understand which domains are relevant to outpatient heart failure disease management programs in Ontario and how the domains differentiate between different types of outpatient heart failure disease management programs. This research needs to be completed in order to establish a firm set of criteria for defining the roles and responsibilities of different types of outpatient heart failure disease management programs in Ontario.

### **2.1.2 Developing an Instrument to Measure Heart Failure Disease Management Program Intensity and Complexity**

Riegel et al (2010) set out to build upon the taxonomy developed by Krumholz et al (2006). Specifically, Reigel wanted to quantify the intensity and complexity of heart failure disease management programs in order to compare between different types of outpatient heart failure disease management programs (Riegel et al., 2010). The instrument incorporates Krumholz’s domains into ten intervention categories and each intervention category includes a hierarchy ranking system (Reigel et al., 2010). Reigel’s complete instrument is included in Appendix 1. Reigel’s work introduces a hierarchy scoring system that can be used to score outpatient heart failure disease management programs. Unlike Krumholz’s work, Reigel has a specific focus on heart failure and outlines a scoring system that can be used to differentiate between different types of outpatient heart failure disease management programs (Reigel et al., 2010). However, there are still a number of issues with Reigel’s work. First, the hierarchy used

for Reigel's instrument varies across the different intervention categories. For example, four levels are used for scoring the recipient category but only three levels are used for scoring the complexity category. If the instrument was to be applied to outpatient heart failure disease management programs in Ontario, ideally each type of outpatient heart failure disease management program should receive the same score across the intervention categories. Similarly, the instrument does not include a total score, which makes it difficult to differentiate between different types of heart failure disease management programs, especially if the programs receive different scores across the intervention categories. Finally, similarly to Krumholz's taxonomy, the instrument does not provide any evidence of use with outpatient heart failure disease management programs in the Canadian healthcare system. Thus, it is unknown whether the instrument would be applicable when comparing different types of outpatient heart failure disease management programs in Ontario. Therefore, further work is required in order to use the instrument to score the different types of outpatient heart failure disease management programs in Ontario.

The gaps identified in Krumholz's and Reigel's work provide research opportunities from which we can form research aims and objectives, which are discussed in a later chapter. A summary of the gaps identified in previous work, as well as highlighting the importance for completing the study is discussed in the next chapter.

### **CHAPTER 3: STUDY RATIONALE**

The “hub and spoke” organization of care was introduced as a potential management model for outpatient heart failure care in Ontario. The model introduces the concept of three different types of outpatient heart failure disease management programs, which include: community care heart failure disease management programs, primary care heart failure disease management programs and specialty care heart failure disease management programs. The latter two types of outpatient heart failure disease management programs are generally characterized as outpatient heart failure clinics within these care settings. Individually, some of the outpatient heart failure disease management programs have shown to be beneficial in managing the condition (CCN, 2014); however, a between program comparison shows them to be fraught with variability and inconsistency across Ontario (Kingsbury, 2014). This was attributed to differences in funding, infrastructure, staffing and/or resources among the various types of outpatient heart failure disease management programs (Kingsbury, 2014). These differences have been shown between similar types of heart failure disease management programs across different jurisdictions, as well as within the same jurisdiction (Kingsbury, 2014). A consequence of the fragmented care is an increased number of hospitalizations for heart failure patients, especially if they cannot receive appropriate care within a timely fashion (Dai et al., 2012; McKelvie et al., 2013). These hospitalization can have disastrous health outcomes for heart failure patients, as well as increasing health care costs in Ontario (Dai et al., 2012; Krumholz et al., 2006). Therefore, a set of criteria which defines the roles and responsibilities of different types of outpatient heart failure disease management programs in Ontario would help with alleviating these negative consequences.

An effort has been made in the literature to develop a set of criteria for defining the roles and responsibilities of different types of outpatient heart failure disease management programs. Krumholz et al (2006) designed a taxonomy for disease management programs and Reigel et al (2010) developed an instrument, which applies a scoring system to Krumholz's taxonomy. A number of issues were identified with using the works as a set of criteria for defining the roles and responsibilities of different types of outpatient heart failure disease management programs in Ontario. A primary theme among these issues is the applicability of the taxonomy and the instrument to the outpatient heart failure disease management programs in Ontario. Specifically, there is no evidence to suggest that the domains of the taxonomy or the scoring system would be relevant, nor would they be readily applicable, to outpatient heart failure disease management programs in Ontario. Thus, it is important to develop a set of criteria for defining the roles and responsibilities of outpatient heart failure disease management programs that are applicable to these types of programs present in Ontario. The process of developing this set of criteria is described in the next chapter.

## **CHAPTER 4: OUTLINE OF STUDY**

The first phase of the study recognized the work that has already been completed. We restructured Reigel et al's (2010) scoring system, according to the findings from a clinical observation. This ensured that it was applicable to the different types of heart failure disease management programs as described in the "hub and spoke" organization of care and served as our preliminary set of criteria. The second phase of this study was completed after the first phase and used the preliminary set of criteria to score four outpatient heart failure disease management programs based on responses from previously collected survey data. The care providers of these outpatient heart failure disease management programs were then invited to participate in focus groups. The survey results provided us with the ability to use the Krumholz et al's (2006) domains and Reigel et al's (2010) scoring system within a Canadian context. Further, the focus groups provided us with an understanding of which domains were applicable to outpatient heart failure disease management programs in Ontario and if any additional domains were required. This served as a guideline for the development of a finalized set of criteria. The focus groups also identified barriers and facilitators to adopting the roles and responsibilities of the different types of outpatient heart failure disease management programs as described by the finalized set of criteria. The input from heart failure care providers into developing the finalized set of criteria, as well as to identifying barriers and facilitators to adopting these roles and responsibilities, was regarded as an important consideration prior to implementing the finalized set of criteria in Ontario. This was an important consideration because these care providers would be most affected by the finalized set of criteria and would be the ones actually implementing it in practice (Berkwits & Inui, 1998). Finally, the information gathered from the second phase of the study was also used to construct a list of recommendations to assist with the

optimization of the quality and role of the different types of outpatient heart failure disease management programs in Ontario. Constructing these recommendations was done to ensure that the different types of outpatient heart failure disease management programs serve the needs of heart failure patients. Consistent role adoption and high quality patient care across the different types of outpatient heart failure disease management programs in Ontario will decrease the risk of hospitalizations, thereby improving the health outcomes for heart failure patients (CCN, 2014). The research aims and objectives for the two phases of the study are outlined in the next chapter.

## **CHAPTER 5: RESEARCH AIMS AND OBJECTIVES**

The overall research aim was to develop a set of criteria for defining the roles and responsibilities of the different types of outpatient heart failure disease management programs in Ontario and to create a list of recommendations to assist with the optimization of the quality and role of these different types of outpatient heart failure disease management programs.

There were four primary research objectives for this study. The first research objective was informed by the first phase of the study and the subsequent three research objectives were informed by the second phase of the study:

1. To use the findings from our clinical observation to restructure a heart failure disease management scoring system developed by Reigel et al (2010) in order to develop a preliminary set of criteria to be used in the second phase of the study.
2. To use responses from an environmental scan survey to classify four outpatient heart failure disease management programs according to the preliminary set of criteria established during the first phase of this study
3. To use input from focus groups with physicians, clinical care coordinators, nurse practitioners, registered nurses and allied health professionals at the four outpatient heart failure disease management programs to:
  - a. Build upon and finalize the set of criteria for defining the roles and responsibilities of the different types of outpatient heart failure disease management programs.
  - b. Determine factors that facilitate or hinder outpatient heart failure disease management programs from adopting the finalized set of criteria

4. To triangulate the data from the second and third objectives in order to construct a list of recommendations to assist the Cardiac Care Network with the optimization of the quality and role of the different types of outpatient heart failure disease management programs in Ontario according to the “hub and spoke” organization of care.

## **CHAPTER 6: PHASE I METHODS AND FINDINGS**

The first phase of the study involved a clinical observation and a description of two outpatient heart failure disease management programs during the summer of 2014. The description was obtained by observing the clinical practices of the clinic, as well as through informal conversation with the heart failure clinic staff. One of the observed outpatient heart failure disease management programs represented a primary care heart failure disease management program and the other represented a specialty care heart failure disease management program. The primary care heart failure disease management program (Program A) was described as an outpatient heart failure clinic located within a family health team and the specialty care heart failure disease management program (Program B) was described as an outpatient heart failure clinic located within a hospital. Program A only accepted referrals from the care providers within their family health team, while Program B accepted referrals from primary care providers and specialists within the geographical area. Program A was staffed by one allied health care professional, one nurse practitioner, one family physician and one geriatrician (heart failure specialist). Program B was staffed by two registered nurses, one nurse practitioner, one geriatrician (heart failure specialist) and one cardiologist. The geriatrician was the same in both heart failure disease management programs, which allowed for smooth transitions between the two types of outpatient heart failure disease management programs. For example, a heart failure patient in Program A can easily be referred to Program B in the event that their heart failure became unstable. The majority of the patient population in Program A were described as NYHA class I or II and the majority of the patient population in Program B were described as NYHA class II to IV. Program A provided medication titrations and patient education; had access to some cardiac diagnostic tests on site; conducted patient surveillance and

follow-up in response to patient decompensation; and completed patient physical assessments and patient risk factor assessments. Program B also provided or had access to these program components, in addition to having access to cardiac interventions and advance care planning on site. Further, Program B had the ability to refer for transplant services at another site. Patients were typically seen less frequently by Program A and more frequently by Program B. Finally, it was observed that Program B completed telephone monitoring and face-to-face clinic appointments but telephone monitoring was not observed in Program A. This does not suggest that it is not done but instead that it was not observed during the clinical observation. These findings were used to inform adaptations to Reigel et al's (2010) heart failure disease management scoring system and thus to create a preliminary set of criteria for defining the roles and responsibilities of the different types of outpatient heart failure disease management programs.

### **6.1 Restructuring Reigel's Scoring System**

In Chapter 2, it was described that Reigel had incorporated Krumholz et al's (2006) domains into her scoring instrument. For the purposes of developing our preliminary set of criteria, the only domains that were used were those which were directly observed and described in the clinical observation. These included: the patient risk status domain, the delivery personnel domain, the method of communication domain, the intensity domain, the complexity domain, and the environment domain. The preliminary set of criteria will serve to score three types of outpatient heart failure disease management programs, which were described previously as: community care heart failure disease management programs, primary care heart failure disease management programs, and specialty care heart failure disease management programs. It should be noted that the specialty care heart failure disease management programs include both "tertiary

care hubs” and “quaternary care hubs” as described in Chapter 1. Thus, the preliminary set of criteria for the “quaternary care hub” would be representative of that for the “tertiary care hub” with the exception of offering transplant services (i.e., the “tertiary care hub” would refer for transplants and the “quaternary care hub” would offer transplant services). Each domain is described in the following sections based on Krumholz’s work in developing the domain. The rationale for modifying the domain with Reigel’s scoring system is also described and as mentioned was based on our clinical observation.

### **6.1.1 Patient Risk Status Domain**

Effective outpatient heart failure disease management programs should be designed around primary care in order to decrease hospitalization rates and improve organizational outcomes (Krumholz et al, 2006). Patients should be monitored by a community care heart failure disease management program, which can refer patients to more complex care environments (i.e., primary care heart failure disease management programs and specialty care heart failure disease management programs) should the risk status of the patient increase (Krumholz et al., 2006). The patient risk status was not originally included in Reigel’s scoring instrument but it was felt that the patient risk status may differ based on the type of outpatient heart failure disease management program, as was observed in the clinical observation. Thus, the patient risk status domain was incorporated into the preliminary set of criteria based on a suggested hierarchy scoring system, as follows:

- Community Care Heart Failure Disease Management Program
  - NYHA Class I only
    - 1 point
- Primary Care Heart Failure Disease Management Program

- NYHA Class II
  - 2 points
- Specialty Care Heart Failure Disease Management Program
  - NYHA Class III or IV
    - 3 points

### **6.1.2 Delivery Personnel Domain**

A number of health care professionals are integral to outpatient heart failure disease management programs and will be actively involved in all levels of care (Krumholz et al, 2006). According to Krumholz et al (2006), the role of physicians is variable, however. Physicians are normally always involved in the more intensive management phases of heart failure but a combination of different healthcare personnel are involved in the ongoing monitoring phases (Krumholz et al., 2006). The clinical observation observed that the more complex outpatient heart failure disease management programs tended to have greater involvement from heart failure and cardiac specialists. We revised Reigel's scoring system to represent this phenomenon and altered it from a maximum of four possible points across the domain to a maximum of three possible points across the domain to reflect the three types of outpatient heart failure disease management programs. Thus, the delivery personnel domain was incorporated into the preliminary set of criteria based on a suggested hierarchy scoring system, as follows:

- Community Care Heart Failure Disease Management Program
  - Family Physicians
    - 1 point
- Primary Care Heart Failure Disease Management Program

- HF Specialists (i.e., geriatrician/internist supporting a family physician/nurse practitioner with an interest in HF)
  - 2 points
- Specialty Care Heart Failure Disease Management Program
  - Cardiologist/geriatrician/internist
    - 3 points

### **6.1.3 Method of Communication Domain**

The method of communication is becoming increasingly important in outpatient heart failure disease management programs with the advent of technology (Krumholz et al 2006). While face-to-face communication is the most prominent form of communication according to Krumholz et al (2006), some programs are increasingly using some form of mediated communication, such as electronic monitoring or telephone follow-up (Krumholz et al, 2006). The clinical observation did not indicate a difference in the frequency of the different methods of communication but it was observed that the specialty care heart failure disease management program saw heart failure patients on a more frequent basis than the primary care heart failure disease management program. Thus, it was suggested that perhaps face-to-face communication is more suitable for an unstable patient who is referred to a more complex type of outpatient heart failure disease management program. We revised Reigel's scoring system to reflect this hypothesis and again altered it from a maximum of four possible points across the domain to a maximum of three possible points across the domain to reflect the three types of outpatient heart failure disease management programs. Thus, the method of communication domain was incorporated into the preliminary set of criteria based on a suggested hierarchy scoring system, as follows:

- Community Care Heart Failure Disease Management Program
  - Mainly person-to-person by telephone/electronic monitoring with some face-to-face contact
    - 1 point
- Primary Care Heart Failure Disease Management Program
  - Face-to-face contact with regular electronic/telephone monitoring
    - 2 points
- Specialty Care Heart Failure Disease Management Program
  - Primarily face-to-face contact with some electronic/telephone monitoring
    - 3 points

#### **6.1.4 Intensity Domain**

The intensity of an outpatient heart failure disease management program can be described as either the duration of the patient participation or the frequency of patient follow-up (Krumholz et al., 2006). The clinical observation was consistent with the notion that heart failure patients in the specialty care heart failure disease management program were seen at a higher frequency than those in the primary care heart failure disease management program. We revised Reigel's scoring system based on this observation and again altered it from a maximum of four possible points across the domain to a maximum of three possible points across the domain to reflect the three types of outpatient heart failure disease management programs. Thus, the intensity domain was incorporated into the preliminary set of criteria based on a suggested hierarchy scoring system, as follows:

- Community Care Heart Failure Disease Management Program
  - > 6 months (between face-to-face appointments)

- 1 point
- Primary Care Heart Failure Disease Management Program
  - $\leq 6$  months
    - 2 points
- Specialty Care Heart Failure Disease Management Program
  - $\leq 3$  months
    - 3 points

### **6.1.5 Complexity Domain**

The complexity of an outpatient heart failure disease management program can range and is often characterized by the overall program structure, which is defined by the intervention content (Krumholz et al., 2006). This is defined as the number of disease management components, the level of specialist or cardiology involvement and the program's approach to patient care (Krumholz et al., 2006). The clinical observation suggested that the specialty care heart failure disease management program offered a higher number of disease management components, had access to cardiologists and offered an individualized approach to patient care. Further, the clinical observation suggested that the primary care heart failure disease management program offered fewer disease management components, had access to heart failure specialists as opposed to cardiologists and offered a more uniform approach to patient care. We revised Reigel's scoring system based on this observation and the definition of complexity by Krumholz et al (2006). Thus, the complexity domain was incorporated into the preliminary set of criteria based on a suggested hierarchy scoring system, as follows:

- Community Care Heart Failure Disease Management Program
  - Low complexity

- 1 point
- Primary Care Heart Failure Disease Management Program
  - Moderate complexity
    - 2 points
- Specialty Care Heart Failure Disease Management Program
  - High complexity
    - 3 points

#### **6.1.6 Environment Domain**

Heart failure disease management programs can be defined as either inpatient or outpatient. An inpatient program refers to a program, which provides services to heart failure patients who are hospitalized (Krumholz et al., 2006). An outpatient program refers to a program, which provides services to heart failure patients who are not hospitalized (Krumholz et al., 2006). The clinical observation suggested that the services offered in the primary care heart failure disease management program were provided in an outpatient setting and the services offered in the specialty care heart failure disease management program were also typically provided in an outpatient setting, although patients may be recruited during the inpatient phase. We revised Reigel's scoring system based on this information and altered it from a maximum of four possible points across the domain to a maximum of three possible points across the domain to reflect the three types of outpatient heart failure disease management programs. Thus, the environment domain was incorporated into the preliminary set of criteria based on a suggested hierarchy scoring system, as follows:

- Community Care Heart Failure Disease Management Program
  - FHT/Community; outpatient only

- 1 point
- Primary Care Heart Failure Disease Management Program
  - HF Clinic; outpatient only
    - 2 points
- Specialty Care Heart Failure Disease Management Program
  - Hospital; inpatient/outpatient
    - 3 points

## **6.2 Preliminary Set of Criteria**

The revised domains were incorporated into the preliminary set of criteria, which is included in Table 2. As a reminder, the preliminary set of criteria only addresses six of the eight domains. As well, the preliminary set of criteria serves to score three types of outpatient heart failure disease management programs: community care heart failure disease management programs, primary care heart failure disease management programs and specialty care heart failure disease management programs.

Table 2. Preliminary Set of Criteria for Defining Heart Failure Disease Management Programs

<b>Domain</b>	<b>Points Assigned</b>	<b>Comment</b>
<b>Patient Risk Status</b>	1 = NYHA class I only 2 = NYHA class I/II 3 = NYHA class III/IV	
<b>Delivery Personnel</b>	1 = generalist provider 2 = HF expert provider 3 = cardiology & HF expert provider	*Provided in a multidisciplinary team environment *HF expert can either be a geriatrician or a nurse practitioner that is specialized in HF
<b>Method of Communication</b>	1 = mainly person-to-person by telephone/electronic monitoring with some face-to-face contact 2 = face-to-face contact with regular electronic/telephone monitoring 3 = primarily face-to-face contact with some electronic/telephone monitoring	
<b>Intensity</b>	1 = > 6 mo. 2 = ≤ 6 mo. 3 = ≤ 3 mo.	*Between face-to-face appointments
<b>Complexity</b>	1 = low complexity 2 = moderate complexity 3 = high complexity	*Complexity is defined as the number of disease management components, level of specialist or cardiology involvement and their approach to patient care (uniform or individualized).
<b>Environment</b>	1 = FHT/Community; outpatient only 2 = HF Clinic; outpatient only 3 = Hospital; inpatient/outpatient	

According to the preliminary set of criteria, a community care heart failure disease management program should receive 1 point in each domain, which accounts for a total score of 6 points and

an average score of 1 point. A primary care heart failure disease management program should receive 2 points in each domain, which accounts for a total score of 12 points and an average score of 2 points. Finally, a specialty care heart failure disease management program should receive 3 points in each domain, which accounts for a total score of 18 points and an average score of 3 points. The preliminary set of criteria will be used and finalized during the second phase of the study as outlined in the next chapter.

## **CHAPTER 7: PHASE II METHODS**

A mixed methods design, that combines both quantitative and qualitative research methods, was used to address the research aim and objectives for the second phase of the study. A significant amount of background work was completed in an attempt to improve the outpatient management of heart failure in Ontario. This work provided us with insight into the current state of the outpatient heart failure management in Ontario and it is important to o this into our analysis. It was also important to integrate the perspectives of care providers into the development of the finalized set of criteria to define the roles and responsibilities of outpatient heart failure disease management programs in Ontario. In order to accomplish these two objectives, two different approaches were combined, which was why a mixed methods approach that combines both quantitative and qualitative research methods was the most appropriate design for this study. There are a number of advantages to using a mixed methods design. The first is the practicality of a mixed methods design (Padiha, 2012). The practicality allows researchers to use a number of different types of research methods in order to answer a research question (Padiha, 2012). In an alternative approach the researcher would be constrained to using only those methods appropriate for one type of research design, even if other research methods are applicable to the study (Padiha, 2012). The second is the ability to combine two or more research designs (Padiha, 2012). This combination reduces the limitations of only using one of the research designs for answering the research question (Padiha, 2012). Finally, a mixed methods design allows for a significant amount of data collection across multiple sources to be combined (Padiha, 2012). This can reinforce and/or improve the results produced from the analysis of the study leading to more significant and valid findings (Padiha, 2012). This increase in data collection and evidence produced, however, can be overwhelming. A mixed

methods design requires a researcher to be knowledgeable in more than one type of research design. Further, a mixed methods research design requires a significant amount of time and energy on the part of the researcher as well as requiring the researcher to have strong organizational and communication skills in order to present the research in a clear and correct manner (Padiha, 2012). The strength of using a mixed methods design was significantly greater than the associated consequences. The design provided a strong basis for the development of a set of criteria for defining the roles and responsibilities of outpatient heart failure disease management programs in Ontario, as well as increased the strength and validity of the recommendations established from this work.

The quantitative component of the mixed methods design explored the first research objective by using secondary data analysis to score four outpatient heart failure disease management programs in Ontario according to the preliminary set of criteria established during the first phase of the study. This served as a confirmation of the outpatient heart failure disease management program classification, as well as to identify any issues with using the preliminary set of criteria. According to the first phase of the study there were three types of outpatient heart failure disease management programs in Ontario. With this knowledge we were able to pre-classify the outpatient heart failure disease management programs. Since the preliminary set of criteria served to describe the roles and responsibilities for each type of outpatient heart failure disease management program, we were able to use this to score our programs and confirm our classification. The qualitative component addressed the second research objective by using an ontological approach, which is a philosophical assumption whereby the researcher questions the nature of reality as seen through multiple views. The qualitative component of the mixed methods design served to finalize the set of criteria by understanding what domains of the

preliminary set of criteria are applicable to the different types of outpatient heart failure disease management programs in Ontario. The focus groups also determined factors that facilitated or hindered outpatient heart failure disease management programs from adopting the roles and responsibilities of their type of outpatient heart failure disease management program. Finally, the data from the quantitative component and qualitative component were methodologically triangulated in order to inform the third research objective. The triangulation process combined the information collected from the analysis of the survey and the focus group responses to create a list of recommendations to assist the Cardiac Care Network with the optimization of the quality and role of the different types of outpatient heart failure disease management programs in Ontario. The use of data triangulation complemented the quantitative and qualitative components, which in turn increased the validity of the recommendations. The quantitative component, qualitative component and data triangulation process are described in the following sections.

## **7.1 Quantitative Component**

The quantitative component used secondary data analysis to descriptively analyze survey responses from four outpatient heart failure disease management programs in Ontario. The survey responses were collected as part of an environmental scan survey completed by the Cardiac Care Network. This environmental scan survey served as the basis for the quantitative sample, as described in the next section.

### **7.1.1 Quantitative Sample**

The Heart Failure Working Group at the Cardiac Care Network completed an environmental scan survey (Appendix 2) to identify gaps in outpatient heart failure services based on the resources provided within each LHIN. The results of the environmental scan

survey served to provide the groundwork for the development of the initial “hub and spoke” organization of care and also allowed for the identification of different types of outpatient heart failure disease management programs in Ontario. The latter of which served to provide the quantitative sample for this study. The working group distributed the online survey via seven different platforms to family health teams, health care centres and CCN member hospitals. The platforms included:

- OHA Healthscape
- Association of Family Health Teams
- THETA Report
- Google
- Personal contacts
- Individual Family Health Team and Hospital websites
- Nurse Practitioner’s Association of Ontario

The survey was distributed to 186 family health teams and 26 health care centres/hospitals. Overall, the survey had a 26% (48/186) response rate for family health teams and a 92% (24/26) response rate for health care centres/hospitals. Sixteen family health teams (33%) indicated that they had an outpatient heart failure disease management program and all 24 health care centres/hospitals (100%) indicated they had an outpatient heart failure disease management program. These outpatient heart failure disease management programs were used for the quantitative sample.

As mentioned in the first chapter, there are three different types of outpatient heart failure disease management programs. The environmental scan survey identified two of these three types of outpatient heart failure disease management programs. The 16 outpatient heart failure

disease management programs within family health teams represent primary care heart failure disease management programs and the 24 outpatient heart failure disease management programs within health care centres/hospitals represent specialty care heart failure disease management programs. These types of outpatient heart failure disease management programs are generally referred to as primary care heart failure clinics and specialty care heart failure clinics (CCN, 2014). For the purposes of this study the survey responses were analyzed from these two types of outpatient heart failure disease management programs. The third type of outpatient heart failure disease management programs, community care heart failure disease management programs, were not identified in the environmental scan survey and are therefore not included in the quantitative sample. Since community care heart failure disease management programs are a significant part of the “hub and spoke” organization of care, their exclusion was concerning, as it interferes with garnering a complete understanding of heart failure management in Ontario. It was also concerning that work to date has primarily focused on the primary care heart failure disease management programs and the specialty care heart failure disease management programs, and evidence that understands or evaluates community care heart failure disease management programs is significantly lacking. A reason for this may be due to the vast diversity of community care heart failure disease management programs and thus, a substantial amount background work needs to be completed on the community care heart failure disease management programs before our type of study was applied to them. Therefore, the quantitative sample only drew from primary care heart failure disease management programs and specialty care heart failure disease management programs.

We descriptively analyzed the survey responses from two primary care heart failure disease management programs and two specialty care heart failure disease management

programs. The outpatient heart failure disease management programs within each type of outpatient heart failure disease management program classification (i.e., primary care and specialty care) differed based on geographical characteristics, specifically whether they represented an urban or rural geographical location. Previous work had indicated that geographical differences could represent an important difference in resource allocation, funding, staffing or infrastructure, which in turn could alter the way the programs are defined (CCN 2014). Due to time and budget constraints we chose one outpatient heart failure disease management program that represented each of the four criteria, which are listed as follows: (1) primary care, rural; (2) specialty care, rural; (3) primary care, urban; and (4) specialty care; urban. The outpatient heart failure disease management programs are described in Table 3.

Table 3. Quantitative Sample Description

<b>Heart Failure Disease Management Program</b>	<b>Description</b>
Clinic A	Speciality care outpatient heart failure disease management program located in an urban setting
Clinic B	Speciality care outpatient heart failure disease management program located in a rural setting
Clinic C	Primary care outpatient heart failure disease management program located in an urban setting
Clinic D	Primary care outpatient heart failure disease management program located in a rural setting

The recruitment of these four outpatient heart failure disease management programs is discussed in the next section.

### **7.1.2 Heart Failure Disease Management Program Recruitment**

The recruitment procedures for the outpatient heart failure disease management programs are described in the qualitative component of this study. We required the analysis of the survey

responses and the focus groups to take place with the same outpatient heart failure disease management program. The outpatient heart failure disease management program was informed that we gathered their contact information from the environmental scan survey. The Cardiac Care Network received prior ethics approval for the use of this information and was therefore able to provide us the contact information and gave us permission to analyze the survey responses. Once the outpatient heart failure disease management program agreed to participate in the qualitative component, we descriptively analyzed their survey response. This analysis was completed prior to completing the focus group with the outpatient heart failure disease management program and is described in the next section.

### **7.1.3 Data Analysis**

We descriptively analyzed the survey responses from the four outpatient heart failure disease management programs according to the preliminary set of criteria established during the first phase of the study. The preliminary set of criteria is included in Table 4 for reference.

Table 4. Preliminary Set of Criteria for Defining Heart Failure Disease Management Programs

<b>Domain</b>	<b>Points Assigned</b>	<b>Comment</b>
<b>Patient Risk Status</b>	1 = NYHA class I only 2 = NYHA class I/II 3 = NYHA class III/IV	
<b>Delivery Personnel</b>	1 = generalist provider 2 = HF expert provider 3 = cardiology & HF expert provider	*Provided in a multidisciplinary team environment *HF expert can either be a geriatrician or a nurse practitioner that is specialized in HF
<b>Method of Communication</b>	1 = mainly person-to-person by telephone/electronic monitoring with some face-to-face contact 2 = face-to-face contact with regular electronic/telephone monitoring 3 = primarily face-to-face contact with some electronic/telephone monitoring	
<b>Intensity</b>	1 = > 6 mo. 2 = ≤ 6 mo. 3 = ≤ 3 mo.	*Between face-to-face appointments
<b>Complexity</b>	1 = low complexity 2 = moderate complexity 3 = high complexity	*Complexity is defined as the number of disease management components, level of specialist or cardiology involvement and their approach to patient care (uniform or individualized).
<b>Environment</b>	1 = FHT/Community; outpatient only 2 = HF Clinic; outpatient only 3 = Hospital; inpatient/outpatient	

The student investigator individually scored each of the four outpatient heart failure disease management programs based on the preliminary set of criteria. A complete description of the six

domains and an explanation for how the scores represented the different types of outpatient heart failure disease management programs was provided in the first phase of the study. The findings from the descriptive analysis reported the overall score in each domain, as well as the total score and average score across the six domains. The findings also provided a rationale for the scoring across each of the six domains. According to the first phase of the study, a primary care heart failure disease management program should have received a total score of 12 points and an average score of 2 points across each of the six domains when the preliminary set of criteria was used to score their outpatient heart failure disease management program. If the primary care heart failure disease management program received these scores then it suggested that the program was correctly classified during the recruitment phase of the study. Likewise, a specialty care heart failure disease management program should have received a total score of 18 points and an average score of 3 points across each of the six domains when the preliminary set of criteria was used to score their outpatient heart failure disease management program. If the specialty care heart failure disease management program received these scores then it suggested that the program was correctly classified during the recruitment phase of the study. Accounting for difficulties in interpreting survey response data, the total score for each program could vary +/- 2 points before it was unclear as to what type of outpatient heart failure disease management program was being represented in the survey response. Therefore a score of less than 10 points or greater than 15 points was inappropriate for a primary care heart failure disease management program and a score of less than 15 points was inappropriate for a specialty care heart failure disease management program. Likewise the average score was able to vary +/- 0.4 points, meaning the primary care heart failure disease management programs should have received an average score between 1.6 points and 2.4 points and the specialty care heart failure disease

management programs should have received an average score between 2.6 points and 3.0 points. The results of this classification are verified in the qualitative component of the study. If the qualitative component of the study identified that the outpatient heart failure disease management program did not represent the type of outpatient heart failure disease management program that it was classified as during the recruitment phase of the study, a different outpatient heart failure disease management program was recruited and analyzed in order to have study findings that were representative of the four outpatient heart failure disease management programs described previously. The qualitative component of the study is described in the next section.

## **7.2 Qualitative Component**

The overarching philosophical assumption is an ontological approach (Creswell, 2007). The researcher questions the nature of reality, which is seen through multiple views (Creswell, 2007). Thematic development occurs as the researcher reports different perspectives (Creswell, 2007). This is accomplished in two ways. First, the qualitative component used focus groups with different care providers within the four different outpatient heart failure disease management programs described in the quantitative component in order to revise and finalize the preliminary set of criteria, as well as to identify any barriers or facilitators to adopting the roles and responsibilities as outlined by the finalized set of criteria. The different care providers within the outpatient heart failure disease management programs offered a unique perspective when providing feedback on the preliminary set of criteria, as well as when identifying the barriers and facilitators to adopting the roles and responsibilities of the finalized set of criteria. Further, the classification of the outpatient heart failure disease management programs described in the previous section provided the researcher with their own perspective of the outpatient heart

failure disease management program. The researcher had previous knowledge of the outpatient heart failure disease management program, which allowed the researcher to adequately direct the discussion of the focus group while acknowledging their perspective in the findings.

In order to finalize the set of criteria, the researcher first surveyed the focus group participants for ideas concerning the development of different domains for defining the roles and responsibilities of outpatient heart failure disease management programs. The researcher then presented the focus group participants with the preliminary set of criteria and asked for them to score their outpatient heart failure disease management program, thereby confirming the classification determined in the quantitative component. The researcher then gave the participants the opportunity to provide feedback on the preliminary set of criteria. This included a discussion on how the domains of the preliminary set of criteria should be refined or if any new domains should be added, which provided the researcher with data for finalizing the set of criteria. Finally, the researcher directed discussion of the barriers and facilitators associated with adopting the roles and responsibilities this finalized set of criteria. Please note that the finalized set criteria was not fully developed until after the completion of the four focus groups so the discussion of the barriers and facilitators were concerned with the future set of finalized set of criteria and participants were able to use the preliminary set of criteria or their feedback as a guide when they discussed the barriers and facilitators. The sample that was drawn from to conduct the focus groups is described in the next section.

### **7.2.1 Qualitative Sample**

The sample that was used for the focus groups has been previously described under the quantitative component. We purposely chose four outpatient heart failure disease management programs, based on the type of program they represented and their geographical location to

participate in focus group sessions. Four focus groups were completed with the care providers within each of the outpatient heart failure disease management programs. The recruitment of the four outpatient heart failure disease management programs and their care providers is described in the next section.

### **7.2.2 Heart Failure Disease Management Program and Care Provider Recruitment**

As mentioned in the quantitative component, the environmental scan survey identified 16 primary care heart failure disease management programs and 24 specialty care heart failure disease management programs. We recruited one urban and one rural primary care heart failure disease management program from the 16 identified and one urban and one rural specialty care heart failure disease management program from the 24 identified. The Cardiac Care Network has established working relationships with a number of the outpatient heart failure disease management programs in Ontario. It was expected that those outpatient heart failure disease management programs may be more inclined to participate in the focus groups and similarly, may have a higher percentage of participation from their care providers. Since the study was using an ontological approach, it was useful to have as many care providers participate in the focus group as possible. As such, the outpatient heart failure disease management programs with working relationships that matched the required characteristics of the study (i.e., primary care rural and urban heart failure disease management programs and specialty care urban and rural heart failure disease management programs) with the Cardiac Care Network were recruited first. The clinical care coordinator of each of outpatient heart failure disease management programs were contacted by email (Appendix 3) and received a recruitment information letter (Appendix 4) to recruit the program and the program's care providers to participate in the focus group session. The clinical care coordinator was asked to provide consent for the outpatient heart

failure disease management program to participate in the study at this time. The clinical care coordinator was then asked to invite care providers within their outpatient heart failure disease management program to participate in the focus groups. The care providers who agreed to participate in the focus group were given a copy of the information letter and a consent form at the beginning of the focus group and were also able to decline to participate at that time. The clinical care coordinator was also given the option of participating in the focus group and the same consent procedures were followed. In order to respect privacy and confidentiality we only contacted the clinical care coordinator for recruitment purposes, as this was the email that we received from the environmental scan survey. We followed up with the clinical care coordinator once a week to ensure that recruitment of the health care providers was occurring and assisted with providing any information that was required to assist with recruitment. This helped with alleviating the risk of a low response rate for participation in the focus groups. The clinical care coordinator also had the option to decline the heart failure disease management program's participation. If the clinical care coordinator decided that the outpatient heart failure disease management program was not participating in the focus groups, the clinical care coordinator of another outpatient heart failure disease management program was approached. The new outpatient heart failure disease management program was identified from the environmental scan survey and categorized similar to the outpatient heart failure disease management program (i.e., type of outpatient heart failure disease management program and geographical location) that declined participation. A description of the focus groups is included in the next section.

### **7.2.3 Focus Groups**

The design and format of the focus groups was adapted from the process described by Krueger and Casey (2000). According to Krueger and Casey (2000) a focus group is described

as “a carefully planned series of discussions designed to obtain perceptions on a defined area of interest in a permissive, nonthreatening environment” (Krueger & Casey, 2000, pp. 5). Focus groups are conducted with a group of homogenous participants, who are defined based on a characteristic that all participants have in common, such as occupation, gender, age, etc. (Krueger & Casey, 2000). The participants in our focus group were health care providers who practice within an outpatient heart failure disease management program. We used a double-layer design with two populations. The two populations include the type of outpatient heart failure disease management program and the geographical location. Each population has two different groupings used to describe the population. Each grouping identifies two of the four outpatient heart failure disease management programs identified as either Clinic A, B, C or D. This is outlined in Table 5.

Table 5. Heart Failure Disease Management Program Population Groupings

Population
<ul style="list-style-type: none"> <li>• Type of Program <ul style="list-style-type: none"> <li>○ Primary care outpatient heart failure disease management program <ul style="list-style-type: none"> <li>▪ Clinic C</li> <li>▪ Clinic D</li> </ul> </li> <li>○ Speciality care outpatient heart failure disease management program <ul style="list-style-type: none"> <li>▪ Clinic A</li> <li>▪ Clinic B</li> </ul> </li> </ul> </li> </ul>
<ul style="list-style-type: none"> <li>• Geographic location <ul style="list-style-type: none"> <li>○ Urban <ul style="list-style-type: none"> <li>▪ Clinic A</li> <li>▪ Clinic B</li> </ul> </li> <li>○ Rural <ul style="list-style-type: none"> <li>▪ Clinic C</li> <li>▪ Clinic D</li> </ul> </li> </ul> </li> </ul>

The groupings allowed us to account for any differences in the type of outpatient heart failure disease management program or geographical location when developing the finalized set of criteria and/or in identifying barriers and facilitators to adopting the roles and responsibilities as outlined in the finalized set of criteria. This was identified in the analysis.

The literature suggests that three or four focus groups should be conducted with each group of homogenized participants until you reach data saturation, which is defined as the point in which additional focus groups do not identify themes or patterns that have been previously established (Krueger & Casey, 2000). However, due to time and budget constraints we chose to conduct only two focus groups with each identified homogenized group. For reference, the homogenized populations include: primary care heart failure disease management programs, specialty care heart failure disease management programs, urban outpatient heart failure disease management programs and rural outpatient heart failure disease management programs. Since the findings and recommendations derived from these focus groups are at a low risk of harming individual outpatient heart failure disease management programs or their care providers it is

sufficient to conduct fewer focus groups with the limited resources available (Krueger & Casey, 2000). Further, if there is no new thematic development after the second focus group within the two groups of homogenized population, it is sufficient to conclude that data saturation had taken place. However, if sufficiently different themes were identified after the second focus group within a homogenized population (i.e., after the second group with a rural outpatient heart failure disease management program), it may have been warranted to conduct further focus groups. It was found, however, that this was not the case and four focus groups were sufficient for data saturation. The focus group sample and setting are outlined in the next section.

#### **7.2.3.1 Focus Group Sample and Setting**

All members of the healthcare team, including medical doctors, clinical care coordinators, nurse practitioners, registered nurses and allied health professionals; were invited to participate in a two hour focus group session that took place in a room located in the outpatient heart failure disease management program. While it was possible to conduct different focus groups with different types of providers at each outpatient heart failure disease management program, the staffing levels were small and therefore did not provide the diversity of opinions that a focus group sets out to achieve. The diverse occupations within the healthcare team also offered the opportunity to contrast opinions within the focus group if the different care providers all participated in the same focus group. The disadvantage of this approach was that if a provider was in a power of authority it may discourage group discussion if the other participants were uncomfortable with the presence of this individual (Krueger & Casey, 2000). Since, the first phase of the study revealed that the care providers collaborated in a group setting on a daily basis, it was concluded that one provider should not be in a position of authority over others.

The student researcher aimed to keep the focus group to six or eight people, which was determined to be the size for outpatient heart failure disease management programs from the first phase of the study and is also the optimal size for focus groups (Krueger & Casey, 2000). The size of the focus group allowed for all participants to have the opportunity to share their experiences and opinions, while being large enough to allow for a diverse range of perspectives (Krueger & Casey, 2000). A disadvantage of choosing a care providers, who interacted on a daily basis, to be the focus group participants was that this may cause them to avoid disclosing information on certain topics (Krueger & Casey, 2000). However, we required the opinions of these care providers in order to serve the purpose of this research, as they all shared the characteristic of providing outpatient heart failure disease management care within one of the predefined program classifications. The data collection from the focus groups is described in the next section.

#### **7.2.3.2 Data Collection**

The student researcher contacted the clinical care coordinator two weeks prior to the focus group taking place to ensure all participants were aware of the location and time of the focus group. The student researcher also contacted the clinical care coordinator the day before the scheduled session to serve as a final reminder. The student researcher was joined by a research assistant from the University of Waterloo. As the facilitator, the student researcher was responsible for engaging participation in the discussion and directing the conversation according to a pre-defined script (Krueger & Casey, 2000). The focus group script is included in Appendix 5 and was written according to the method devised by Krueger & Casey (2000). Given the time constraints of the study, the focus group questions were not pilot tested but instead the questions pertaining to the focus group were discussed and finalized with the student researcher's faculty

advisors. The student researcher and the research assistant also discussed and revised the script after the completion of the focus group. The facilitator was responsible for taking a few notes for reference during thematic analysis and transcription (Krueger & Casey, 2000). The research assistant was responsible for the organizational duties, such as handing out information letters, collecting consent forms, and operating the audio recorder (Krueger & Casey, 2000). Unlike the facilitator, the research assistant took detailed notes pertaining to the discussion (Krueger & Casey, 2000). The student researcher and the research assistant arrived 30 minutes prior to the scheduled focus group in order to set-up and prepare for the focus group so that it could begin within 10 minutes of the participants arriving.

The focus group featured short, open-ended questions that move from general to specific in order to develop a finalized set of criteria to define the roles and responsibilities of the different types of outpatient heart failure disease management programs in Ontario, as well as to collect information on the barriers and facilitators to adopting the roles and responsibilities as outlined by the finalized set of criteria (Krueger & Casey, 2000). The only demographic information collected from the participants of the focus group was their occupation, so long as they were comfortable with disclosing that information. This was verbally collected during the focus group introductions, which were documented in the detailed notes from the focus group, as well as on the audio recorder. This information was collected in the event that the different providers had conflicting opinions on a topic pertaining to the research objective and this difference was relevant to our analysis. It was explained to the focus group participants that if the care provider's occupation was disclosed; the outpatient heart failure disease management program's information, including type of outpatient heart failure disease management program and geographical location, would not be included alongside their demographic information.

Following the completion of the focus groups the participants received a feedback letter (Appendix 6).

As mentioned previously, the student researcher and research assistant debriefed immediately following the focus group and revised the script, if necessary, for the subsequent focus group. A revision may have occurred, for example, if a sufficient topic emerged from the focus group discussion that we wished to discuss in subsequent focus groups. Finally, the student researcher transcribed each focus group within 48 hours of the focus group taking place. Once the transcription of the focus group took place, the focus group could be thematically analyzed, which is described in the next section.

#### **7.2.4 Thematic Analysis**

The focus groups were coded for themes using an inductive process by the student researcher and research assistant. The transcripts were coded using a hierarchy coding system in order to establish theoretical concepts from the data. The student researcher and research assistant began coding using an open coding methodology and culminated using axial coding methodology. Beginning with open coding allowed the data to be coded into broad categories (Creswell, 2007). These categories were then the focus for axial coding, in which the researcher used the broad category to go back to the transcripts to develop subthemes around this foundational phenomenon (Creswell, 2007). The student researcher and research assistant individually coded the focus groups using open coding and axial coding. Once the initial coding was completed the student researcher and research assistant met to discuss their themes and subthemes in order to come to a consensus regarding the final themes and subthemes to be used in the thesis dissertation. In order to account for natural variability in the coding and determine the agreement between the two coders an inter-rater agreement statistic was calculated (McHugh,

2012). The Kappa Statistic was chosen as the measure of inter-rater agreement between the two coders. The Kappa Statistic is a measure of reliability that is calculated based on the “difference between how much agreement is actually present (‘observed’ agreement) compared to how much agreement would have be expected by chance alone (‘expected’ agreement)” (Viera & Garrett, 2005, pp.361). The Kappa Statistic was calculated based using the following calculation in Figure 3.

$$Kappa (K) = \left[ \frac{(p_o - p_e)}{(1 - p_e)} \right] \times 100\%$$

where  $p_o$  is the 'observed' agreement and  $p_e$  is the 'expected' agreement

Figure 3. Kappa Statistic Calculation (Viera & Garrett, 2005)

The ‘observed’ agreement and ‘expected’ agreement were calculated according to Figure 4.

		Coder 1		
		Theme Present	Theme Not Present	Row Total
Coder 2	Theme Present	$A$	$b$	$m_1$
	Theme Not Present	$c$	$D$	$m_0$
	Column Total	$n_1$	$n_0$	$n$

$$'observed' agreement = \frac{a + d}{n}$$

$$'expected' agreement = \left[ \left( \frac{n_1}{n} \right) \times \left( \frac{m_1}{n} \right) + \left( \frac{n_0}{n} \right) \times \left( \frac{m_0}{n} \right) \right]$$

Figure 4. ‘Observed’ Agreement and ‘Expected’ Agreement Calculation (Viera & Garrett, 2005)

The range of interpretation of the Kappa Statistic can be described in terms of degree of agreement according to the Table 6.

Table 6. Kappa Interpretation (Viera & Garrett, 2005)

<b>Kappa</b>	<b>Agreement</b>
<0	Less than chance agreement
0.01-0.20 (1% - 20%)	Slight agreement
0.21-0.40 (21% - 40%)	Fair agreement
0.41-0.60 (41% - 60%)	Moderate agreement
0.61-0.80 (61% - 80%)	Substantial agreement
0.81-0.99 (81% - 99%)	Almost perfect agreement

The thesis work should aim to have a Kappa Statistic over 0.80 (80%) in order to have good inter-rater reliability (McHugh, 2012). The definition of “good inter-rater” reliability is based on the “almost perfect agreement” category instead of the “substantial agreement” category because the substantial agreement can include Kappa Statistics as low as 60% (McHugh, 2012). This would mean that almost 40% of the findings are faulty, which is problematic (McHugh, 2012). The benefit to using a Kappa Statistic over another reliability statistic (i.e., percent agreement) is that the Kappa Statistic accounts for agreement that could have occurred by chance, thus providing a more precise measurement of reliability (Sim & Wright, 2005). However, as with any measure of inter-rater reliability the use of the Kappa Statistic is subject to limitations, if the data collected is an inaccurate representation of opinions of the care providers in the outpatient heart failure disease management program (McHugh, 2012). There are various techniques, such as member checks, that can avoid this limitation.

A member check is a validation technique that ensures that the themes developed through research are an accurate representation of the participants views (Koelsch, 2013). Following the completion of the theme development the student researcher performed a member check with the care providers involved in the focus groups to ensure that the themes developed from the focus groups were accurate portrayals of opinions of the care providers in the outpatient heart failure disease management programs. The care providers were asked to consent to a member check at

the beginning of the focus group and were asked to provide an email address that the student researcher could contact them at to perform the member check. If the student researcher found that the themes developed did not align with the opinions of the care providers, then the themes were modified according to the care provider's feedback and sent back to the focus group participants for a final confirmation.

The use of a member check as well as the use of multiple coders increased the credibility of the findings (Rauf et al., 2014). In addition the use of an audit trail, which is described as a clear and complete description of the research methods, also increased the credibility of the study (Cohen & Crabtree., 2006; Rauf et al., 2014). The thoroughness of the described research methods in this chapter, as well as the results in the subsequent chapter, served the purposes of the audit trail. Finally, adhering to the ontological approach and thoroughly collecting the data as described in the audit trail increased the rigour of the study (Krefting et al., 1991). The credibility and rigour of the findings are key aspects to increasing the validity of qualitative research methods (Krefting et al., 1991; Rauf et al., 2014). The validity of the work was also increased through the use of data triangulation, which is described in the next section.

#### **7.4 Triangulation of Quantitative and Qualitative Data**

Data triangulation in a mixed methods study is a process that externally validates the findings by using multiple methods to collect the data on the same study question (Jick, 1979). The data from the quantitative component and qualitative component were methodologically triangulated in order to inform the third research objective. The triangulation process combined the information collected when scoring the outpatient heart failure disease management programs as well as the focus group responses, particularly those related to the development of the finalized set of criteria and the barriers and facilitators to adopting roles and responsibilities

of the finalized set of criteria. This combined served to create a list of recommendations to assist the Cardiac Care Network with the optimization of the quality and role of the different types of outpatient heart failure disease management programs in Ontario. The data triangulation, as well as the quantitative and qualitative components were subject to consent and confidentiality procedures, which are described in the next section.

### **7.5 Consent and Confidentiality**

The clinical care coordinator had to provide consent for the outpatient heart failure disease management program to participate in the study before the quantitative component or qualitative components were performed. All care providers, who agreed to participate in the focus groups, were provided with an information letter and consent form at the beginning of the focus group. All care providers were required to provide consent and the consent forms were collected prior to the beginning of the focus group. The care providers consented to participation in the focus group, the use of anonymous quotations, the ability to contact them regarding the member check and the use of an audio recorder to record the focus groups. All care providers were required to provide consent in order for the focus group to be audiorecorded. Participation in the focus groups was voluntary. Consent could be withdrawn at any time before, during or after the focus groups without penalty by informing the student researcher. During the focus groups care providers could decline answering any questions and/or decline participating in any way. A copy of the focus group information and consent form for care providers is included in Appendix 7.

The analysis of the survey data or the focus group transcripts did not identify the outpatient heart failure disease management program or the care providers by name. For example, when describing the reasons for scoring each domain, information that could be used to

identify the outpatient heart failure disease management program was not included in this description. For both the quantitative and qualitative components, the outpatient heart failure disease management program was given a pseudonym and only identified by the type of outpatient heart failure disease management program and was described as either an urban or rural outpatient heart failure disease management program in associated reports and thesis dissertations. Further, we did not identify the care providers by name or when using direct quotations from the focus groups. If we used the care provider's occupation in a direct quotation from the focus group, the outpatient heart failure disease management program, which the care provider was associated with, was not identified with the quotation. Aside from a direct quotation from the focus group, all information was grouped with responses from the other participants in the focus group. The survey and transcripts from the focus groups were de-identified and stored in a locked cabinet in the student investigator's office. The de-identified information was replaced with codes and the master file containing the code information was stored in a password protected file on the student researcher's locked computer. All information was kept for one year and after that time was confidentially shredded and destroyed.

## **CHAPTER 8: PHASE II FINDINGS**

Four outpatient heart failure disease management programs were chosen for the purpose of this study. Two of these programs represented primary care heart failure disease management programs and two of these programs represented specialty care heart failure disease management programs. One program in each type of outpatient heart failure disease management program was characterized as an urban centre and the other was characterized as a rural centre.

### **8.1 Quantitative Component**

The purpose of the quantitative component of the study was to use responses from an environmental scan survey to classify four outpatient heart failure disease management programs according to the preliminary set of criteria established during the first phase of this study. The use of the preliminary set of criteria and the rationale behind each program's scores are included in the following subsections.

#### **8.1.1 Clinic A**

Clinic A was classified as an urban specialty care heart failure disease management program. According to Chapter 7, as a specialty care heart failure disease management program Clinic A should receive a score of 3 points for each domain for an average score of 3 +/- 0.4 points across all six domains and a total score of 18 +/- 2 points on the preliminary set of criteria. A summary of Clinic A's scores on the preliminary set of criteria and the rationale behind these scores are included in Table 7.

Table 7. Scores and Scoring Rationale for Clinic A.

<b>Domain</b>	<b>Points Assigned</b>	<b>Rationale</b>
<b>Patient Risk Status</b>	1 = NYHA class I only 2 = NYHA class I/II <b>3 = NYHA class III/IV</b>	According to the survey the majority (60%) of the patients are NYHA class III
<b>Delivery Personnel</b>	1 = generalist provider 2 = HF expert provider <b>3 = cardiology &amp; HF expert provider</b>	According to the survey a cardiologist is part of the team in addition to RNs and NPs
<b>Method of Communication</b>	1 = mainly person-to-person by telephone/electronic monitoring with some face-to-face contact <b>2 = face-to-face contact with regular electronic/telephone monitoring</b> 3 = primarily face-to-face contact with some electronic/telephone monitoring	According to the survey the program does both face-to-face contact and telephone monitoring but does not include the frequency of either method
<b>Intensity</b>	1 = > 6 mo. 2 = ≤ 6 mo. <b>3 = ≤ 3 mo.</b>	According to the survey patients typically have 1-4 follow-up visits a year. Needs further evaluation
<b>Complexity</b>	1 = low complexity 2 = moderate complexity <b>3 = high complexity</b>	According to the survey the program provides patient education; provides up-titration of medication; has access to cardiac diagnostics, cardiac intervention and advance care planning; and completes surveillance and follow-up response to patient decompensation. Survey does not include information on whether patient physical assessment or risk factor assessment occurs. Therefore, program has 6 confirmed disease management components of 8 possible components. The program also has access to a cardiologist.

		Survey does not provide information on approach to patient care.
<b>Environment</b>	1 = FHT/Community; outpatient only 2 = HF Clinic; outpatient only <b>3 = Hospital; inpatient/outpatient</b>	According to the survey the program is located and connected with a hospital
<b>Summary</b>	Patient Risk Status: 3 Delivery Personnel: 3 Method of Communication: 2 Intensity: 3 Complexity: 3 Environment: 3	
<b>Total Score:</b>	17	
<b>Average Score</b>	2.83	

The total score for Clinic A according to the preliminary set of criteria was 17 points out of a possible 18 points. The average score across the six domains was 2.83 points. Since 17 points and 2.83 points are within the standard deviation of +/- 2 points and +/- 0.4 points, respectfully, this suggests that Clinic A is a specialty care heart failure disease management program. Since we were unable to properly assess the frequency of the method of communication, it was difficult to determine whether the program did more face-to-face communication or telephone monitoring. This may explain the discrepancy between the scores Clinic A should have received according to the first phase of the study and the scores reported based on Clinic A's environmental scan survey responses.

We were also unable to assess two of the disease management components within the complexity domain, which were the patient physical assessment and the risk factor assessment disease management components, based on Clinic A's responses in the environmental scan survey. Given that Clinic A had access to a cardiologist and that Clinic A offered more than the

average number of disease management components, they received 3 points for the complexity domain. In addition, the majority of patients seen in the program were highly complex based on their NYHA classification. Therefore, it can be inferred that Clinic A has an individualized approach to patient care and therefore should receive 3 points for the complexity domain. Additional information is required in order to properly assess the complexity domain. The intensity domain also requires further information in order to be properly assessed. Clinic A's environmental scan survey responses indicated that they conducted 1-4 follow-up visits a year. Again, since the majority of patients seen in the program are highly complex it can be interpreted that they are frequently seen in the program and therefore should receive 3 points for the intensity domain. In summary, further information is required for the method of communication, intensity and complexity domains. This was gathered during Clinic A's focus group and updated total and averages scores on the preliminary set of criteria were determined for Clinic A.

#### **8.1.1.1 Summary of Focus Group Scores**

During the focus group Clinic A's care providers were asked to use the preliminary set of criteria to score their outpatient heart failure disease management program. The scoring summary is included in Table 8.

Table 8. Summary of the Focus Group Scores for the Urban Speciality Care Heart Failure Disease Management Program

<b>Summary</b>	Patient Risk Status: 3 Delivery Personnel: 3 Method of Communication: 2 Intensity: 3 Complexity: 3 Environment: 3
<b>Total Score:</b>	17
<b>Average Score</b>	2.83

Clinic A scored 3 points for each domain except for the method of communication domain, which gave them with an overall score of 17 points and an average score of 2.83 points. This score mirrors the score they received during the secondary data analysis, which confirms that they are a specialty care heart failure disease management program. However, due to the method of communication domain it does not match the score reported in the first phase of the study for specialty care heart failure disease management programs. It was indicated that this may be due to the wording of the method of communication domain, which is discussed in the qualitative results.

### **8.1.2 Clinic B**

Clinic B was classified as a rural specialty care heart failure disease program. According to Chapter 7, as a specialty care heart failure disease management program Clinic B should receive a score of 3 points for each domain for an average score of 3 +/- 0.4 points across all six domains and a total score of 18 +/- 2 points on the preliminary set of criteria. A summary of Clinic B's scores on the preliminary set of criteria and the rationale behind these scores are included in Table 9.

Table 9. Scores and Scoring Rationale for Clinic B

<b>Criteria</b>	<b>Points Assigned</b>	<b>Rationale</b>
<b>Patient Risk Status</b>	1 = NYHA class I only 2 = NYHA class I/II <b>3 = NYHA class III/IV</b>	According to the survey the majority (80%) of patients are NYHA class III/IV
<b>Delivery Personnel</b>	1 = generalist provider 2 = HF expert provider <b>3 = cardiology &amp; HF expert provider</b>	According to the survey a cardiologist is part of the team in addition to RNs and NPs
<b>Method of Communication</b>	1 = mainly person-to-person by telephone/electronic monitoring with some face-to-face contact <b>2 = face-to-face contact with regular electronic/telephone monitoring</b> 3 = primarily face-to-face contact with some electronic/telephone monitoring	According to the survey the program does both face-to-face contact and telephone monitoring but does not include the frequency of either method
<b>Intensity</b>	1 = > 6 mo. 2 = ≤ 6 mo. <b>3 = ≤ 3 mo.</b>	According to the survey patients typically > 4 visits a year
<b>Complexity</b>	1 = low complexity 2 = moderate complexity <b>3 = high complexity</b>	According to the survey the program provides patient education; provides up-titration of medication; has access to cardiac diagnostics, cardiac intervention and advance care planning; and completes surveillance and follow-up response to patient decompensation. Survey does not include information on whether patient physical assessment or risk factor assessment occurs. Therefore, program has 6 confirmed disease management components of 8 possible components. The program also has access to a cardiologist. Survey does not provide information on approach to patient care.

<b>Environment</b>	1 = FHT/Community; outpatient only 2 = HF Clinic; outpatient only <b>3 = Hospital; inpatient/outpatient</b>	According to the survey the program is located and connected with a hospital
<b>Summary</b>	Patient Risk Status: 3 Delivery Personnel: 3 Method of Communication: 2 Intensity: 3 Complexity: 3 Environment: 3	
<b>Total Score:</b>	17	
<b>Average Score</b>	2.83	

The total score for Clinic B according to the preliminary set of criteria was 17 points out of a possible 18 points. The average score across the six domains was 2.83 points. Since 17 points and 2.83 points are within the standard deviation of +/- 2 points and +/- 0.4 points, respectfully, this suggests that Clinic B is a specialty care heart failure disease management program. Since we were unable to properly assess the frequency of the method of communication, it was difficult to determine whether the program did more face-to-face communication or telephone monitoring. This may explain the discrepancy between the scores Clinic B should have received according to the first phase of the study and the scores reported based on Clinic B's environmental scan survey responses.

We were also unable to assess two of the disease management components within the complexity domain, which were the patient physical assessment and the risk factor assessment disease management components, based on Clinic B's environmental scan survey responses. Given that Clinic B had access to a cardiologist and that Clinic B offered more than the average number of disease management components, they received 3 points for the complexity domain. In addition, since the majority of patients seen in Clinic B are highly complex based on their

NYHA classification, it can be interpreted that they have an individualized approach to patient care and therefore should receive 3 points for the complexity domain. It is clear that further information is required in order to properly assess complexity domain. In summary, additional information is required for scoring the method of communication and complexity domains. This was gathered during Clinic B's focus group and updated total and average scores on the preliminary set of criteria were determined for Clinic B.

#### 8.1.2.1 Summary of Focus Group Scores

During the focus group Clinic B was asked to use the preliminary set of criteria to score their outpatient heart failure disease management program. The scoring summary is included in Table 10.

Table 10. Summary of the Focus Group Scores for the Rural Speciality Care Heart Failure Disease Management Program

<b>Summary</b>	Patient Risk Status: 3 Delivery Personnel: 3 Method of Communication: 3 Intensity: 3 Complexity: 3 Environment: 3
<b>Total Score:</b>	18
<b>Average Score</b>	3

Clinic B scored 3 points for each domain, which gave them an overall score of 18 points and an average score of 3 points. This confirms that Clinic B is a specialty care heart failure disease management program, since their scores match the scores reported in the first phase of the study for specialty care heart failure disease management programs.

#### 8.1.3 Clinic C

Clinic C was classified as an urban primary care heart failure disease management program. According to Chapter 7, as a primary care heart failure disease management program

Clinic C should receive a score of 2 points for each domain for an average score of  $2 \pm 0.4$  points across all six domains and a total score of  $12 \pm 2$  points on the preliminary set of criteria. A summary of Clinic C's scores on the preliminary set of criteria and the rationale behind these scores are included in Table 11.

Table 11. Scores and Scoring Rationale for Clinic C

Criteria	Points Assigned	Rationale
<b>Patient Risk Status</b>	1 = NYHA class I only 2 = NYHA class I/II 3 = NYHA class III/IV	Question not answered on survey
<b>Delivery Personnel</b>	1 = generalist provider <b>2 = HF expert provider</b> 3 = cardiology & HF expert provider	According to the survey a geriatrician is part of the team in addition to family physicians, RNs, NPs and allied health
<b>Method of Communication</b>	1 = mainly person-to-person by telephone/electronic monitoring with some face-to-face contact <b>2 = face-to-face contact with regular electronic/telephone monitoring</b> 3 = primarily face-to-face contact with some electronic/telephone monitoring	According to the survey the program does both face-to-face contact and telephone monitoring but does not include the frequency of either method
<b>Intensity</b>	1 = > 6 mo. 2 = ≤ 6 mo. <b>3 = ≤ 3 mo.</b>	According to the survey patients typically > 4 visits a year
<b>Complexity</b>	1 = low complexity <b>2 = moderate complexity</b> 3 = high complexity	According to the survey the program provides patient education; provides up-titration of medication; has access to cardiac diagnostics, cardiac intervention and advance care planning (although the latter two are at another site); and completes surveillance and follow-up response to patient decompensation. Survey does not include information on whether patient physical assessment or risk factor assessment occurs. Therefore, program has 4 confirmed disease management components of 8 possible components. The program does not have access to a cardiologist on site but does have heart failure specialists. Survey does not provide information on approach to patient care.

<b>Environment</b>	1 = FHT/Community; outpatient only <b>2 = HF Clinic; outpatient only</b> 3 = Hospital; inpatient/outpatient	According to the survey the program is located and connected with a family health team
<b>Summary</b>	Patient Risk Status: N/A Delivery Personnel: 2 Method of Communication: 2 Intensity: 3 Complexity: 2 Environment: 2	
<b>Total Score:</b>	11	
<b>Average Score</b>	2.20	

The total score for Clinic C according to the preliminary set of criteria was 11 points out of a possible 18 points. The average score across the six domains was 2.20 points. Since 11 points and 2.20 points are within the standard deviation of +/- 2 points and +/- 0.4 points, respectfully, this suggests that Clinic C is a primary care heart failure disease management program. We were unable to properly assess the patient risk status domain. As well, Clinic B received 3 points for the intensity domain, as opposed to the 2 points it was suggested they receive in the first phase of the study. These issues may explain the discrepancy between the scores Clinic C should have received according to the first phase of the study and the reported scores based on Clinic C's environmental scan survey responses.

We were also unable to properly assess the method of communication domain. Clinic C's environmental scan survey responses indicated that they did both face-to-face communication and telephone monitoring but it did not indicate the frequency of the methods. Therefore, further information is required in order to properly assess this domain. Clinic C's environmental scan survey responses also did not provide information on two of the disease management components within the complexity domain, which were the patient physical

assessment and the risk factor assessment disease management components. Given that Clinic C had access to a heart failure specialist as opposed to a cardiologist and offered an average number of disease management components, they received 2 points for the complexity domain. Since Clinic C's environmental scan survey responses did not provide information concerning the patient risk status domain, the type of patient approach cannot be inferred for the complexity domain. Thus, the complexity domain also requires further information in order to be properly assessed. In summary, further evaluation is required for the method of communication, intensity and complexity domains. This was gathered from focus group conversations and a new score was determined for the program.

#### 8.1.3.1 Summary of Focus Group Scores

During the focus group Clinic C was asked to use the preliminary set of criteria to score their outpatient heart failure disease management program. The two members of the focus group provided different scores for the method of communication and intensity domains. The two sets of scores are included in Table 12.

Table 12. Summary of the Focus Group Scores for the Urban Primary Care Heart Failure Disease Management Program

	Score 1	Score 2
<b>Summary</b>	Patient Risk Status: 2 Delivery Personnel: 2 Method of Communication: 2 Intensity: 3 Complexity: 2 Environment: 1	Patient Risk Status: 2 Delivery Personnel: 2 Method of Communication: 3 Intensity: 2 Complexity: 2 Environment: 1
<b>Total Score:</b>	12	12
<b>Average Score</b>	2	2

Both set of scores provide an overall score 12 points and an average score of 2 points. This confirms that Clinic C is a primary care heart failure disease management program since their scores match the scores reported in the first phase of the study for primary care heart failure

disease management programs. The differences in the method of communication domain and intensity domain between the two sets of scores may be due to the wording of these domains. Further, the care provider's assigned Clinic C 1 point in the environment domain, as opposed to 2 points as suggested in the first phase of the study. This may be due to the fact that a score of 1 point was for a family health team and they may have identified as a family health team as opposed to a heart failure clinic within a family health team due to the wording of the domain. The wording of the environment domain also requires further evaluation. This is discussed in the qualitative results section.

#### **8.1.4 Clinic D**

Clinic D is a rural primary care heart failure disease management program. According to Chapter 7, as a primary care heart failure disease management program Clinic D should receive a score of 2 points for each domain for an average score of  $2 \pm 0.4$  points across all six domains and a total score of  $12 \pm 2$  points on the preliminary set of criteria. A summary of Clinic D's scores on the preliminary set of criteria and the rationale behind these scores are included in Table 13.

Table 13. Scores and Scoring Rationale for Clinic D

<b>Criteria</b>	<b>Points Assigned</b>	<b>Rationale</b>
<b>Patient Risk Status</b>	1 = NYHA class I only <b>2 = NYHA class I/II</b> 3 = NYHA class III/IV	The program only indicated the number (40%) of NYHA class II patients they see
<b>Delivery Personnel</b>	1 = generalist provider <b>2 = HF expert provider</b> 3 = cardiology & HF expert provider	According to the survey an internist is part of the team in addition to RNs
<b>Method of Communication</b>	1 = mainly person-to-person by telephone/electronic monitoring with some face-to-face contact <b>2 = face-to-face contact with regular electronic/telephone monitoring</b> 3 = primarily face-to-face contact with some electronic/telephone monitoring	According to the survey the program does both face-to-face contact and telephone monitoring but does not include the frequency of either method
<b>Intensity</b>	1 = > 6 mo. <b>2 = ≤ 6 mo.</b> 3 = ≤ 3 mo.	According to the survey patients typically 1-4 visits a year
<b>Complexity</b>	1 = low complexity <b>2 = moderate complexity</b> 3 = high complexity	According to the survey the program provides patient education; provides up-titration of medication; has access to some cardiac diagnostics but is limited in their access to cardiac intervention and advance care planning. The program also completes surveillance and follow-up response to patient decompensation. Survey does not include information on whether patient physical assessment or risk factor assessment occurs. Therefore, program has 3 confirmed disease management components of 8 possible components. The program does not have access to a cardiologist but does have heart failure specialists. Survey does not provide information on approach to patient care.

<b>Environment</b>	1 = FHT/Community; outpatient only <b>2 = HF Clinic; outpatient only</b> 3 = Hospital; inpatient/outpatient	According to the survey the program is located and connected with a family health team
<b>Summary</b>	Patient Risk Status: 2 Delivery Personnel: 2 Method of Communication: 2 Intensity: 2 Complexity: 2 Environment: 2	
<b>Total Score:</b>	12	
<b>Average Score</b>	2.00	

The total score for Clinic D according to the preliminary set of criteria was 12 points out of a possible 18 points. The average score across the six domains was 2 points. This suggests that Clinic D is a primary care heart failure disease management program.

As per the other programs, further information is required in order to properly assess some of the domains. We were unable to properly assess the patient risk status domain since Clinic D's environmental scan survey responses only provided a statistic for 40% of the patients that they see. Further, Clinic D indicated that they did both face-to-face communication and telephone monitoring but did not indicate the frequency of the methods. Additionally, Clinic D's environmental scan survey responses indicated that patients have typically have 1-4 visits per year. This range can indicate that a score of either 1, 2 or 3 points is appropriate for the intensity domain. Given the complexity of the Clinic D's outpatient heart failure disease management program, it was inferred that 1 visit a year and 4 visits a year may represent outliers in the data and 2 or 3 visits a year may be more normal. Finally, we were unable to properly assess two of the disease management components within the complexity domain, which were the patient physical assessment and the risk factor assessment disease management components,

based on Clinic D's environmental scan survey responses. Given that Clinic D had access to a heart failure specialist as opposed to a cardiologist and offered an average number of disease management components, they received 2 points for the complexity domain. Since Clinic D's environmental scan survey responses did not provide adequate information concerning the patient risk status domain, the type of patient approach cannot be inferred for the complexity domain. In summary, further evaluation is required for the patient risk status, method of communication, intensity and complexity domains. This was gathered during Clinic D's focus group and updated total and average scores on the preliminary set of criteria were determined for Clinic D.

#### 8.1.2.1 Summary of Focus Group Scores

During the focus group Clinic D was asked to use the preliminary set of criteria to score their outpatient heart failure disease management program. The scoring summary is included in Table 14.

Table 14. Summary of the Focus Group Scores for the Rural Primary Care Heart Failure Disease Management Program

<b>Summary</b>	Patient Risk Status: 2 Delivery Personnel: 2 Method of Communication: 2 Intensity: 2 Complexity: 2 Environment: 2
<b>Total Score:</b>	12
<b>Average Score</b>	2

Clinic D scored 2 points for each domain, which gave them a total score of 12 points and an average score of 2 points. This confirms that Clinic D is a primary care heart failure disease management program, since their score matches the score reported in the first phase of the study for primary care heart failure disease management programs.

## 8.2 Qualitative Component

The purpose of the qualitative component was to use input from focus groups with physicians, clinical care coordinators, nurse practitioners, registered nurses and allied health professionals at four outpatient heart failure disease management programs to: (1) build upon and finalize the set of criteria for defining the roles and responsibilities of different types of outpatient heart failure disease management programs; and (2) determine factors that facilitated or hindered outpatient heart failure disease management programs from adopting the finalized set of criteria.

In total, we completed three focus groups and seven provider interviews. One of the provider interviews was completed with one of the outpatient heart failure disease management programs instead of a focus group because only one care provider was available to participate. Aside that provider interview, all of the other provider interviews were completed to complement the focus groups and consisted of a smaller number of questions. Four of these complementary provider interviews were completed through email. The email provider interviews were not described in Chapter 7 since provider interviews conducted by email were not in the proposed methods. Instead the provider interviews conducted over email were completed at the suggestion of care providers within the focus groups. The care providers generally suggested that a complementary provider interview should be completed if they were unable to answer a question and/or thought that the input from a different provider was warranted. These providers were past (n=3) or present (n=1) care providers of the outpatient heart failure disease management program. The care providers were able to give their consent to participate either directly in the email message or by attaching a scanned copy of the consent form to the email.

Ten providers participated in the focus groups and included: two medical doctors (one cardiologist and one family physician), four nurse practitioners (two of whom were also clinical care coordinators), three registered nurses and one allied healthcare professional (who was also a clinical care coordinator). A registered nurse (who was also a clinical care coordinator) participated in the in-person provider interview that was completed instead of a focus group and two medical doctors (one cardiologist and one psychiatrist) participated in the complementary in-person provider interviews. Finally, two medical doctors (one family physician and one internist), one nurse practitioner and one allied healthcare professional participated in the complementary provider interviews completed through email. The themes developed from the qualitative findings are presented according to each research objective. Due to time and budget constraints on the study, the second coder was unable to provide complete coding information and thus, we were unable to calculate a Kappa Statistic to determine the agreement between the two coders for thematic development. Instead, the second coder reviewed the first coder's list of themes and cross-referenced it with one of the transcripts in order to ensure that there was agreement for the thematic development.

### **8.2.1 Finalizing the Set of Criteria**

As previously mentioned the purpose of this section was to use input from focus groups with physicians, clinical care coordinators, nurse practitioners, registered nurses and allied health professionals at four outpatient heart failure disease management programs to build upon and finalize the set of criteria for defining the roles and responsibilities of different types of heart failure disease management programs in Ontario. The focus group discussions identified seven themes, with one of the themes being unique to a rural perspective. The seven themes include: confusion with the criteria; describing the patient population; factors determining the frequency

of visits; care provision (intervention vs. monitoring); timely access to care; type of delivery personnel present; and all program types under one roof (rural theme). When finalizing the preliminary set of criteria, since we only conducted focus groups with two of the three different types of outpatient heart failure disease management programs, the finalized set of criteria only differentiate between these two types of disease management programs. The scoring system is also removed and replaced with a checklist for each domain to allow for the finalized set of criteria to be more descriptive.

#### **8.2.1.1 Confusion with the Criteria**

The confusion with using the preliminary set of criteria was a theme that was evident across all interactions with care providers. First, Clinic C gave their outpatient heart failure disease management program 1 point in the environment domain, instead of the suggested 2 points, due to the inexplicit wording of the domain. It is suggested that this is reworded to avoid future confusion and to explicitly outline the care environment in which the outpatient heart failure disease management program is being provided in. The care providers also described an inability to score the method of communication section. Clinic D noted that the descriptions beside each score do not adequately describe the practice. Clinic A, B and C described significant using telephone monitoring in addition to face-to-face communication, which was not described adequately under the method of communication domain. Additionally, variance between similar types of outpatient heart failure disease management programs was seen when using the preliminary set of criteria to score the method of communication domain. It is advised that this domain is heavily modified or removed entirely, as is described under a latter theme. Further, the complexity domain was consistently scored based on the complexity of the patients seen in the outpatient heart failure disease management programs and not as the complexity of

the program itself, which was the intention of this domain as described in the first phase of the study. It was suggested that perhaps listing the characteristics of a low, moderate and high complexity outpatient heart failure disease management program may alleviate this issue. Finally, three of the outpatient heart failure disease management programs had difficulty in using the preliminary set of criteria because the characteristics of their program could not be used to determine a score within a certain domain. For example, Clinic A had difficulty in scoring the patient risk status domain because their outpatient heart failure disease management program had patients that could be classified as NYHA class II-IV. The preliminary set of criteria requires an explicit description for how to determine what score care provider should use for each domain.

#### **8.2.1.2 Describing the Patient Population**

It was apparent across all care provider interactions that the patient risk status was not a useful description for the heart failure patients who are typically seen in these programs. It was suggested that a heart failure patient's geriatric or frailty status; a heart failure patient's instability, as classified as number of emergency room visits or number of medication changes; a heart failure patient's support system; and a heart failure patient's mental status should be used to describe and differentiate between the different types of outpatient heart failure disease management programs within the patient population domain. It was suggested that a heart failure patient who is geriatric and/or frail, is highly unstable, has a poor social support system and poor mental health status (i.e., low education level and/or the presence of a mental health disorder) should be seen in a more complex care environment. The way to differentiate between the two types of heart failure disease management programs, however, should be based on the stability of the patient, the support system of the patient and the mental health status of a heart failure patient. The geriatric or frailty status of a heart failure patient can be managed in a lower

complexity care environment if the appropriate providers are present, i.e., geriatricians, and the patient is stable, has a strong support system and a good mental health status. The ability to manage geriatric and frail patients in the primary care setting was highlighted by Clinic C. Clinic C had access to a geriatrician and felt confident that geriatric or frail patients could be seen in their program, as long as they were stable. It is cautioned though that the ability to manage these types of heart failure patients is in the “eye of the beholder” and without the proper staffing support outpatient primary care heart failure disease management program may not feel comfortable managing geriatric and frail patients in the program. It is also very important to manage these patients with the proper staffing support because frailty is associated with an increase in hospitalizations (Harkness et al., 2012). The rationale behind the differentiation of the patient population across the two types of outpatient heart failure disease management programs is provided below.

The mental health status of a heart failure patient was indicated to be extremely important to understanding care instructions and managing the condition. Clinic B had recruited a psychiatrist to conduct research into this phenomenon. The key differences in the mental health status of heart failure patients in the management of the condition is evidenced in the following quotation:

It is incredibly important because when I am doing my teaching they could be NYHA class I and their ejection fraction could be relatively good too, maybe like grade 1, but because they are unable to absorb what I am saying or putting it into use, they are going to end up in the hospital even more frequently than someone who is at a higher education level, NYHA class II with terrible ventricles. The latter patient is getting it and they are managing their symptoms

and they are super proactive and are calling me and understanding my instructions. I think it is paramount. (Clinic D)

Clinic A discussed this as well and described the social support system of the patient to be very helpful, especially if the patient is not capable. Although they cautioned that this may not always be the case so it will be important to determine both factors before determining the appropriate type of outpatient heart failure disease management program for a heart failure patient. Further, Clinic A provided reasoning behind differentiating the patient population based on patient stability as evidenced in the following quotation:

Well I guess a key thing would be stability. I do not know that it makes all that difference the actual nature of the cardiac problem, if the patient is stable. Their medications are set, they have all their gadgets that are likely to do them any good, they should be able to be managed in primary care with the refer back for help or to be seen again should things go off the rails. (Clinic A)

In summary, changes to the patient population should differentiate between the two types of outpatient heart failure disease management programs based on the stability of a heart failure patient, the support system of a heart failure patient and the mental health status of a heart failure patient. Geriatric and frail patients can be seen in less complex outpatient heart failure disease management programs with the appropriate support.

#### **8.2.1.3 Factors Determining the Frequency of Visits**

Clinic A and B both indicated that the frequency of follow-up depended on the type of visit that the patient was attending the program for. Regardless of the type of outpatient heart failure disease management program, if a heart failure patient required medication changes, then they were required to be seen in the program more frequently. Specifically if a heart failure

patient required major medication provisions, which would typically be seen with patients who are unstable and/or do not have the mental status or support system required to manage the disease adequately, they needed to be seen in the program quite frequently and in a more complex outpatient heart failure disease management program. Once they are stabilized, however, they could be slowly transitioned to a less complex outpatient heart failure disease management program. This was evidenced in the following quotation:

I think that the frequency of visits/consultations have to be determined by the purpose. When we see patients initially and they are not on target medications then the frequency of those visits to titrate the medications will follow the algorithm that we tend to use, which is about every 2 weeks. Once they are at target, we arrange for a follow-up assessment on their LD function in about 3 months. I see very little purpose at all to put up with having to do all these visits at set time intervals. If you think about, if somebody is okay without seeing us for 3 months then why not 6 months? And if they are okay after 6 months then why a year? And if they do not need to see us for a year the why not ever?

(Clinic A)

It should be noted that once a heart failure patient is in a lower complexity outpatient heart failure disease management program, they may need to be seen quite frequently during the first couple of visits if the patient's medications are not optimized. In summary it is important to determine the type of visit that the patient attending the outpatient heart failure disease management program for when determining the frequency of follow-up visits. If the patient can be seen less frequently then perhaps discharging them into a lower complexity outpatient heart failure disease management program may be suitable.

### **8.2.1.7 Care Provision (Intervention vs. Monitoring Programs)**

The care provisions offered at each type of outpatient heart failure disease management program was described previously in the complexity of the program domain. It was clear in the focus groups that outpatient heart failure disease management programs defined themselves as moderate or high complexity appropriately but often failed to understand what that complexity meant. The care provision, or disease management components, should be explicitly described in the finalized set of criteria in order to avoid confusion. It was further suggested by Clinic B that the different types of outpatient heart failure disease management programs should be recognized as either intervention programs or monitoring programs. They suggested that lower intensity outpatient heart failure disease management programs should monitor the status of the patient and if a heart failure patient become unstable or requires major changes in their medications that the patient is referred back to the outpatient specialty care heart failure disease management programs. This part of the care provision may only be useful in rural areas with no access to primary care heart failure disease management programs, however. The monitoring programs that rural outpatient heart failure disease management programs are referring to would be the community care heart failure disease management programs and once these programs are added to the finalized set of criteria, this should be considered a component. Clinic B also indicated that advance care planning is a necessity in lower complexity outpatient heart failure disease management programs, specifically in the community care heart failure disease management programs as evidenced by the following quotation:

End-of-life care is huge part of heart failure clinics and we are being challenged to address that but you get a patient in for the first time and they are

85. To me, perhaps end of life should have been discuss at some point with the GP or whoever. (Clinic B)

In summary, an explicit list of disease management components should be incorporated into the finalized set of criteria for each type of outpatient heart failure disease management program. Further, both primary care and specialty care heart failure disease management programs should be considered intervention type programs and have advance care planning included as one of their disease management components. If community care heart failure disease management programs are added to the finalized set of criteria, it may be useful to refer to these programs as monitoring programs.

#### **8.2.1.5 Timely Access to Care**

Timely access to care was a key component of all outpatient heart failure disease management programs. Both primary care and specialty care heart failure disease management programs indicated that their programs were successful because patients had timely access to care and could easily contact the program if they experienced difficulty with managing their condition. Clinic D alone logged 300 phone calls in 3 months and Clinic B indicated that they answered 10 to 20 calls a day. The importance of timely access to care is evidenced in the following quotations:

Patients being able to have timely interventions either by telephone or by clinic.

Because I think that is what makes a big difference in heart failure clinics – is the timely interventions. So they are not sitting at home and going down the tubes. And the default is not always emergency. (Clinic A)

So we do telephone support as a key part so you have constant communication and people learn to call us maybe instead of going to emergency. So if they call

us we can actually do something. For example, we can change medications, order diagnostics, whatever we feel is appropriate and hopefully avoid an emergency visit. (Clinic A)

This timely access to care in both types of outpatient heart failure disease management programs would explain the inconsistency and inability to scoring the method of communication domain on the preliminary set of criteria. Therefore, it is advised to remove this domain in the finalized set of criteria and replace it with a domain outlining timely access to care. Timely access to care across both types of outpatient heart failure disease management programs is essential and should not be used to differentiate between two types of outpatient heart failure disease management programs.

#### **8.2.1.6 Type of Delivery Personnel**

Similar to the timely access to care, the type of delivery personnel present in the outpatient heart failure disease management programs was paramount to the success of the program. The focus group indicated the specialist involvement might differ between the two types of outpatient heart failure disease management programs. Both Clinic A and Clinic B had cardiologists in their outpatient heart failure disease management programs. Clinic C and Clinic D either had geriatricians or internists (heart failure specialists) in their outpatient heart failure disease management programs in addition to family physicians. However, cardiologists can be associated with primary care heart failure disease management programs and due to availability might not have been seen in the outpatient heart failure disease management programs we conducted focus groups with. Regardless of these differences, the nursing support was key to the success of the program across all four outpatient heart failure disease management programs. It is particularly important to have advanced practice nurses; as well as to have registered nurses,

who are well versed in the management of heart failure and are provided with medical directives, as members of your outpatient heart failure disease management program. Clinic C indicated that advanced practice nurses were an integral part of their program. When their outpatient heart failure disease management program was first developed, the advanced practice nurses led the program and were supported by specialist oversight. The involvement of family physicians was for referral purposes only. Similarly, in Clinic D, the registered nurse oversaw the general management of the program and was supported by specialist run clinics. Therefore, nursing support is integral to the management of the outpatient heart failure disease management program. This was evidenced in the following quotation:

We have registered nurses here that help us out and have medical directives for medication titration and diagnostics so that they can order certain bloodwork.

So that is helpful; so if a patient calls and it is not the advanced practice nurses that answer the phone, the registered nurses can actually intervene and do something. If something is not done during the phone call, people will just hang up and go to emergency so we can avoid that. (Clinic A)

Clinic B also indicated that having allied health professionals as members of the specialty care heart failure disease management programs would be useful to the effective management of heart failure. Further, they also indicated that the involvement of other specialists in the care of heart failure patients, would be useful due to the number of comorbidities that the patient presents with; “I would like to see more resources but covering more comorbidities so it is a ‘one-stop-shop’ for all your big 1’s that are causing people grief” (Clinic B). This is especially important so that patients do not experience “appointment fatigue,” which was described as having an overwhelming number of

appointments to attend and choosing not to attend any. “Appointment fatigue” will jeopardize the optimal management of heart failure and may be able to be alleviated by having multiple specialists involved in the specialty care heart failure disease management programs. In summary, all types of outpatient heart failure disease management programs should have advanced practices nurses and/or knowledge registered nurses with medical directives as part of their program. Family physicians may or may not be direct members of the primary care heart failure disease management program and cardiac specialist involvement is typically seen in higher complexity outpatient heart failure disease management programs. In addition, allied health care professionals and the involvement of other disease management specialists would be useful in specialty care heart failure disease management programs.

#### **8.2.1.7 All Programs Types Under One Roof**

As a final theme for this section, Clinic B described a lack of primary care heart failure disease management programs and ineffective community care heart failure disease management programs. They found that they were unable to discharge from their outpatient heart failure disease management program and describe their program as being encompassing of all types of outpatient heart failure disease management programs. For this reason, the finalized set of criteria may not be useful to rural specialty care heart failure disease management programs. While they should adopt the roles and responsibilities as outlined by their type of outpatient heart failure disease management program, it will have to be respected that the characteristics of the primary care heart failure disease management programs may also be included in the program’s roles and responsibilities. Once community care heart failure disease management programs become more consistent and represent high quality outpatient heart failure disease management

programs, the rural specialty care heart failure disease management programs may be able to offset some of these roles and responsibilities to them. Until that time though the rural specialty care heart failure disease management programs are representative as both primary care and specialty care heart failure disease management programs.

### **8.2.2 Finalized Set of Criteria**

The finalized set of criteria to define the roles and responsibilities of the different types of outpatient heart failure disease management programs in Ontario is represented in Table 15.

Table 15. Finalized Set of Criteria for Defining the Roles and Responsibilities of the Different Types of Heart Failure Disease Management Programs in Ontario

Domain	Roles and Responsibilities
Patient Population	<b><u>Primary Care HF Disease Management Program</u></b>
	<input type="checkbox"/> Good mental health status (characterized as high education level or lack of a mental health condition)
	<b>AND/OR</b>
	<input type="checkbox"/> Strong social support
	<b>AND</b>
	<input type="checkbox"/> Stable heart failure (i.e., no hospitalizations and/or few medication changes)
	<b><u>Specialty Care HF Disease Management Program</u></b>
	<input type="checkbox"/> Poor mental health status (characterised as low education level or presence of a mental health condition)
	<b>AND/OR</b>
	<input type="checkbox"/> Lack of social support (i.e., informal care giver) at home
Frequency of Follow-up Appointments (intended to be followed sequentially in specialty care programs but may reverse if patients run into trouble; average follow-up periods)	<b>AND</b>
	<input type="checkbox"/> Unstable heart failure (i.e., multiple hospitalizations, and/or multiple medication changes)
	<b>AND</b>
	<input type="checkbox"/> Presence of geriatric syndromes or frailty <b>AND</b> no geriatric specialist support at the primary care heart failure disease management program
	<b><u>Primary Care HF Disease Management Program</u></b>
	1. Follow-up appointment every 3 months following the initial appointment (patient may need to be seen more frequently if medications are not stabilized)
	2. Some, minor medication changes are acceptable and follow-up as needed during this monitoring period
	3. If major medication changes become increasingly required with patient <b>AND/OR</b> the patient has unstable heart failure refer to specialty care heart failure disease management program

	<b><u>Specialty Care HF Disease Management Program</u></b> <ol style="list-style-type: none"> <li>1. Every two weeks until medications are stabilized</li> <li>2. Follow-up every 3 months as long as patient is stabilized</li> <li>3. Discharge to primary care if stable for 6 months</li> </ol>
Complexity of Program	<b><u>Primary Care HF Disease Management Program</u></b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Provide patient and caregiver education</li> <li><input type="checkbox"/> Complete patient risk factor assessment</li> <li><input type="checkbox"/> Complete patient physical assessment</li> <li><input type="checkbox"/> Complete patient surveillance and follow-up response to patient decompensation (in-person appointment available 1-2/week)</li> <li><input type="checkbox"/> Encourage advance care planning</li> <li><input type="checkbox"/> Access to minor cardiac diagnostics</li> <li><input type="checkbox"/> Access to some cardiac interventions</li> <li><input type="checkbox"/> Provide routine medication management</li> </ul> <b><u>Specialty Care HF Disease Management Program</u></b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Provide patient and caregiver education</li> <li><input type="checkbox"/> Complete patient risk factor assessment</li> <li><input type="checkbox"/> Complete patient physical assessment (more advanced)</li> <li><input type="checkbox"/> Complete patient surveillance and follow-up response to patient decompensation (in-person appointment available Mon-Fri)</li> <li><input type="checkbox"/> Encourage advance care planning with prognostic information</li> <li><input type="checkbox"/> Access to all cardiac diagnostics (on site)</li> <li><input type="checkbox"/> Ability to up-titrate and make major changes to medications</li> <li><input type="checkbox"/> Access to all cardiac interventions (including ability to refer for transplant)</li> </ul>
Timely Access to Care	<ul style="list-style-type: none"> <li><input type="checkbox"/> Frequent telephone monitoring is required in both types of disease management programs</li> <li><input type="checkbox"/> Patients should receive timely access to care (i.e., care provider answering the phone, timely in-clinic visit if needed) in both types of disease management programs</li> </ul>

Type of Delivery Personnel	<p><b><u>Primary Care HF Disease Management Program</u></b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Registered nurse(s) with medical directives <b>AND/OR</b></li> <li><input type="checkbox"/> Advanced practice nurse(s) <b>AND/OR</b></li> <li><input type="checkbox"/> Family physician(s)</li> <li><input type="checkbox"/> Allied health professional(s) (on site or access to)</li> <li><input type="checkbox"/> Specialist support from a heart failure specialist (geriatrician(s) <b>AND/OR</b> internist(s) <b>AND/OR</b> cardiologist(s))</li> </ul> <p><b><u>Specialty Care HF Disease Management Program</u></b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Registered nurse(s) with medical directives</li> <li><input type="checkbox"/> Advanced practice nurse(s)</li> <li><input type="checkbox"/> Allied health professional(s) (on site or access to)</li> <li><input type="checkbox"/> Heart failure specialists (internist(s) <b>AND/OR</b> cardiologist(s))</li> <li><input type="checkbox"/> Additional specialist support (on site or access to) in: <ul style="list-style-type: none"> <li>○ Geriatrics</li> <li>○ Pulmonary diseases</li> <li>○ Renal diseases</li> <li>○ Palliative care</li> <li>○ Oncology</li> </ul> </li> </ul>
Environment	<p><b><u>Primary Care HF Disease Management Program</u></b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Heart Failure Clinic within a FHT</li> </ul> <p><b><u>Specialty Care HF Disease Management Program</u></b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Hospital-based Heart Failure Clinic</li> </ul>

While this is referred to as the finalized set of criteria, there are a number of barriers and facilitators to adopting the roles and responsibilities as outlined by it and therefore it may require future revisions. The barriers and facilitators to adopting the roles and responsibilities are described in the following sections.

### 8.2.3 Barriers to Adopting the Roles and Responsibilities

As previously mentioned, the purpose of this section was to use input from focus groups with physicians, clinical care coordinators, nurse practitioners, registered nurses and allied health professionals at four outpatient heart failure disease management programs to identify barriers to

adopting the finalized set of criteria. The focus group discussions identified nine barriers. A number of the barriers reflect issues with community care heart failure disease management programs. While those programs were not included in the finalized set of criteria, they are an integral part to the overall management of heart failure in Ontario. It was noted that all of the outpatient heart failure disease management programs were generally able to meet the roles and responsibilities described in the finalized set of criteria. It was suggested that this is a possible reason that the programs identified barriers with the community care heart failure disease management programs and had a general tendency to mention issues with the health care system as opposed to issues with role adoption. The nine barriers include: lack of education/knowledge/training in managing heart failure; provider comfort/ability in managing heart failure; difficulty discharging patients; poor communication across the continuum of care; nurse's scope of practice; nature of the disease; administrative barriers; resource availability; and rural issues with managing heart failure.

#### **8.2.3.1 Lack of Education/Knowledge/Training in Managing Heart Failure**

The lack of education/knowledge/training in managing heart failure was identified as a key barrier to the adoption of the roles and responsibilities of the finalized set of criteria. Clinic B identified this barrier as a key issue for community care heart failure disease management programs, as evidenced in the following quotation:

There are a lot of people that are managing heart failure and do not know the guidelines and are not educated. We will start medications here that are according to the guidelines and try to titrate them only to have them go wherever they are in the “spoke” and the patient comes back and the medications have stopped because they do not understand the rationale for them. (Clinic B)

This was echoed by Clinic A. Clinic A noted the development of community care heart failure disease management programs but identified a lack of interest by their care providers with participating in training opportunities, as evidenced in the following quotation:

We have had discussions with other family health teams and when we are talking to each other, everyone is enthusiastic. We offer for their nurses to come to the clinic and get to know what goes on here but nothing much has come of that. (Clinic A)

Allied health care professionals in the outpatient heart failure disease management programs suggested that there are a lack of training opportunities available for them to become well versed in the management of heart failure. If the allied health care professionals are not well-versed in the management of heart failure it interferes with the ability to properly adopt the roles and responsibilities that are required in their type of heart failure disease management program. This is evidenced in the following quotation:

You could not go and take the primary care heart failure course offered at wherever so that there is some formalized training that you could achieve and bring back to the clinic. Instead it is all on the job training based on the skillset you have in house and then kind of seeking out, you know, bits and pieces elsewhere to support your own skills. (Clinic A)

Clinic A also discussed how a lack of education in managing heart failure generally resulted in the breakdown in the management process, which subsequently caused an increase in emergency room visits. The purpose of the finalized set of criteria is to properly manage heart failure patients by defining the roles and responsibilities of each type of management program. This ensures that a heart failure patient is seen in the appropriate care setting and in a timely manner,

thereby avoiding hospitalizations. If the patient is not being properly managed due to a lack of education and is experiencing an increasing number of emergency room visits it is evident that the finalized set of criteria is not serving its intended purpose. In summary, it was noted that outpatient heart failure disease management programs experience a lack of education and training in order to properly adopting the roles and responsibilities of their type program. This may be due to a lack of interest or due to a lack of a formalized training programs. Without the interest and proper training or education, there is an inability to properly manage heart failure patients in different types of outpatient heart failure disease management programs since the roles and responsibilities cannot be adopted in any type of outpatient heart failure disease management program.

#### **8.2.3.2 Provider Comfort/Ability in Managing Heart Failure**

As mentioned in the previous section a lack of interest in managing heart failure interferes with the ability to adopt the roles and responsibilities required to properly manage the condition. This lack of interest, however, may be in part due to the care provider's comfort in managing heart failure. If the care provider is not comfortable with managing the condition, the outpatient heart failure disease management program cannot adopt the roles and responsibilities required of them, as evidenced in the following quotation:

There is a huge disparity with family care physicians in their comfort level and their willingness to manage things. We have criteria for discharge but often people get bounced back to us for really foolish reasons. (Clinic A)

This lack of comfort may be primarily due to the fact that community care heart failure disease management programs are generally not just focused on heart failure disease management. This

suggests that their knowledge or ability to manage the disease may be significantly lacking, as evidenced in the following quotation:

They have advanced practice nursing but they are doing 1000 different things and in their world heart failure is not even close to the top of the problems that they have to deal with in chronic disease. You know mental health, diabetes, arthritic conditions and lung disease. Those are far, far more numerous than heart disease. (Clinic A)

Finally, even if care providers are comfortable with managing heart failure, wait times in rural areas to see these providers are very lengthy and result in the inability of care providers to properly manage the condition. Thus, the specialty care heart failure disease management programs are sometimes the only option for heart failure patients, regardless if they are representative of the appropriate patient population. In summary, a care provider's comfort and/or ability to manage heart failure can interfere with the ability to adopt the roles and responsibilities of the different types of outpatient heart failure disease management programs. While, the quotations seemed to relate to issues with community care heart failure disease management programs, this will backlog the system and prevent primary care and specialty care heart failure disease management programs from adopting their appropriate roles and responsibilities.

### **8.2.3.3 Difficulty Discharging Patients**

Both Clinic A and Clinic B experienced an inability to discharge patients from their programs. This was often due to a lack of appropriate outpatient heart failure disease management programs to discharge to because of the aforementioned barriers. Specifically, care providers in Clinic B felt that even if heart patients were discharged from their programs, more

often than not these patients ended up back in Clinic B overtime, as evidenced in the following quotation:

There is a push on for us to discharge patients out of the program but we know that they are going to have an exacerbation so to us we leave them in the folds. We leave them at the 6month/1year and if they start having trouble we bring them back in. They are going to start running into problems again. There are lots of heart failure clinics that are saying in the literature that you should start transitioning your patients back to GPs but once they start getting sick and older they get into trouble and can not get into see their GPs and then they just end up in the hospital. (Clinic B)

Further, the care providers in Clinic B indicated a reluctance to discharge patients from their programs because of the amount of work required for this practice, especially if the patient was just going to end up back in their care. This was evidenced in the following quotation.

And the workload to discharge them out of our heart failure program and then if they call us in 6 months to start over is huge so we would rather just leave charts to collect dust then to start again when we need to. (Clinic B)

These sentiments were echoed by Clinic A, who suggested that the nature of the disease and the established comfort level between the heart failure patients and providers in the specialty care heart failure disease management programs, may be the key reasons why appropriate discharge practices are not happening. In terms of the relationship between providers and heart failure patients it was suggested that, “people tend to appreciate the fact that they can pick up the phone and call someone and they will listen and be able to do something” (Clinic A). Clinic B also mentioned that, “often times since the patient knows they have access to care here they will call

and say ‘I am in trouble’ and we will bring them in today, maybe tomorrow” (Clinic B). Another potential reason for the inability to discharge patients is that specialty care heart failure disease management programs often do not recognize the work of the primary care heart failure disease management programs, as evidenced in the following quotation:

We have ongoing challenges with communication especially with tertiary hospitals/providers and academic centres who do not recognize our role in management despite providing often the initial referral for complex patients. Most of these patients still require a local provider with direction from tertiary care. (Clinic D)

Thus, given the issues care providers experience with community care heart failure disease management programs and the lack of awareness of the existence of the primary care heart failure disease management programs, the specialty care heart failure disease management programs may be reluctant to discharge.

This failure to discharge heart failure patients from specialty care heart failure disease management programs, however, results in inability to adopt the appropriate roles and responsibilities of the different types of outpatient heart failure disease management programs. For example, an inability to discharge heart failure patients does not allow for a differentiation between patient populations across the different types of outpatient heart failure disease management programs. In summary, specialty care heart failure disease management programs cited a lack of available options for discharging heart failure patients. This inability to discharge patients was often due to the ineffective management in community care heart failure disease management programs and the patient’s willingness to call the specialty care heart failure disease

management program if they ran into trouble regardless of if they were enrolled in the program. This revolving door scenario and the amount of work to discharge patients saw specialty care heart failure disease management programs not completing the practice. It was noted by primary care heart failure disease management programs that specialty care heart failure disease management programs often do not recognize their role in managing the condition and therefore fail to discharge heart failure patients to them. However, if heart failure patients could not be discharged, the roles and responsibilities of the finalized set of criteria cannot be properly adopted.

#### **8.2.3.4 Poor Communication across the Continuum of Care**

All outpatient heart failure disease management programs cited an inability to communicate across the continuum of care, as a significant barrier to implementing the roles and responsibilities of a particular outpatient heart failure disease management program. Clinic D cited the use of a combination of paper based and electronic based referral and record systems as contributing to the problem. This variety of referral and record systems is a huge barrier to properly communicating across the continuum of care and more often than not care providers repeated assessments or did not send patient information during the referral process. The amount of work required to track down patient information, as well as the amount of work required to dictate notes saw all types of outpatient heart failure disease management programs levels not completing this practice and therefore duplicating assessments. The duplication of assessments creates an inability to properly define and implement the roles and responsibilities of the outpatient heart failure disease management programs, specifically with respect to defining the care provisions of the program. In summary, the lack of communication between different types of outpatient heart failure disease management programs is a significant barrier to properly

defining and implementing the roles and responsibilities of the finalized set of criteria. This lack of communication was cited to be due to the absence of a common platform for sharing heart failure patient information. This led to information not being sent with heart failure patients as they transitioned between outpatient heart failure disease management programs and therefore there was inappropriate duplication of tests and procedures.

#### **8.2.3.5 Nurse's Scope of Practice**

An integral part of all of the outpatient heart failure disease management programs was the presence of an advanced practice nurse or a registered nurse with medical directives in managing heart failure. Clinic A described an outpatient heart failure disease management program that did not have advanced practice nurses or registered nurses with medical directives as ineffective. These programs often saw registered nurses being unable to directly intervene when a patient called and had to wait on physician guidance and therefore the program could not properly adopt the roles and responsibilities as outlined by the finalized set of criteria. As mentioned, if a patient does not receive care in a timely manner, the patient is more likely to go to emergency, thereby defeating the purpose of outpatient heart failure disease management programs. This sentiment was echoed by Clinic D but in concern with the lack of medical directives present in the community care heart failure disease management programs, as evidenced in the following quotation

Yeah so limited. So very limited. There is the whole issue with do they have med directives in place that would allow them to actually be of an asset when they go to visit the home or is it just 'yeah I saw that they have puffy legs' and that is it. (Clinic D)

Clinic D described the lack of medical directives to be a strong factor to limiting the effectiveness of the disease management programs. In summary, the ability of advanced practice nurses or registered nurses to function in outpatient heart failure disease management programs without medical directives is significantly curtailed.

#### **8.2.3.6 Nature of the Disease**

Heart failure patients are complex and often require extensive management. Clinic A indicated that the telephone monitoring associated with heart failure patients was a lengthy process that often resulted in numerous parties being contacted in order to solve the problem. It was suggested that this was a primary reason for why community care heart failure disease management programs could not properly manage the condition, as evidenced in the following quotation:

They are high maintenance and time consuming. I mean those telephone calls, they are not just quick little phone calls and often you are not just talking to the patient. You are also calling the son or daughter to confirm what the patient told you because it is not always clear cut and then you are phoning the pharmacist to figure out the pills. So a lot of these things are very time consuming and that is why doctors cannot do it, doctors will not do it. (Clinic A)

Clinic C also echoed these findings and suggested that the complexity of the condition requires establishing a strong knowledge base concerning the management of the condition. Thus, the complexity heart failure provides further evidence of physician discomfort with managing heart failure in primary care heart failure disease management programs, as evidenced in the following quotation:

Heart failure is a highly complex and challenging chronic disease, both from the physical assessment perspective as well as the complex medication regimens/strategies/titrations. Even though I had good experience in critical care and acute management of heart failure, I had a lot to learn about the medication titration and issues surrounding pharmacotherapy in chronic heart failure management. It certainly took some time for all of us to be more comfortable with managing this patient population. (Clinic C)

If the nature of the disease is associated with discomfort and unwillingness to managing the condition in less complex outpatient heart failure disease management programs then defining the roles and responsibilities of the different types of heart failure disease management programs proves ineffective. In summary, due to the complex nature of the condition, care providers in the primary care heart failure disease management programs or community care heart failure disease management programs may be unwilling to manage the condition. This creates a backlog of heart failure patients in the specialty care heart failure disease management programs and does not allow for the roles and responsibilities of the different types of outpatient heart failure disease management programs to be properly adopted.

#### **8.2.3.7 Administrative Barriers**

The primary administrative barrier, which was identified by both Clinic A and Clinic B was the refusal by a third-party care provider to have a heart failure patient followed by their outpatient heart failure disease management program. The two main care providers who were likely to refuse to have their patients followed by the specialty care heart failure disease management programs were cardiologists and family physicians. Primary care outpatient heart failure disease management programs were less likely to see this because they were located

within a family health team and were likely to receive patient referrals from care providers with whom they had a good working relationship with (i.e., family physicians). Clinic B described this phenomenon in the following quotation:

We often have patients stuck in the middle saying “I really like my cardiologist but he told me that if I continue to come here that I cannot...I have to choose one” but they like being able to pick up the phone and call us because they are getting into trouble. (Clinic B)

If a heart failure patient cannot be seen in the specialty care heart failure disease management program, then that program is unable to properly adopt the roles and responsibilities required of their type of outpatient heart failure disease management program because they are not seeing the appropriate quota in the patient population domain. This was echoed by Clinic A, who noted that the patients who were unable to be seen in their program due to physician refusal tended to have worse health outcomes than those who were able to come to their program as evidenced in the following quotation:

Why do we need a heart failure clinic? I know how to treat heart failure, I’m a cardiologist. I know how to treat heart failure just as well as he/she does, which was true (referring to the cardiologist’s ability to manage heart failure) but because they (the cardiologist) had never worked in partnership with advanced practice nurses and registered nurses with medical directives, they did not realize the benefit to the patients and held onto their patients. And those patients (not managed in the outpatient heart failure disease management program) tend not to do as well (Clinic A)

The ability to define the roles and responsibilities of the specialty care heart failure disease management programs is essential to properly managing the condition. However, if heart failure patients are not being referred to these types of outpatient heart failure disease management programs, the program cannot properly adopt their roles and responsibilities. The other administrative barriers that were identified were most prominent when the outpatient heart failure disease management programs were first being established. Clinic C identified the coordination required and a lack of understanding of how to operate an outpatient heart failure disease management program to be barriers from an administrative perspective. The program requires “buy in” from the human resource department, as well as an understanding of the length and frequency of patient follow-up appointments prior to adopting the roles and responsibilities of the outpatient heart failure disease management program. In summary, in order to properly adopt the roles and responsibilities of specialty care heart failure disease management programs, third-party cardiologist and family physicians must be willing to allow their patients to receive care in the specialty care heart failure disease management programs. Further, proper coordination and an understanding of how the outpatient heart failure disease management programs are intended to be operated is required prior to adopting the roles and responsibilities of that program.

#### **8.2.3.8 Resource Availability**

In addition to overcoming administrative barriers, outpatient heart failure disease management programs also have to overcome resource availability barriers. Clinics A, B, C and D all identified resource barriers that were present in their outpatient heart failure disease management program or in another type of outpatient heart failure disease management program. The general types of resource constraints included funding, staffing and space, which were

identified in previous chapters to be associated with differences in outpatient heart failure disease management programs. Clinic A indicated that their outpatient heart failure disease management program is not provided with any funding in order to operate. Additionally, they identified that staffing was the biggest resource constraint in less intense outpatient heart failure disease management programs, as evidenced by the following quotation:

A physician has to have the interest and extra training that allows them to function adequately but more importantly it is the non-physician nursing type support and the skills that need to be there in that area. (Clinic A)

Clinic B and C also discussed issues with staffing, particularly with the lack of cardiologists in their regions. These staffing concerns inhibit outpatient heart failure disease management programs from adopting the roles and responsibilities of the finalized set of criteria, particularly in the delivery personnel domain. In addition, Clinic B also indicated that there were no primary care heart failure disease management programs within their vicinity, which makes defining the roles and responsibilities of their type of heart failure disease management programs more difficult. Finally, Clinic C also identified an issue with space availability. Clinic C indicated that if their outpatient heart failure disease management program were to expand to offer their program to patients who were not members of the family health team care, the size of the building may not accommodate this change. This significantly limits the quota of patients the outpatient heart failure disease management program can manage. In summary, resource barriers identified in the focus groups did not differ from the resource barriers identified in the literature and generally included barriers to funding, staffing and space. Further, these resource constraints inhibit outpatient heart failure disease management programs from properly adopting the roles and responsibilities of the finalized set of criteria.

### **8.2.3.9 Rural Issues with Managing Heart Failure**

Clinic B identified the vast geographical location from which their program draws its patients from to be an issue specific to rural outpatient heart failure disease management programs. The vast geographical location presents transportation issues as a barrier for heart failure patients, specifically if they have to travel long distances or have no family support system. Further, the transportation services offered to elderly persons requires advanced bookings and therefore would not be useful in an emergency situation. These transportation barriers create issues in adopting the patient population, frequency of visits and timely access to care domains outlined in the finalized set of criteria. Further, it was mentioned by both Clinic B and Clinic D that rural areas do not have access to specialists in their regions. This will present difficulties when adopting the roles and responsibilities associated with the delivery personnel domain. In summary, the rural issues associated with managing heart failure, specifically the transportation barriers and the lack of access to specialists, are important considerations concerning when determining whether the rural outpatient heart failure disease management programs are able to adopt the roles and responsibilities of their type of program.

### **8.2.4 Facilitators to Adopting the Roles and Responsibilities**

While there are a significant number of barriers to adopting the roles and responsibilities of the different types of outpatient heart failure disease management programs, there are also a number of facilitators to assist with this process. As previously mentioned, the purpose of this section was to use input from focus groups with physicians, clinical care coordinators, nurse practitioners, registered nurses and allied health professionals at four outpatient heart failure disease management programs to identify facilitators to adopting the finalized set of criteria. The focus group discussions identified four facilitators, which include: positive patient

outcomes; mentorship from established programs; previous success in managing other chronic diseases; and support and relationships with other care settings. All of the outpatient heart failure disease management programs felt as though they represented the appropriate type of outpatient heart failure disease management program and were able to provide examples for how this was accomplished through these facilitators.

#### **8.2.4.1 Positive Patient Outcomes**

Positive patient outcomes were identified as a facilitator in adopting the roles and responsibilities of the outpatient heart failure disease management programs. Clinic A was able to overcome the administrative barriers, particularly the physician refusal, presented in the previous section by showing positive patient outcomes associated with their outpatient heart failure disease management program, as evidenced in the following quotation:

Many if not most of the cardiologists thought “oh that is a good idea, I’m going to start sending you people that I have although that tended to happen later...and there were a few cardiologists who stuck with the “well I know how to look after heart failure” but they did not realize the benefit to the patients so that took a while. (Clinic A)

This was echoed by Clinic B, as evidenced by the following quotation:

So initially we were patting around the hospital very quietly and we would get requests just to go educate patients but not to bring them into our clinic but because we then started to gather the data for our heart failure readmission rate or our readmission rate for our patients versus the hospitals, they were able to bring that back to MAC three things and get the physicians to understand that it is to benefit the patients so that became a huge facilitator. (Clinic B)

These positive patient outcomes were associated with establishing the appropriate type of outpatient heart failure disease management program and resulted in the ability for that program to adopt the appropriate roles and responsibilities. In summary, the production of positive patient outcomes will encourage the acceptance of an outpatient heart failure disease management program, which in turn increases the ability to adopt the roles and responsibilities of the finalized set of criteria.

#### **8.2.4.2 Mentorship from Established Programs**

Clinic D identified mentorship from established outpatient heart failure disease management programs as a key factor to the success of adopting the roles and responsibilities of their outpatient heart failure disease management program, as evidenced by the following quotation:

Well on my own part I really needed some help to know my role in the clinic here where there are four doctors and just one nurse. So for me it was seeking out other nurses in established heart function programs. So I went to the larger hospital and I went to other areas and then introduced some things back. So for example, patient education. We expanded on how much we do. But certainly we learned a lot from other programs. (Clinic D)

The well-established outpatient heart failure disease management programs were able to provide Clinic D with examples and encouragement for adopting the appropriate roles and responsibilities required to function as a primary care heart failure disease management program. In summary, the mentorship from well-established outpatient heart failure disease management programs was a key facilitator, which allowed new outpatient heart failure disease management

programs to realize and adopt the appropriate roles and responsibilities of the finalized set of criteria.

#### **8.2.4.3 Previous Success in Managing Other Chronic Diseases**

Previous success in managing other chronic diseases was identified as key facilitator to assisting outpatient heart failure disease management programs with adopting the roles and responsibilities of the finalized set of criteria. Clinic C described how this facilitated the adoption of their roles and responsibilities in the following quotation:

Fortunately, we had already been managing other chronic diseases very effectively in the primary care setting (memory clinic, pharmacist-led anticoagulation program, diabetes management, Heart and Stroke Foundation of Ontario hypertension management initiative, asthma/chronic obstructive pulmonary disorder etc.). If we had not been successfully running those programs, it likely would have been impossible to manage a heart failure program, as these are very complex patients that require a strong team base.

(Clinic C)

As evidenced by the quotation, had the program not been comfortable with the previous management of complex chronic diseases, the adoption of their roles and responsibilities in the outpatient management of heart failure would have proven difficult. In summary, previous success with managing complex, chronic diseases is a key facilitator to adopting the roles and responsibilities associated with an outpatient heart failure disease management program.

#### **8.2.4.4 Support and Relationships with Other Care Settings**

Both Clinic C and Clinic D identified an established relationship with a specialty care heart failure disease management program. This relationship provided them with support and

mentorship, as well as the ability to refer patients and streamline care between programs. This provides an excellent illustration to how the roles and responsibilities as outlined by the finalized set of criteria would be eventually applied in the clinical setting. Since communication of care across the continuum was identified as a significant barrier to adopting the roles and responsibilities of the different types of outpatient heart failure disease management programs, it is important to keep this facilitator in mind going forward. A list of the recommendations for optimizing of the quality and role of the different types of outpatient heart failure disease management programs in Ontario is discussed in the subsequent chapter.

## **CHAPTER 9: DISCUSSION AND CONCLUSIONS**

The purpose of this research study was to develop a set of criteria for defining the roles and responsibilities of the different types of outpatient heart failure disease management programs and to create a list of recommendations to assist with the optimization of the quality and role of the different types of outpatient heart failure disease management programs in Ontario. This study was completed in two phases. The first phase sought to use the findings from a clinical observation to restructure a heart failure disease management scoring system developed by Reigel et al (2010) in order to develop a preliminary set of criteria. This preliminary set of criteria for defining the roles and responsibilities of the different types of outpatient heart failure disease management programs was used for the second phase of the study. The second phase of the study used a mixed methods design, which combined quantitative and qualitative research methods, to answer two research objectives. The first research objective was to use responses from an environmental scan survey to classify four outpatient heart failure disease management programs according to the preliminary set of criteria established during the first phase of this study. This was accomplished using secondary data analysis. The second research objective was to use input from focus groups with physicians, clinical care coordinators, nurse practitioners, registered nurses and allied health professionals at the four outpatient heart failure disease management programs to: (a) build upon and finalize the set of criteria for defining the roles and responsibilities of different types of outpatient heart failure disease management programs; and (b) determine factors that facilitated or hindered outpatient heart failure disease management programs from adopting the finalized set of criteria. The final research objective was to triangulate the data from the second and third research objectives in order to construct a list of recommendations to assist the Cardiac Care Network

with the optimization of the quality and role of the different types of outpatient heart failure disease management programs in Ontario according to the “hub and spoke” organization of care. This fourth and final research objective is discussed in this chapter. Prior to presenting these recommendations, it is important to summarize the findings thus far.

## **9.1 Summary of Research Findings**

The complete results of the quantitative and qualitative components of the study are presented in the previous chapter. The quantitative and qualitative components were completed with four outpatient heart failure disease management programs in Ontario. The environmental scan survey classified these programs as either primary care heart failure disease management programs or specialty care heart failure disease management programs. The quantitative component found that there was agreement between the preliminary set of criteria and the environmental scan survey regarding the classification of all four outpatient heart failure disease management programs. The preliminary set of criteria indicated that a primary care heart failure disease management program should receive a score of 12 points +/- 2 points and an average score of 2 points +/- 0.4 points. Likewise, a specialty care heart failure disease management program should receive a score of 18 points +/- 2 points and an average score of 3 points +/- 0.4 points. The total and average scores based on scoring each of the outpatient heart failure disease management programs according to the preliminary set of criteria is included in Table 16.

Table 16. Summary of our Scores for the Heart Failure Disease Management using the Preliminary Criteria

Heart Failure Disease Management Program	Total Score	Average Score
Clinic A <ul style="list-style-type: none"> <li>urban specialty care heart failure disease management program</li> </ul>	17 points	2.83 points
Clinic B <ul style="list-style-type: none"> <li>rural specialty care heart failure disease management program</li> </ul>	17 points	2.83 points
Clinic C <ul style="list-style-type: none"> <li>urban primary care heart failure disease management program</li> </ul>	11 points	2.20 points
Clinic D <ul style="list-style-type: none"> <li>rural primary care heart failure disease management program</li> </ul>	12 points	2.00 points

The main issue with using the preliminary set of criteria to score each of the disease management programs was the difficulty in obtaining complete and accurate information from the environmental scan survey. More often than not, a domain on the preliminary set of criteria could not be properly scored due to a lack of information from the environmental scan survey responses. In order to overcome this issue, we asked the care providers at the outpatient heart failure disease management programs to use the preliminary set of criteria during the focus group to score their outpatient heart failure disease management program.

The care providers were able to clear up the issues with obtaining complete and adequate information required to score the outpatient heart failure disease management programs but did not always score a domain similar to our scoring. This was attributed to a general confusion about the description of domains, which was discussed in the results of the qualitative component. Nonetheless, the care providers all scored their outpatient heart failure disease management programs within the acceptable standard deviation and thus, provided additional confirmation that the outpatient heart failure disease management programs were classified

correctly. The total and average scores based on the care providers' scoring of each of the outpatient heart failure disease management programs is included in Table 17.

Table 17. Summary of the Care Providers' Scores for the Heart Failure Disease Management using the Preliminary Criteria

Heart Failure Disease Management Program	Total Score	Average Score
Clinic A <ul style="list-style-type: none"> <li>urban specialty care heart failure disease management program</li> </ul>	17 points	2.83 points
Clinic B <ul style="list-style-type: none"> <li>rural specialty care heart failure disease management program</li> </ul>	18 points	3.00 points
Clinic C <ul style="list-style-type: none"> <li>urban primary care heart failure disease management program</li> </ul>	12 points	2.00 points
Clinic D <ul style="list-style-type: none"> <li>rural primary care heart failure disease management program</li> </ul>	12 points	2.00 points

As mentioned, the qualitative component of the study identified confusion with using the preliminary set of criteria to score outpatient heart failure disease management programs. The wording of the domains, particularly the complexity, method of communication and environment domains; was identified as the main source of confusion. Further, other domains, including the patient risk status, delivery personnel and intensity domains required additional information in order to provide a complete picture of the roles and responsibilities of the different types of outpatient heart failure disease management programs in Ontario.

The preliminary set of criteria were modified and finalized based on the feedback from focus group participants. The preliminary set of criteria was modified to include only two types of outpatient heart failure disease management programs, since focus groups with community care heart failure disease management programs did not take place. As mentioned in the Phase I methods and findings, the preliminary set of criteria was developed by restructuring Reigel's scoring instrument and thus, the finalized set of criteria is a reflection of Reigel's work using

observations and input from outpatient heart failure disease management teams within a Canadian context. Our work complements the theory derived from Reigel's scoring instrument but provides additional work that serves to encourage the adoption of a restructured version of this scoring instrument in practice. Further, the quantitative results demonstrated the use of the scoring instrument for outpatient heart failure disease management programs in Ontario. The domains reflected from Reigel's work were determined to be applicable within a Canadian context; however, some of the domains were renamed and additional information was added to either avoid future confusion or assist care providers with identifying the roles and responsibilities that need to be adopted in their type of disease management program. The scoring , which was originally developed by Reigel and incorporated into the preliminary set of criteria was removed and replaced with a checklist of characteristics under each domain to improve ease of use in the finalized set of criteria. The finalized set of criteria is included in the previous chapter.

The qualitative component also addressed barriers and facilitators to adopting the finalized set of criteria. There were significantly more barriers identified than facilitators but since all four of the outpatient heart failure disease management programs considered that they had adopted the roles and responsibilities of their type of program, the facilitators are of key importance to future use of the finalized set of criteria for adopting the roles and responsibilities of outpatient heart failure disease management programs. In total nine barriers and four facilitators were identified. The nine barriers included: lack of education/knowledge/training in managing heart failure; provider comfort/ability in managing heart failure; difficulty discharging patients; poor communication across the continuum of care; nurse's scope of practice; nature of the disease; administrative barriers; resource availability; and rural issues with managing heart

failure. Additionally, the four facilitators included: positive patient outcomes; mentorship from established programs; previous success in managing other chronic diseases; and support and relationships with other care settings. The third research objective methodically triangulated the data from the quantitative and qualitative components to construct a list of recommendations, as previously mentioned.

## **9.2 List of Recommendations**

There were four recommendations identified that will assist the Cardiac Care Network with optimizing the role and quality of the different types of outpatient heart failure disease management programs in Ontario. The recommendations were developed using a methodological data triangulation process. While, the data triangulation process required data from both of the quantitative and qualitative components to inform the recommendations, it was noted that the quantitative data component was significantly lacking. This was due to the inability to infer data from the environmental scan survey because it was vague or incomplete. Further, the focus group responses found that the finalized set of criteria was sufficient for defining the roles and responsibilities of outpatient heart failure disease management programs and instead had a tendency to recommend changes to the system that needed to take place in order to optimize the quality and role of the different types of outpatient heart failure disease management programs. Thus, the recommendations are based on the triangulation process, with significant emphasis on the data from the qualitative component. The recommendations are displayed in Figure 5.

### **LIST OF RECOMMENDATIONS**

1. Develop a guideline and/or education program on how to use the finalized set of criteria for defining the roles and responsibilities of the different types of outpatient heart failure disease management programs
2. Encourage the practice of having registered nurses with medical directives in outpatient heart failure disease management programs
3. Increase access to care in primary care heart failure disease management programs
4. Establish and encourage mandates for building relationships across the continuum of care

Figure 5. List of Recommendation for the Cardiac Care Network.

The rationale for each of the recommendations is included in the following section.

#### **9.2.1 Rationale for Recommendations**

The first recommendation is to develop a guideline and/or education program to teach outpatient heart failure disease management programs how to properly use the finalized set of criteria for defining the roles and responsibilities of the different types of outpatient heart failure disease management programs. The quantitative component identified issues with using the preliminary set of criteria to score outpatient heart failure disease management programs based on the vague environmental scan survey responses. It was recognized that further information was required in order to properly use the preliminary set of criteria for scoring purposes.

Further, when the outpatient heart failure disease management programs used the preliminary set of criteria, there was general confusion among care providers and an inability to properly score their program based on the wording and way the domains of the preliminary set of criteria were defined. Efforts have been made to clear up wording difficulties and to develop a comprehensive checklist, as opposed to a scoring system, which should alleviate the confusion and difficulties with using the preliminary set of criteria. However, it is suggested that a guideline and an education program, such as a group tutorial session, is developed to teach care providers how to

properly use the finalized set of criteria. This should avoid future instances of confusion surrounding the use of the finalized set of criteria, thereby allowing the roles and responsibilities of the outpatient heart failure disease management programs to be adopted and quality of outpatient heart failure management to be optimized. An example of a tutorial program may be one that assists care providers with determining which disease management components should be implemented and how they should be implemented in different types of outpatient heart failure disease management programs. Further, an example of a guideline may be teaching outpatient heart failure disease management programs how and when to appropriately refer heart failure patients, according to the finalized set of criteria.

As suggested by the finalized set of criteria one of the key elements to determining how and when to appropriately refer heart failure patients was based on the complexity of these patients. The complexity of heart failure patients was defined as a heart failure patient's geriatric or frailty status; a heart failure patient's instability, as classified as number of emergency room visits or number of medication changes; a heart failure patient's support system; and a heart failure patient's mental status. This complexity generally dictated the frequency of follow-up appointments, the type of delivery personnel present in the program, the care provisions required by the program and the environment in which the program took place. Specifically, if a heart failure patient was geriatric and frail, it would be important for a geriatrician or a care provider knowledgeable in managing geriatric patients, to be present in the outpatient heart failure disease management program in order to effectively manage the condition. If this could not be offered in a primary care heart failure disease management program then it was appropriate to refer the patient to a specialty care heart failure disease management program or to co-manage the patient with a geriatrician associated with a community care heart failure disease management program

(i.e., a geriatric clinic). Using the patient's complexity to inform the use of the finalized set of criteria strengthens the role adoption and therefore, the quality of outpatient heart failure disease management programs. Thus, the complexity of heart failure patients is integral to optimizing the role and quality of outpatient heart failure disease management programs in Ontario.

The second recommendation is to encourage the practice of having registered nurses with medical directives in outpatient heart failure disease management programs. It was evident from both the quantitative component and qualitative component that registered nurses are key members of outpatient heart failure disease management programs. Further, the focus groups participants were adamant that the nursing support, which also includes advanced practice nurses, was integral to the outpatient heart failure disease management programs and this was further enhanced if the registered nurses had medical directives. As described in the focus groups, this allows the registered nurses to implement changes without having to first seek physician approval. These medical directives are integral to providing high quality care and avoiding hospitalizations. It is suggested that all registered nurses in heart failure disease management programs are provided with medical directives in order to optimize the quality and role of the different types of outpatient heart failure disease management program.

The third recommendation is to increase access to care in primary care heart failure disease management programs. The environmental scan survey responses from primary care heart failure disease management programs provided information on the referral sources for these programs. The information regarding referral sources were also mentioned during the focus groups. More often than not, primary care heart failure disease management programs could only accept referrals if a heart failure patient was a member of the family health team that the program was associated with. This restricts access to care for the remaining heart failure

patients who are not part of family health teams with primary care heart failure disease management programs. Since community care heart failure disease management programs have not been well described, a heart failure patient who is not a member of a family health team with a primary care heart failure disease management program is stuck in limbo if they are not an appropriate patient for a specialty care heart failure disease management program. If the heart failure patient is able to enter a specialty care heart failure disease management program but cannot be discharged from it, it may cause a backlog in the system that prevents other heart failure patients from entering the specialty care heart failure disease management program, which prevents role adoption and decreases the quality of heart failure care in Ontario. One of the primary care heart failure disease management programs that participated in the focus groups was an internist-run primary care heart failure disease management program. The internist-run primary care heart failure disease management program allowed for heart patients, who were not members of a specific family health team, to be seen in the primary care heart failure disease management within that family health team. While encouraging internist-run primary care heart failure disease management programs may be suitable for increasing the access to care for heart failure patients, internists are in short supply in Ontario. Therefore, a more appropriate solution may be to develop methods that reimburse primary care heart failure disease management programs for seeing patients who are not members of the family health team with whom they are associated with. The reimbursements may be offered in terms of additional funding, additional staffing or additional space in which to accommodate the increased number of heart failure patients. Increasing the access to care in primary care heart failure disease management programs will optimize the quality and role of the different types of outpatient heart failure disease management programs.

The fourth and final recommendation is to establish and encourage mandates for building relationships across the continuum of care. It is suggested that this is the most important recommendation for optimizing the role and quality of heart failure disease management programs in Ontario. All four outpatient heart failure disease management programs identified that building relationships across the continuum of care facilitated the adoption of the roles and responsibilities required of their program and thereby increased the quality of care that their program was able to offer. This was evidenced by the positive patient outcomes associated with their program. Further, a lack of relationship building across the continuum of care led to significant barriers including: communication challenges; a lack of discharge options; and poorly managed heart failure in lower complexity heart failure disease management programs. These barriers resulted in fragmented and duplicated care processes that decreased the quality of care for heart failure patients and did not allow for outpatient heart failure disease management programs to adopt the appropriate roles and responsibilities of their program. Thus, establishing and encouraging a mandate for relationship building across the continuum of care will optimize the quality and role of the different types of outpatient heart failure disease management programs.

The concepts of encouraging the implementation of medical directives with registered nurses, increasing access to primary care heart failure disease management programs, and building relationships across the continuum of care were foundational pieces behind the development of the “hub and spoke” organization of care. These initiatives require the adoption of shared care practices and emphasize the importance of support through a multi-disciplinary care team, which are the cornerstones of the Chronic Disease Management Model (Brand et al., 2007; Scott, 2008). This model supports the development of the recommendations outlined

above for optimizing the role and quality of the different types of outpatient heart failure disease management programs in Ontario. Specifically, the Chronic Disease Management Model suggests that multi-disciplinary care is shown to reduce heart failure related hospital admissions (Scott, 2008). Further, the largest effect sizes for positive clinical outcomes are observed when registered nurses have the ability to make care decisions with the use of medical directives (Scott, 2008). The Chronic Disease Management Model also suggests that patient consultations should be provided to all heart failure patients regardless of whether or not the patient has been referred to the heart failure disease management program (Brand et al., 2007). Thus, this supports the notion of increasing the access to care for heart failure patients in primary care heart failure disease management programs. Finally, the Chronic Disease Management Model, suggests that heart failure care providers operate using a stepped care framework, which is similar to the “hub and spoke” organization of care (Brand et al., 2007). The stepped care framework provides support for building relationships across the continuum of care by suggesting that care providers operate within a collaborative framework (Brand et al., 2007). Operating within a collaborative framework builds relationships across the continuum of care and ensures the optimal efficiency of outpatient heart failure disease management programs (Brand et al., 2007). In summary, the Chronic Disease Management Model provides support for the recommendations identified in this study. It is extremely important, as identified in both the Chronic Disease Management Model and this current study, that relationships between different types of outpatient heart failure disease management programs are emphasized and encouraged. These relationships will eliminate most of the barriers identified in the qualitative component of this study, as outpatient disease management programs are able to effectively communicate with

each other and provide support for capacity building and managing heart failure in primary care and community care heart failure disease management programs.

### **9.3 Strengths and Limitations**

There are a number of strengths associated with this study. First, the finalized set of criteria for defining these roles and responsibilities, as well as the recommendations for optimizing the quality and role of outpatient heart failure disease management programs were developed using the perspectives of all types of care providers across different geographical locations that are managing heart failure. Recognizing the different care providers' perspectives and accounting for geographical differences increases the likelihood that the finalized set of criteria and recommendations will be adopted in practice. Second, in addition to developing the finalized set of criteria, the study also identified barriers and facilitators to adopting the finalized set of criteria. This will allow future researchers to be aware of the barriers and facilitators when attempting to implement the finalized set of criteria in practice. It also offers the opportunity for additional research to be conducted to address these barriers and/or facilitators. Finally, the study offered the first Canadian perspective on the use of the popular disease management framework and instrument in works by Krumholz et al., (2006) and Reigel et al., (2010), respectfully. Using the perspective of care providers in outpatient heart failure disease management programs in Ontario expanded on the definitions of the domains included in Krumholz et al's (2006) framework and Reigel et al's (2010) scoring instrument. Specifically, the patient population domain (or complexity of the patient) was expanded to include the mental health status of heart failure patients and the support system of heart failure patients. It was also suggested that patient co-morbidities do not differ among the different types of outpatient heart

failure disease management programs. However, if the finalized set of criteria is properly implemented this difference may present itself, specifically if the co-morbidities account for destabilizing heart failure patients.

There were also a few limitations to the study. First, the quantitative component was relatively weak due to the limitations in the environmental scan survey responses, which resulted in a weaker data triangulation process than was described in the methods. Second, only four of a possible 40 outpatient heart failure disease management programs were involved in the study. The four programs that participated were also more established outpatient heart failure disease management programs and as such the full scope of the possible barriers and facilitators to adopting the finalized set of criteria may not be represented by this sample. Further, community care heart failure disease management programs did not participate in the study. This also limits the full scope of the barriers and facilitators, as well as the possible domains of the finalized set of criteria. As such, the finalized set of criteria and recommendations are representative of only two of the three types of outpatient heart failure disease management programs in Ontario, which warrants future research prior to implementing either of these in practice. Finally, as mentioned in the qualitative section, we were unable to calculate a Kappa Statistic due to incomplete coding information provided by the second reviewer. While, an informal process for determining the agreement between the two coders was completed, the Kappa Statistic is a much better determination of reliability. Future work should use the recommended methodology for coding transcripts with two coders in order to calculate a Kappa Statistic and increase the reliability of the findings.

## **9.4 Conclusions**

The development of a set of criteria for defining the roles and responsibilities of the different types of outpatient heart failure disease management programs, as well as establishing a list of recommendations for optimizing the quality and role of outpatient heart failure disease management programs were important steps towards establishing a heart failure disease management strategy in Ontario. Further research is required in order to represent and reflect the full scope of heart failure disease management in the finalized set of criteria and recommendations prior to implementing them in practice. However, acknowledgment of the findings on a small scale should show that the adoption of the finalized set of criteria and implementation of the recommendations will improve the quality of heart failure disease management, thereby improving the health outcomes for heart failure patients in Ontario.

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## APPENDICES

### Appendix 1: Reigel's Heart Failure Disease Management Scoring Instrument

Intervention Category	Points to be Assigned
Recipient	1 = Provider alone 2 = Patient alone 3 = Patient with some inclusion of the caregiver 4 = Patient with a caregiver who is central to the intervention
Intervention Content	
<ul style="list-style-type: none"> <li>• Education and counselling aimed at supporting self-care</li> </ul>	0 = No mention of education 1 = Focus solely on importance of treatment adherence 2 = Focus on treatment adherence including some creative methods of improving adherence 3 = Focus on surveillance but no mention of actions to be taken in response to symptoms (e.g., no flexible diuretic management) 4 = Emphasis on surveillance, management, and evaluation of symptoms in addition to treatment adherence
<ul style="list-style-type: none"> <li>• Medication management</li> </ul>	0 = No mention of medication regimen 1 = Some mention of medications (e.g., importance of medication compliance) but not an active part of the intervention. No attempt to intervene with provider to get patients on an evidence-based medication regimen 2 = Evidence-based medication regimen advocated but no follow-up with patient or provider to monitor the suggestion 3 = Medication regimen monitored, attempt made to get patient on evidence-based medications, with follow-up monitoring done with patient or provider
<ul style="list-style-type: none"> <li>• Social support</li> <li>• Peer support</li> </ul>	0 = No mention of a peer support intervention 1 = Peer support mentioned but not integral to intervention 2 = Peer support integral component of intervention
<ul style="list-style-type: none"> <li>• Surveillance by provider: Remote monitoring</li> </ul>	0 = No remote monitoring or telehealth 1 = Remote monitoring is used in conjunction with other interventions that form the main intervention used 2 = Telehealth is essential component of intervention
<ul style="list-style-type: none"> <li>• Delivery personnel</li> </ul>	1 = Single generalist provider (e.g., physician, nurse, pharmacist)

	2 = Single HF expert provider (e.g., physician, nurse, pharmacist) 3 = Multidisciplinary intervention 4 = Multidisciplinary intervention provided in an integrated, choreographed manner
• Method of communication	1 = Mechanized via internet or telephone 2 = Person-to-person by telephone 3 = Face-to-face, individual, or in a group 4 = Combined face-to-face at least once alone or in a group with individual telephone calls in between meetings
Intensity and Complexity	
• Duration	1 = $\leq 1$ mo. 2 = $\leq 2$ mo. 3 = $\leq 6$ mo. 4 = $> 6$ mo.
• Complexity	1 = Low: single contact with little or no follow-up 2 = Moderate: $> 1$ but $< 4$ and/or infrequent contact or contacts of short duration 3 = High: multiple contacts of significant duration
• Environment	1 = Hospital: inpatient only 2 = Clinic/outpatient setting 3 = Home-based 4 = Combination of settings

Adapted from Reigel et al., 2006

## Appendix 2: Cardiac Care Network Environmental Scan Survey

### Heart Failure Management in Ontario

#### Background Information

CCN: Who are we?

The Cardiac Care Network of Ontario (CCN) serves as a system support to the Ministry of Health and Long-Term Care (MOHLTC), Local Health Integration Networks (LHINs), hospitals, and care providers dedicated to improving quality, efficiency, access and equity in the delivery of the continuum of cardiac services in Ontario. CCN's priority is to ensure the highest quality of cardiovascular care, based on evidence, standards and guidelines, and actively monitors access, volumes and outcomes of advanced cardiac procedures in Ontario. In addition, CCN works collaboratively with provincial and national organizations to share ideas and resources and co-develop strategies that enhance and support the continuum of cardiovascular care, including prevention, rehabilitation and end-of-life care.

Working with key stakeholders, CCN helps to plan, coordinate, implement and evaluate cardiovascular care and is responsible for the Ontario Cardiac Registry. The information collected in the Cardiac Registry includes wait time information as well as specific clinical parameters required to evaluate key components of care and determine risk-adjusted outcomes. Through scientific evidence, expert panels, and clinical working groups, CCN uses evidence and consensus driven methods to identify best practice and strategies to effectively deliver cardiovascular services, across the continuum of care.

The Purpose of this Survey

As heart failure patients are a dynamic and heterogeneous group, the CCN Heart Failure Working Group identified the need for a current state assessment of heart failure management in the province of Ontario.

We appreciate your participation in this survey.

If you have any questions, please contact me by phone at 1-416-512-7472 x 234 or by email at [kgoodman@ccn.on.ca](mailto:kgoodman@ccn.on.ca).

#### General Information

Please begin by helping us to generally understand the type of practice you operate.

#### \*1. Please enter the following details about your practice:

Name:

Organization name (if different):

Address:

City/Town:

Postal Code:

Phone Number:

Fax Number:

Email:

Name and Contact Information of Office Administrator (if available):

### Heart Failure Management in Ontario

#### \*2. Which of the following best describes your practice?

- ☐ Family Health Team
- ☐ Family Health Group
- ☐ Community Health Clinic
- ☐ Walk-in Clinic
- ☐ Hospital
- ☐ Primary Care Practice
- ☐ Specialty Practice
- ☐ Other (please specify)

#### \*3. Does your practice have an existing Heart Failure Program/Clinic?

- ☐ Yes
- ☐ No

If no, do you currently refer your patients to an existing heart failure program/clinic? Please provide the name and contact information.

#### 4. As part of your practice do you have dedicated days for your Heart Failure Program/Clinic

- ☐ Yes
- ☐ No

#### 5. Please enter the following information about your Heart Failure Program/Clinic

Days of operation:

Hours of operation:

Total # of new Heart Failure referrals each year:

Average # of Heart Failure Patients seen each week:

Total # of Heart Failure Patients seen in your practice each year:

## Heart Failure Management in Ontario

### 6. Are the majority of patients in your Heart Failure Program/Clinic over the age of 65?

- ☐ Yes  
☐ No  
☐ Equal

### 7. Do you treat more men or women in your Heart Failure Program/Clinic?

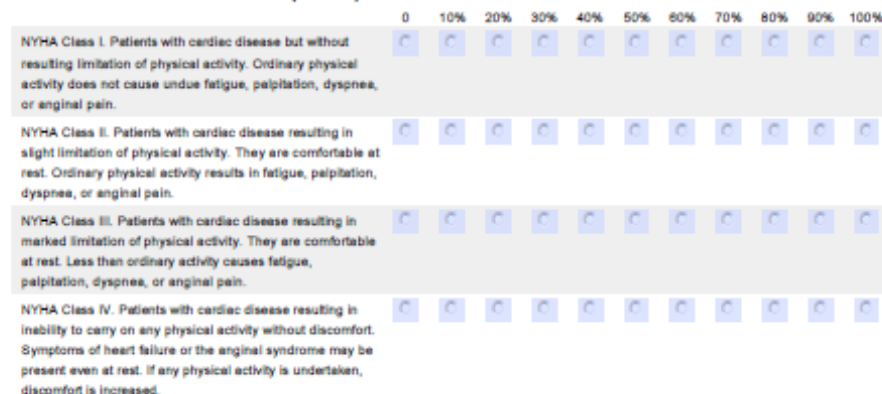
- ☐ Men  
☐ Women  
☐ Equal

### 8. Please indicate all of the staff in your Heart Failure Program/Clinic (if any) who have a specialization or expertise in heart failure:

- ☐ Cardiologist  
☐ Internist  
☐ Family Physician  
☐ Geriatrician  
☐ Registered Nurse  
☐ Advanced Practice Nurse  
☐ Nurse Practitioner  
☐ Physician Assistant  
☐ Social Worker  
☐ Pharmacist  
☐ Physical Therapist  
☐ Occupational Therapist  
☐ Dietitian  
☐ Kinesiologist  
☐ Other (please specify)

## Heart Failure Management in Ontario

### 9. Of the Heart Failure patients seen by your Program/Clinic, what proportion fall into each New York Heart Association (NYHA) Class at first visit?



### 10. Do you accept referrals from?

- ☐ Patient self-referral  
☐ Family Physician referral  
☐ Specialist referral  
☐ Other referral source (Please specify)

## Heart Failure Management in Ontario

**11. Please indicate the main sources of referrals (check all that apply):**

- ☐ Patient
- ☐ Cardiologist
- ☐ Internist
- ☐ Primary Care Physicians
- ☐ Emergency Department Physician
- ☐ Geriatrician
- ☐ Nephrologist
- ☐ Obstetrician
- ☐ Nurse Practitioners
- ☐ Community Care Access Centres

Other (please specify)

**12. Is your Heart Failure Program/Clinic open to any patient in the province of Ontario**

- ☐ Yes
- ☐ No

If no, please specify the criteria for accessing your clinic

**13. Do patients have a standing appointment or do they only schedule appointments only when needed?**

- ☐ Standing appointment
- ☐ Only as-needed

**14. Do you have the capacity to see patients at your Heart Failure Program/Clinic for same day consultations?**

- ☐ Yes
- ☐ No

## Heart Failure Management in Ontario

**15. Which of the following care providers would a patient typically see during one visit to your Heart Failure Program/Clinic?**

- ☐ Physician-only
- ☐ Nurse-only
- ☐ Other care provider-only
- ☐ Multiple care providers in the same visit

If patients are seeing a care provider other than a physician or nurse, please specify.

**16. In your Heart Failure Program/Clinic, are sessions typically conducted one-on-one, in groups, or in a combination of individual and group sessions?**

- ☐ One patient and one care provider
- ☐ Small group of patients
- ☐ Large group of patients
- ☐ Combination of individual and group sessions

**17. Are family/caregivers typically included in patient meetings?**

- ☐ Yes
- ☐ No

**18. How available is peer support in your heart failure program?**

- ☐ Not available
- ☐ Sometimes available
- ☐ Always available

**19. Please indicate the typical frequency of follow-up that patients receive at your Heart Failure Program/Clinic**

- ☐ Single contact with no follow up
- ☐ 1-4 visits in year
- ☐ >4 visits in year

**20. Do you discharge patients from the Heart Failure Program/Clinic**

- ☐ Yes
- ☐ No

If yes, please specify where you discharge them to, and criteria for discharge

## Heart Failure Management in Ontario

### 21. What follow-up method/tools are used by your Heart Failure Program/Clinic

- ☐ Mechanized via internet or telephone (e.g. A daily email to remind them to take medications)
- ☐ Person-to-person via telephone
- ☐ Face-to-face individually
- ☐ Face-to-face in a group
- ☐ Telemonitoring (involves easy-to-use equipment that helps a patient track their vital signs (can include glucose, weight or O2 Saturation) at home)
- ☐ Telehomecare (A form of telemedicine based in the patient's home. It uses a communication and clinical information systems to enable the transmission of voice and health-related data using ordinary telephone lines (not wireless) or the internet.)

Other (please specify)

### 22. Which types of services and interventions does your Heart Failure Program/Clinic provide (please select all that apply)

- ☐ Provides patient education
- ☐ Provides evidenced based drug therapy: Up-titration occurs in the clinic
- ☐ Provides evidenced based drug therapy: Program/Clinic makes recommendation for other health care professional re: up-titration but does not up-titrate in clinic itself
- ☐ Collaborates with homecare for intravenous (IV) meds
- ☐ Provides outpatient intravenous diuretic therapy
- ☐ Provides immunizations (preventative care)

Other activities (please specify)

## Heart Failure Management in Ontario

### 23. Which of the following diagnostic tests are routinely used when a patient visits your Heart Failure Program/Clinic

	Hardly ever	Occasionally	Sometimes	Frequently	Almost always
Routine hematology/biochemistry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinical assessment of functional capacity (6 minute walk test/Peak VO2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ECG	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Echocardiography	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stress Echo	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Regular Exercise Testing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nuclear Exercise Testing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MUGA	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Holter	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cardiac Angiography	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Chest X-Ray	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please specify the length of time you typically wait to receive the results of a Chest X-Ray (Same day, within 48 hours, more than 48 hours)

### 24. How easy is it for you to access another type of care for patients at your Heart Failure Program/Clinic

ex. Cardiac Surgery, Palliative Care, Cardiac Rehabilitation, Community Care Access Centre, Transplantation and/or Left Ventricular Assist Device (LVAD), Cardiac Resynchronization Therapy (CRT), and/or Implantable Cardioverter-Defibrillator (ICD)

☐ Very hard ☐ Hard ☐ Average ☐ Easy ☐ Very Easy

Additional comments?

## Heart Failure Management in Ontario

**25. Please indicate the outcome or process indicators tracked at your Heart Failure Program/Clinic (select all the apply):**

- ☐ Number of heart failure referrals
- ☐ Wait times - time of referral to assessment in heart failure program/clinic
- ☐ Mortality rates
- ☐ Rehospitalisations
- ☐ Achieved optimal dose of evidence-based therapy
- ☐ Achieved patient goal setting

Other (please specify any other indicators tracked at your clinic)

**26. Does your Heart Failure Program/Clinic conduct any Heart Failure Research?**

- ☐ Yes
- ☐ No

If yes, please specify the nature of the research

**27. Please indicate your data collection strategy for patients in your Heart Failure Program/Clinic**

- ☐ Paper Chart
- ☐ Electronic Medical Record (EMR) or Electronic Patient Record (EPR)
- ☐ Local/in-house Database (eg. Excel or Microsoft Access)
- ☐ Provincial Registry
- ☐ National Registry

Other (please specify)

**28. Do you receive dedicated funding to support your Heart Failure Program/Clinic**

- ☐ Yes
- ☐ No

Please specify the source of funding (e.g. Hospital, LHIN, Industry, Other)

## Heart Failure Management in Ontario

**29. Please rate the stability of your Heart Failure Program/Clinic's funding**

- ☐ Very unstable
- ☐ Unstable
- ☐ Do not know
- ☐ Fairly stable
- ☐ Very stable

**30. Please describe your connection with Health Links, if any**

**31. Please describe how do clinicians in your Heart Failure Program/Practice maintain their knowledge of current Heart Failure guidelines?**

**32. Any additional comments**

Thank you for your submission.

### **Appendix 3: Care Coordinator Recruitment Email**

Hello (insert name),

My name is Stephanie Hinton and I am a Master's student working under the supervision of Dr. George Heckman of the University of Waterloo. I am contacting you because you completed a survey sent out by the Cardiac Care Network in the fall of 2013. This survey was sent out by the Cardiac Care Network under seven different platforms, including: the OHA Healthscape, the Association of Family Health Teams, Theta Report, Google, Personal contacts, Individual Family Health Team and Hospital websites, and the Nurse Practitioner's Association of Ontario. The survey was designed to explore the current scope of heart failure management in Ontario by identifying heart failure clinics. My supervisor, Dr. George Heckman, is a member of the heart failure working group for the Cardiac Care Network. He suggested that your clinic may be interested in participating in my study and has provided me with your contact information with the assistance of Karen Harkness of the Cardiac Care Network. The reason that I am contacting you is that we are conducting a study that explores the criteria required for defining the roles and responsibilities of the different levels of care required for the adequate outpatient management of heart failure in Ontario. We are currently seeking heart failure clinic staff members as participants in this study.

Participation in this study involves conducting focus groups to discuss collaboratively and in detail the factors that should go into defining the levels of care required for the adequate outpatient management of heart failure in Ontario. I have attached a complete information letter to this email that further outlines the details of the study.

Participation in this study would take approximately 2 hours. The focus group would ideally take place in your clinic. The final decision about participation is yours. I would like to assure you that the study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee.

If you are interested in participating, please contact me at [snhinton@uwaterloo.ca](mailto:snhinton@uwaterloo.ca) and list your possible dates in early (insert month) that I would be able to conduct the focus group at your clinic. Once we have settled on a date, I will then send a confirmation email to confirm the date and time. In the event that you have to cancel, please email me at [snhinton@uwaterloo.ca](mailto:snhinton@uwaterloo.ca).

Sincerely,

Stephanie Hinton  
Master's Candidate  
School of Public Health and Health Systems  
University of Waterloo

George Heckman  
Associate Professor

School of Public Health and Health Systems  
University of Waterloo

Karen Harkness  
Clinical Lead Heart Failure and CVCDM  
Heart Failure Working Group  
Cardiac Care Network of Ontario

## Appendix 4: Care Coordinator Recruitment Information Letter

Insert Date

This letter is a request for your clinic's/practice's assistance with a project I am conducting as part of my Master's degree in the School of Public Health and Health Systems at the University of Waterloo, Ontario, under the supervision of Dr. George Heckman. The title of my research project is "Developing a set of criteria for defining the roles and responsibilities of the different levels of care required for the adequate outpatient management of heart failure: A mixed methods study". I would like to provide you with more information about this project that explores the criteria required to define the roles and responsibilities of the different levels of care within the Cardiac Care Network's "hub and spoke" organization of care.

The overall research aim is to develop a set of criteria for defining the roles and responsibilities of the different levels of care required for the adequate outpatient management of heart failure and to create a list potential recommendations to assist with the future restructuring of heart failure disease management programs to meet the appropriate roles and responsibilities of their respective level of heart failure care as defined by the criteria.

Three primary research objectives will guide the development and execution of this research study:

1. To use responses from the Cardiac Care Network's environmental scan (survey) conducted in 2013 to classify self-identified heart failure clinics according to a set of criteria established by the "hub and spoke" subcommittee.
2. To present the set of criteria developed by the "hub and spoke" subcommittee to four self-identified heart failure clinics and determine factors that that facilitate or hinder them from adopting this criteria through focus groups with physicians, care coordinators, nurse practitioners and registered nurses at the four self-identified heart failure clinics. This is the component that I am inviting the staff of your heart failure clinic to participate in.
3. To establish a list of potential recommendations to the Cardiac Care Network of Ontario for assisting heart failure clinics with future restructuring of their management program to meet the appropriate roles and responsibilities of their respective level of care as defined by the criteria.

It is my hope to connect with your healthcare providers who are engaged in your heart failure clinic/practice to invite them to participate in the focus group component of this research project. I believe that your healthcare providers can provide unique input into definitions of the roles and responsibilities of the different levels of heart failure care in Ontario. During the course of this study, I will be conducting focus groups to discuss collaboratively and in detail the factors that should go into defining the roles and responsibilities of the different levels of care required for the adequate outpatient management of heart failure in Ontario. At the end of this study the publication of this thesis will share the knowledge gained from this study with the Cardiac Care Network; as well as healthcare providers and heart failure clinics/practices. Participation is voluntary and your clinic/practice may decline to participate or withdraw consent to participate at any time in the study without penalty by advising the researcher.

To respect the privacy and rights of your clinic/practice and staff, I will not be contacting the staff directly. What I intend to do, is to have this information letter be distributed to all healthcare providers at your clinic/practice at your discretion. Contact information for me and my advisor is contained within this letter. If your healthcare providers are interested in participating they will be invited to contact me, Stephanie Hinton, to discuss participation in this study in further detail.

Participation of healthcare providers is completely voluntary. Healthcare providers will make their own independent decision as to whether or not they would like to participate in the focus groups. Healthcare providers will be informed and reminded of their rights to participate or withdraw their participation at any time in the study without penalty by advising the researcher. Healthcare providers will receive an information letter including detailed information about this study, as well as informed consent forms.

To support the findings of this study, quotations and excerpts from the focus groups will be used labelled with pseudonyms to protect the identity of the participants. Names of participants will not appear in the thesis or reports resulting from this study. If the participant's occupation is identified it will not be associated with the location of the clinic to protect the confidentiality of the clinic. Aside from direct quotes, information concerning participant's occupation will be grouped together with responses from those with similar occupations. If the location of the clinic is used participants will not be identifiable, and only

200 University Avenue West, Waterloo, ON, Canada N2L 3G1  
519-888-4567 | fax 519-746-2510 | [ahs.uwaterloo.ca/sphhs](http://ahs.uwaterloo.ca/sphhs)

described as a healthcare team. Observations and notes from focus groups will be grouped together in the discussion to assist with maintaining confidentiality.

The name of your clinic/practice will not be identified to help to ensure that the confidentiality of your healthcare team is maintained. All field notes and transcripts from the focus groups will be retained locked in my office and in a secure cabinet in the School of Public Health and Health Systems at the University of Waterloo. All notes will be confidentially destroyed after one year. Further, all electronic data with participant identifiers will be stored in a password protected file on a locked computer for one year. Finally, only myself and my advisor, George Heckman in the School of Public Health and Health Systems at the University of Waterloo, as well as the Heart Failure Working Group at the Cardiac Care Network will have access to these materials. There are no known or anticipated risks to participants in this study.

I would like to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee. However, the final decision about participation belongs to your clinic/practice. If you have any comments or concerns with this study, please feel free to contact Dr. Maureen Nummelin, the Director, Office of Research Ethics, at 1-519-888-4567, Ext. 36005 or [maureen.nummelin@uwaterloo.ca](mailto:maureen.nummelin@uwaterloo.ca).

If you have any questions regarding this study or would like additional information to assist you in reaching a decision about participation, please contact me by email [[snhinton@uwaterloo.ca](mailto:snhinton@uwaterloo.ca)]. You may also contact my supervisor: George Heckman by phone [(519)-888-4567, ext. 31028] or by email [[ggheckman@uwaterloo.ca](mailto:ggheckman@uwaterloo.ca)]. You may also contact Karen Harkness at the Cardiac Care Network by phone [(416)-512-7477] or by email [[kharkness@ccn.on.ca](mailto:kharkness@ccn.on.ca)].

I hope that the results of my study will be beneficial to your clinic/practice, to your healthcare team, and to your heart failure patients, as well as the broader research community. I very much look forward to speaking with you and thank you in advance for your assistance with this project.

Yours sincerely,

Stephanie Hinton  
Master's Candidate  
School of Public Health and Health Systems  
University of Waterloo

George Heckman  
Associate Professor  
School of Public Health and Health Systems  
University of Waterloo

Karen Harkness  
Clinical Lead Heart Failure and CVCDM  
Heart Failure Working Group  
Cardiac Care Network of Ontario

**Organization Permission Form**

We have read the information presented in the information letter about a study being conducted by Stephanie Hinton of the School of Public Health and Health Systems at the University of Waterloo, Ontario, under the supervision of Dr. George Heckman at the University of Waterloo. We have had the opportunity to ask any questions related to this study, to receive satisfactory answers to our questions, and any additional details we wanted.

We were informed that this organization may withdraw from assistance with the project at any time. We were informed that study participants may withdraw from participation at any time without penalty by advising the researcher.

We have been informed this project has been reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo and that questions we have about the study may be directed to Stephanie Hinton or by email [snhinton@uwaterloo.ca], George Heckman by phone [(519)-888-4567, ext. 31028] or by email [gheckman@uwaterloo.ca] and/or Karen Harkness by phone [(416)-512-7477] or by email [kharkness@ccn.on.ca].

We were informed that if we have any comments or concerns with in this study, we may also contact the Director, Office of Research Ethics at (519) 888-4567 ext. 36005.

Stephanie Hinton  
Master's Candidate  
School of Public Health and Health Systems  
University of Waterloo

George Heckman  
Associate Professor  
School of Public Health and Health Systems  
University of Waterloo

Karen Harkness  
Heart Failure Working Group  
Cardiac Care Network of Ontario

We agree to help the researchers recruit members of our healthcare team to participate in focus groups

☐ YES ☐ NO

Clinical Care Coordinator Name: \_\_\_\_\_ (Please print)

Clinical Care Coordinator Signature: \_\_\_\_\_

Witness Name: \_\_\_\_\_ (Please print)

Witness Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix 5: Focus Group Script

The student researcher and research assistant will arrive 30 minutes prior to the start of the focus group. The following tasks need to be completed:

- Room set-up (tables and chairs)
- Set-up and testing of the audio recorder
- Information letters and consent forms (with pens) placed in front of each place setting
- Set-up additional materials required for the focus group (i.e., name tags, poster board)

As participants begin to arrive, the student researcher and research assistant will welcome participants, hand out name tags and direct them to the table. At this time the student researcher will explain the following:

“You will find an information and consent form in front of you. Please read the information letter, and if you have any questions, please feel free to ask. Once you have all questions answered, please fill out the consent forms. The focus group cannot begin until all consent forms are completed and collected by the research assistant”

The focus group may begin once these tasks are fulfilled.

Student Researcher (SR): Good afternoon and welcome to our focus group. We would like to thank you for taking the time to be here with us today and would like to remind you of a few things before we begin.

All information you provide will be considered confidential and grouped with responses from other participants. Excerpts may be used from the focus groups but will remain anonymous. The excerpts will not identify you by name or any other identifying information other than your occupation. If your occupation is used in an excerpt or anywhere else in the report, we will not provide any identifying information concerning the clinic at which you are employed. In all other instances, the clinic/practice will not be identified and instead will be given a pseudonym and identified as either “urban” or “rural” in the report and thesis dissertation that the facilitator produces for this session. All field notes and transcripts will be de-identified and stored in a locked cabinet in the student investigator’s office. The de-identified information will be replaced with codes and the masterfile containing the code information will be stored in a locked file on the student researcher’s computer. All information will be kept for one year and after that time will be confidentially shredded and destroyed. Please be reminded that given the group format of this focus group session we will ask you to keep in confidence information that identifies or could potentially identify a participant and/or his/her comments

This focus group will be approximately 2 hours in length. You are free to leave at any time during those 2 hours, as participation is completely voluntary. There are no right

or wrong answers to the questions we will be asking and you have the option of declining to answer any questions you wish. Additionally, you do not have to have the same opinion as other members of the group and are free to disagree with any comment but we ask that you do so in a respectful manner. Finally, we ask that you speak one at a time and if you feel comfortable stating either your name or your position before you speak as this will help us when we have to transcribe the focus group but this information will be de-identified in the transcripts. If there are no questions, we will begin

\*pause for questions\*

- The audio recorder is turned on (if given permission by all participants)

SR: Let us begin with introductions. Let us go around the table and have everyone say their name and affiliation with the (heart failure clinic name), including how long you have worked here.

\*pause for answer; introduce yourself and student researcher\* ~ 5 minutes

SR: The “hub and spoke” organization of care was developed by the Cardiac Care Network in 2014. Have you heard of the “hub and spoke” organization of care? (If no, explain briefly). If yes, what do you know about it?

\*pause for answer\* ~ 10 minutes

SR: What do you think of the way the “hub and spoke” organization of care organizes heart failure?

\*pause for answer\* ~ 10 minutes

SR: Now that we have talked a bit about the “hub and spoke” organization of care (make sure they know), can you describe what you do here in your clinic.

\*pause for answer\* ~ 10 minutes

SR: If you were to define your clinic where would you classify it in the “hub and spoke” organization of care and why?

\*pause for answer\* ~ 10 minutes

SR: Is it important to define the roles and responsibilities of the different levels of heart failure care in Ontario and why?

\*pause for answer\* ~ 10 minutes

SR: If you could think of ways to define the different roles and responsibilities of the different levels of heart failure care, how would you go about this? What elements would you incorporate? (May discuss specific level or all levels).

- Probe about how they would define/incorporate each of the following:
  - Patient Population

- Method of Communication
- Intensity/Complexity
- Environment
- Delivery Personnel

\*pause for answer\* ~ 30 minutes

SR: There are criteria which can be used to describe and score heart failure programs in Ontario. We used the literature, specifically articles by Krumholz et al (2006) and Reigel et al (2010) to define the roles and responsibilities of different levels of heart failure care. We summarized them into a criteria that we have used to score heart failure programs in Ontario. We are going to pass out this criteria and let you have a moment or two to look at it.

\*hand out criteria and allow them to look at it\* ~5 minutes

SR: Now that you have had a chance to look at it, what do you think about the definitions to 'categorize' each level?

\*pause for answer\* ~ 10 minutes

SR: Do you have any questions or comments?

\*pause for answer\* ~ 10 minutes

SR: Is there anything that you would change about the criteria?

\*pause for answer\* ~ 10 minutes

SR: Can you score your clinic?

\*allow them to fill out the criteria\* ~ 10 minutes

SR: Can we discuss the scoring as a group?

\*pause for answer\* ~ 10 minutes

SR: OK, the following shows the results of our scoring of your clinic (show them poster board). What do you think about this? Do you see some gaps? Do you see some disagreements? Where did you differ?

\*pause for answer\* ~ 20 minutes

SR: (Need to have a feel in the group that they think that this is a good idea – before this question is asked). What would you identify as possible barriers to adopting the roles and responsibilities of your level of care?

\*pause for answer\* ~ 10 minutes

SR: What would you identify as possible facilitators to adopting the roles and responsibilities of your level of care?

\*pause for answer\* ~ 10 minutes

SR: The purpose of this focus group was to discuss the factors that should go into defining the roles and responsibilities of the different levels of care required for the adequate outpatient management of heart failure in Ontario. Is there anything we missed or is there anything that you came here today wanting to say that you did not get a chance to say?

\* pause for answer\* ~ 5 minutes

SR: If that is everything I would like to thank you again for coming today and providing us with your input. We are handing out a feedback letter that you may take home with you. Your comments were very useful to us and will help moving forward with this research project. We would appreciate it if you left your completed criteria handout to be included as part of the analysis (by leaving the handout you are consenting that it may be used for the study analysis). There is no obligation to leave it and if you do not want it to be used in the study analysis you are free to take the handout with you.

Hand out feedback letter

End of focus group

Collect handouts and clean-up space.

The student researcher and research assistant should now take 30 minutes to debrief and revise the focus group script, if necessary. The focus group questions are likely to be revised overtime. Questions may be removed and the current set of questions may be revised to become more in-depth in order to allow us to understand the full range of perspectives regarding this topic.

## Appendix 6: Participant Feedback Letter

University of Waterloo

Insert Date

Dear (Insert Name),

I would like to thank you for your participation in this study entitled “Developing a criteria for defining the care organization required for the adequate outpatient management of heart failure: A mixed methods study.” As a reminder, the purpose of this study is to develop a set of criteria for defining the levels of care required for the adequate outpatient management of heart failure and to create a list potential recommendations to assist with future restructuring a heart failure disease management program to fit the criteria and/or revising the criteria as acknowledged by four self-identified heart failure clinics.

The data collected during the participant observation and focus groups will contribute to a better understanding of the factors that facilitate or hinder your clinic from adopting the set of criteria and revise the components of the criteria according to themes developed through this iterative process.

Please remember that any data pertaining to you as an individual participant will be kept confidential. Once all the data are collected and analyzed for this project, I plan on sharing this information with the research community through my thesis dissertation, conference presentations, and journal articles. If you are interested in receiving more information regarding the results of this study, or would like a summary of the results, please provide your email address, and when the study is completed, anticipated by June 30, 2015, I will send you the information. In the meantime, if you have any questions about the study, please do not hesitate to contact me or my supervisor by email or telephone as noted below. As with all University of Waterloo projects involving human participants, this project was reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee. Should you have any comments or concerns resulting from your participation in this study, please contact Dr. Maureen Nummelin, the Director, Office of Research Ethics, at 1-519-888-4567, Ext. 36005 or [maureen.nummelin@uwaterloo.ca](mailto:maureen.nummelin@uwaterloo.ca).

Stephanie Hinton  
University of Waterloo  
School of Public Health and Health Systems  
(519)-770-6755  
[snhinton@uwaterloo.ca](mailto:snhinton@uwaterloo.ca)

George Heckman  
University of Waterloo  
School of Public Health and Health Systems  
(519)-888-4567 x 31028  
[ggheckma@uwaterloo.ca](mailto:ggheckma@uwaterloo.ca)



## Appendix 7: Care Provider Information and Consent Letter

Insert Date

**Developing a set of criteria for defining the roles and responsibilities of the different levels of care required for the adequate outpatient management of heart failure: A mixed methods study**

### Organizers:

*Stephanie Hinton*, University of Waterloo, School of Public Health and Health Systems

Dr. George Heckman, University of Waterloo, School of Public Health and Health Systems,

(519)-888-4567, ext. 31028

The student researcher (Stephanie Hinton) will be conducting focus groups with your clinic/practice. This focus group session focuses on the factors that should go into defining the roles and responsibilities of the different levels of care required for the adequate outpatient management of heart failure in Ontario and will be facilitated by Stephanie Hinton of the School of Public Health and Health Systems at the University of Waterloo. Participation in this session is voluntary and involves a 2 hour time commitment. With your permission the focus group session will be audiorecorded to ensure an accurate recording of participant responses. All healthcare providers must provide permission in order for the focus group to be audiorecorded. With your permission the student researcher Stephanie Hinton will contact you via email once the focus group responses have been put into themes as part of a member check to ensure that the themes developed in the thesis dissertation or reports are accurate portrayals of the practice/clinic.

There are no known or anticipated risks to your participation in the focus group session. Participation is voluntary and you may decline to participate or withdraw your consent to participate in the focus group at any time without penalty. You may decline answering any questions you feel you do not wish to answer and may decline contributing to the focus group session in other ways if you so wish. All information you provide will be considered confidential and grouped with responses from other participants. Excerpts may be used from the focus groups but will remain anonymous. The excerpts will not identify you by name or any other identifying information other than your occupation. If your occupation is used in an excerpt or anywhere else in the report, we will not provide any identifying information concerning the clinic at which you are employed. In all other instances, the clinic/practice will not be identified and instead will be given a pseudonym and identified as either "urban" or "rural" in the report and thesis dissertation that the facilitator produces for this session. All field notes and transcripts will be de-identified and stored in a locked cabinet in the student investigator's office. The de-identified information will be replaced with codes and the Masterfile containing the code information will be stored in a locked file on the student researcher's computer. All information will be kept for one year and after that time will be confidentially shredded and destroyed.

Given the group format of this focus group session we will ask you to keep in confidence information that identifies or could potentially identify a participant and/or his/her comments. If you have any questions about participation in this session, please feel free to discuss these with the facilitator, or later, by contacting Dr. George Heckman at 519-888-4567, ext. 33160. If you are interested in receiving a copy of the executive summary of the session outcomes, please contact Dr. George Heckman at [ggheckman@uwaterloo.ca](mailto:ggheckman@uwaterloo.ca).

I would like to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee. However, the final decision about participation is yours. Should you have comments or concerns resulting from your participation in this study, please contact Dr. Maureen Nummelin in the Office of Research Ethics at 1-519-888-4567, ext. 36005 or [maureen.nummelin@uwaterloo.ca](mailto:maureen.nummelin@uwaterloo.ca).

Thank you for your assistance with this project.

Yours sincerely,

Stephanie Hinton  
Student Researcher



### Agreement to Participate

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

---

I have read the information presented in the information letter about the focus group session being facilitated by Stephanie Hinton for her thesis dissertation. I have had the opportunity to ask the facilitator any questions related to this focus group session, to receive satisfactory answers to my questions, and any additional details I wanted. I am aware that I may withdraw from the focus group session without penalty at any time by advising the facilitator of this decision.

I am aware that I have the option of allowing the focus group to be audio recorded to ensure an accurate recording of my responses. I am also aware that excerpts from the focus group may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous. I was informed that I may withdraw my consent at any time without penalty by advising the researcher. I am also aware that I may give the student researcher Stephanie Hinton permission to perform a member check to ensure that the themes developed in the thesis dissertation or reports are accurate portrayals of the practice/clinic.

This project has been reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee. I understand that if I have any comments or concerns resulting from my participation in this study, I may contact the Director, Office of Research Ethics at 519-888-4567 ext. 36005.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this session and to keep in confidence information that could identify specific participants and/or the information they provided.

With full knowledge of all foregoing, I agree, of my own free will, to participate in the focus group.

0YES 0NO

I agree to have the focus group audio recorded.

0YES 0NO

I agree to be contacted for a member check.

0YES 0NO

If "yes" please provide an email that you can be contacted at: \_\_\_\_\_

I agree to the use of anonymous quotations in any thesis or publication that comes of this research.

0YES 0NO

Participant Name: \_\_\_\_\_ (Please print)

Participant Signature: \_\_\_\_\_

Witness Name: \_\_\_\_\_ (Please print)

Witness Signature: \_\_\_\_\_



Date: \_\_\_\_\_

