Strategy for Community Management of Heart Failure in Ontario

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Executive Summary

The Cardiac Care Network of Ontario

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.

Heart Failure in Ontario

The purpose of this document is to highlight gaps in the current treatment of Heart Failure and propose a model aimed at improving the care provided to Heart Failure patients in the province.

Heart failure (HF) is a complex and progressive disease where the heart cannot pump sufficient blood to meet the body’s demands, resulting in poor exercise tolerance, fatigue, and reductions in quality of life and survival. Patients with HF typically pass through a number of advancing stages before reaching the end stage condition. This means that the eventual deterioration of heart function due to HF can be predicted early in the course of the disease and ideally, clinical strategies can be deployed early on to stabilize symptoms and prevent or slow disease progression and improve the quality of life.

The patient with HF experiences periods of relative stability, interspersed with unpredictable acute episodes that result in declining health, repeated hospitalizations and ultimately death. The typical HF patient is elderly and may have multiple comorbidities in addition to coronary artery disease (CAD including hypertension, atrial fibrillation, diabetes mellitus or chronic obstructive pulmonary disease (COPD).
Approximately one percent of Canada’s population is estimated to be living with HF and it is the leading cause of hospitalization for the elderly in Canada. When admitted to hospital, HF patients generally stay longer than most other patients, resulting in a relatively high burden on the health care system. Appropriate management of their condition and the support of HF patients in the community is critical to ensuring optimal quality of life for the patients and their caregivers, and minimizing the burden on Ontario’s strained health care system. It is expected that the numbers of individuals living with HF as a chronic disease will continue to increase, in part due to treatment successes and increased survival rates for certain forms of heart disease as well as the aging population.

The burden of HF in Ontario should not be underestimated:

- Data from 2005-06 indicate that HF was the cause of 1.9% of all hospitalizations in Canada and was listed as a comorbidity or primary diagnosis in 4.9% of hospitalizations (Dai et al., 2012). It is estimated that between 1996 and 2025, hospitalizations in Canada due to HF will increase from approximately 110,000 in 2013 to 150,000 in 2025, due primarily to the aging population (Johansen et al., 2003);
- With respect to aging, HF is the single most common cause of hospitalization in patients over 65 years of age (Dai et al., 2012);
- Patients over 75 years of age account for two-thirds of all hospital days for HF patients; the 90 day readmission rate for these patients ranges from 23% to 50% (Bierman et al., 2009);
- HF patients also stay in hospital longer than average. Length of stay (LOS) for HF patients in 2005-06 was approximately 12 days, nearly double the LOS for all other causes (Dai et al., 2012). It has been estimated that hospitalizations account for 70% of the costs associated with management of HF patients (McMurray, 2010); and
- Recent Ontario data shows that HF patients contributed to 20,504 Alternate Level of Care (ALC) days in 2011. In the cardiac patient groups, people admitted with HF account for 29% of the acute LOS days and 49% of the ALC days (Discharge Abstract Database, IntelliHEALTH Ontario, 2011). In a recent study from Ontario, HF patients were observed to have a 10-year mortality rate of 99% (Chun et al., 2012). The median survival time of these patients was 1.75 years, demonstrating that one-half had died within two years and highlighting the clinical instability of these patients. Recently, the Public Health Agency of Canada published a paper that indicated patients hospitalized for HF had an in-hospital mortality rate of 13.3%; nearly triple the rate for all other causes (Dai et al., 2012).

Existing Challenges in HF Care in Ontario

Population growth is outstripping the capacity to provide the appropriate care where it is needed the most. While the acute phase of HF may require admission to hospital for diagnostic testing and intervention, the majority of patients live with HF as a chronic disease and this aspect of care must be effectively delivered in community and primary care settings. Health care providers are concerned about gaps in access to care for HF patients that are contributing to suboptimal clinical outcomes and avoidable use of high cost resources. Some of the key gaps include the following:

1. Small/solo primary care practices may not have the capacity to meet the needs of HF patients with complex needs and multiple morbidities;
2. Providers are not informed/ have knowledge gaps regarding clinical best practices for management of HF;
3. Variations in access to HF specialty clinics across the province, given the geography of Ontario;
4. Referral criteria for HF clinics are not standardized;
5. Some HF patients do not have a Primary Care Provider (PCP);
6. Wait times to access specialty clinics are not measured, but are believed to be unacceptably long;
7. Models of HF care vary across the province;
8. High proportion of emergency department (ED) visits and hospital readmissions within 30 days of discharge, with readmission rates ranging from 23% to 50%;
9. One in five patients is not evaluated by a cardiologist or PCP within 30 days of discharge;
10. Long Term Care (LTC) home residents with HF are high users of EDs and have suboptimal access to recommended therapies;
11. There is no cohesive strategy for the care of end-stage HF patients with only 4% of HF patients receiving palliative care;
12. The system of care is fragmented, with insufficient emphasis on chronic disease prevention and management (CDPM) including self-care; and
13. The cost associated with obtaining appropriate therapies and coordinated care is not affordable to all patients.

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1 The PCP is typically a general practitioner (GP) or family physician (FP). A GP is a generalist who was certified by the Royal College of Physicians and Surgeons before Family Medicine became a specialty. A FP is a physician who is certified in the practice of Family Medicine. Other regulated health professionals, (e.g., nurse practitioners, physiotherapists, pharmacists) also provide some primary care.
HF patients are high users of health care services. They often see multiple providers in multiple settings of care including outpatient, hospital, home care, and rehabilitation settings. Care in each of these settings may be suboptimal because transitions across settings of care are not well defined or coordinated. Furthermore, HF care varies across the province, largely dependent on factors such as availability of specialty and primary care clinical resources between urban, rural and remote settings. In addition, most people with HF are older and have multiple chronic conditions that may also contribute to their frailty and poor quality of life, which requires extra care and attention to ensure the best possible outcomes. HF patients and their care givers require education and support in managing their treatment plan, as they need to know how to make necessary lifestyle modifications, how to manage their medications, including adjusting their diuretics when needed, and when to contact a physician for worsening symptoms. The care giving burden associated with HF should not be underestimated, and supports need to extend beyond the patient and include the primary care giver.

The Ideal System

The ideal, patient centered system to manage HF must be firmly rooted in a primary care sector that is highly integrated with specialty services and with community-based teams of allied health professionals, including home care and related community supports for patients (including palliative care and geriatrics), and well defined transition points for HF patients as they move through the system. In addition, special considerations for patients with unique needs, such as the frail elderly, those with multiple morbidities, and end of life/palliation must be accounted for in the model of care. The ideal HF system should be based on a Chronic Disease Prevention and Management (CDPM) framework that fosters the development of self-care strategies and supports HF patients and caregivers in an overall model of self-management. A highly collaborative clinical practice model that deploys “hub and spoke” organization of care is a critical component to ensure limited resources are effectively deployed, building capacity between primary care and speciality care and linking the appropriate community supports. Evidence-based guidelines are available for the management of HF patients, and these should be observed by specialists as well as PCPs to reduce the variability associated with the clinical management of HF. In addition, effective HF management requires multiple strategies including pharmacologic, lifestyle, and device therapy. There is excellent evidence for these therapies for the majority of HF patients with the significant potential to decrease morbidity and mortality and improve the quality of life for patients with HF. It is well recognized that current HF management in Ontario could be greatly improved by a coordinated and systems-based approach to HF management to ensure that best practices are consistently deployed rendering the highest quality care for this fragile patient population, and to ensure appropriate utilization of health care resources.

Ontario Ministry of Health and Long-Term Care Priorities

In the context of developing a coordinated HF strategy for Ontario, it is important to recognize that there are key initiatives currently underway in Ontario (discussed in detail in section 2 of this document). This HF Strategy can serve to define the key components of out-of-hospital care provided by PCF, specialist and other community resources, articulating a “hub and spoke” model that can be effectively deployed to serve the population of Ontario across urban, rural and remote settings. Fundamental to the strategy is to ensure a common standard of care is deployed, with patient risk stratification and appropriate clinical intervention with mechanisms in place to monitor access and quality of care/clinical outcomes.

Ontario HF Strategy - Summary of Recommendations

The CCN Ontario HF Strategy includes 10 recommendations that focus on 3 key priority areas: Standardizing tools and resources for patients, caregivers, and clinicians, improving organization of care, and enabling measurement and improvement.

<table>
<thead>
<tr>
<th>Key Priority Area</th>
<th>CCN Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Standardize Tools and Resources for Patients, Caregivers, and Clinicians</td>
<td>1. General information on HF must be available to improve public awareness and knowledge of HF.</td>
</tr>
<tr>
<td></td>
<td>2. Standardized tools for self-care management should be developed and implemented.</td>
</tr>
<tr>
<td></td>
<td>3. Self-help groups should be established to support HF patients and caregivers.</td>
</tr>
<tr>
<td></td>
<td>4. Standardized tools and resources for optimal management of HF patients must be made available to HF Clinicians across the province, in particular unique patient groups (e.g. frail elderly, and end of life patients) will require additional standard assessments and resources (e.g. system navigation, palliation) to support care and transition stages.</td>
</tr>
</tbody>
</table>
1. Introduction

1.1 Why a Provincial Heart Failure Strategy is Necessary

Heart failure (HF) is a complex chronic cardiac condition in which the patient experiences periods of relative stability, interspersed with unpredictable acute episodes that result in declining health, hospitalization and death (Goodlin, 2009). Many of the same concerns that are driving health policy reforms in Ontario today triggered this review of HF management in Ontario. Population growth is outstripping our capacity to provide the right care where it is needed the most. Health care providers (HCP) are concerned about gaps in access to care for this at risk population contributing to suboptimal patient outcomes and avoidable use of high cost resources. HF has a clinical and demographic profile correlated to the growth and structural changes in the population of Ontario. With the aging demographic of the population, the prevalence of HF is expected to increase, and consequently the strain on the health care system to accommodate increased demands for the management of HF patients will continue to grow.

Approximately one percent of Canada’s population is estimated to be living with HF (Chow et al., 2005), and it is the leading cause of hospitalization for the elderly in Canada (Dai et al., 2012). When admitted to hospital, HF patients generally stay longer than most other patients (Dai et al., 2012), contributing significantly to Alternative Level of Care (ALC) days within the hospital setting. There are far too many HF patients to be cared for by cardiologists or even internists. HF management requires multiple strategies including pharmacologic, lifestyle, and device therapy. Most of the HF patients living in the community are over 65 years of age (Foebel, 2011). As our population ages, more people will survive and live with heart disease later in life, and be at a greater risk of living with HF. The burden of caring for patients with HF should not be underestimated.

In recognition of the impact of HF, population growth, and the need for improved care, the Ministry of Health and Long Term Care (MOHLTC) asked the Cardiac Care Network of Ontario (CCN) to prepare an environmental scan of the diagnosis and management of HF patients in Ontario as a foundation for the development of a provincial strategy for this patient population. The purpose of this document is to highlight gaps in the current treatment of HF and propose a model aimed at improving the care provided for HF patients in Ontario. (Please see Appendix A for a list of the CCN HF Working Group members).

### Implementation Plan

Through its Heart Failure Working Group, CCN is well positioned to action the majority of the recommendations. CCN has experience working with cardiac service providers to standardize referral and active cardiac access management, and reporting on metrics of care relative to access and quality. In addition, CCN maintains the Ontario Cardiac Registry and is well positioned to include additional minimum data set/metrics relative to HF care. As part of the implementation plan, CCN is currently completing an environmental scan to define HF resources by LHIN and will identify where gaps in services exist. Follow up to the gap analysis will be recommendations to augment regional/local resources to support the care of HF patients across the continuum of care. A standard tool kit for HF risk assessment and clinical pathways to define best clinical practices to optimize care based on risk stratification will be developed and shared as a resource to support initiatives underway at the LHIN and regional level (e.g. supported by Health Links). Finally, development of a patient portal is underway to provide patient level information to support a self-management model of care.

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1 Environmental scan currently underway at CCN
1.2 Benefits of a Provincial Heart Failure Strategy

The development of an integrated province-wide strategy for the management of HF is supportive of and furthers several key MOHLTC priorities:

1.2.1 Health Links

Health Links is a provincial priority focused on improving care for the 1% to 5% of Ontarians who are high users of the health care system. While the definition of a high user will vary from one region to another, one would expect that many of these high users would have chronic health conditions, including HF. Health Links bring together HCPs in a community to better and more quickly coordinate care for high-needs patients. Health Links will encourage greater collaboration between existing local HCPs (including family care providers and specialists), hospitals, long-term care, home care and other community supports. With improved coordination and information sharing, patients will receive faster care, will spend less time waiting for services and will be supported by a team of HCP at all levels of the health care system. In the context of HF, Health Links provides a key opportunity to support local HCPs together as a team, helping primary care providers to connect patients more quickly with specialists, home care services and other community supports, including mental health services. For patients being discharged from hospital, the Health Link will allow for faster follow-up and referral to services like home care, helping reduce the likelihood of re-admission to hospital. There are more than 40 operational Health Links, with many more being planned. While it is up to the individual Link to determine which cohort of patients to target, one would expect, given the complexity of and high costs incurred by HF patients that many of the Links will be focusing on HF patients.

1.2.2 Patient Centred Care and Chronic Disease Management

There is a great deal of attention at the provincial and sectoral level for improving the patient experience within health care as well as on the provision of patient-centred care. The Excellent Care for All Act puts the patient at the centre of the health care system and encourages everyone working within the system to put the needs of the patients first. A large component of patient centred care is empowering patients with tools, resources and information to play an active role in their health care and be the driver of their health care experience. Active patient engagement is a key component of achieving symptom stability and improving quality of life when living with HF (Riegel 2011) and an essential component within the context of Chronic Disease Prevention and Management (CDPM) framework adapted by the MOHLTC and building upon the evidence-based Chronic Disease Model (Wagner et al., 1996). The CDPM framework refers to personal skills and self-management support as a key enabler for helping people with chronic diseases more actively manage their conditions.

1.2.3 Quality Based Procedures

As part of the Ontario Health System Funding Reform, work has recently been undertaken by Health Quality Ontario (HQO) to develop a Quality Based Procedure (QBP) focusing on the clinical care of patients hospitalized for HF with an aim to improve the quality of care provided to such patients by decreasing the variation in clinical practice (QBPs, 2013). While hospital-based care is key to effective management of HF, it is essential that HF care delivered in the community by primary care providers (PCPs) and specialty clinics is also defined with appropriate resources in place to support ongoing care, follow up of HF patients in community settings, and prevention of readmissions. The QBP Clinical Handbook provides excellent suggestions for optimizing the patient journey while hospitalized. A provincial HF strategy will enhance and complement recommendations from the QBP Clinical Handbook by discussing the ongoing management of HF patients in the community, and the prevention of unnecessary readmissions.

1.2.4 System Capacity

Numerous reports have highlighted the challenges with the current capacity of the health care system to continue to deliver care through the current model. Emergency department (ED) overcrowding, code gridlock, “ALC” - these are all too familiar terms that speak to a health care system that is strained at its seams. The goal of the HF strategy is to provide organized and coordinated care to this high user group such that they do not end up unnecessarily in the ED or in an ALC bed awaiting transfer.

1.2.5 Healthy Change: Ontario’s Action Plan for Health

In early 2012, the Ministry of Health and Long-Term Care unveiled Ontario’s Action Plan for Health. The goal of the Action Plan is to ensure that patients receive the right care, at the right time, in the right place, with a focus on patient engagement and a stronger role for primary care. The current design of the HF system is fragmented and hospital and specialist focused, with many patients experiencing challenges during transitions in care. To ensure that HF patients can receive timely access to care that is close to home, the role of primary care must be supported. The intention of the HF strategy is to provide patients, caregivers, and clinicians with the evidence-based tools they need to manage HF effectively. The Action Plan is also focused on ensuring that healthcare dollars are being spent to improve outcomes. The HF strategy will address this issue by aiding with the collection of continuous feedback on patient outcomes and the measurement of key performance indicators.

1.2.6 Living Longer, Living Well: A Seniors Strategy for Ontario

With the number of Ontarians aged 65 and older set to more than double in the next two decades, the need to address the provision of care to older adults has never been greater. Dr. Samir Sinha’s report, ‘Living Longer, Living Well’, 2012 outlines several key recommendations that address how care for older adults living with chronic illnesses should optimally be provided. The need for collaboration between HCPs across the continuum of care and a greater role for primary care are key components of the recommendations. The negative outcomes associated with poorly managed transitions between care providers are highlighted throughout the report. The need
for comprehensive standards of care, and the necessity of implementing outcome and process indicators to measure performance are key to the successful development of a system that delivers cohesive and consistent care to older adults, including those living with HF.

### 1.3 CCN Role in Cardiac Service Delivery in Ontario

CCN serves as a system support to the MOHLTC, Local Health Integration Networks (LHIN), 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 for adult cardiovascular procedures 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.

### 1.4 The CCN Heart Failure Working Group

Recognizing the complexity of managing HF in a large and heterogeneous province like Ontario, CCN established a Heart Failure Working Group (CCN-HFWG) in the Summer of 2011. The CCN-HFWG is a multidisciplinary group comprised of key stakeholders (involved in the care of HF patients across the province). A list of the CCN-HFWG members is provided in Appendix A.

The mandate of the CCN-HFWG is to focus on key aspects of clinical care for HF patients, to identify opportunities to enhance services in Ontario, and to identify and resolve obstacles to supporting optimal care.

The CCN-HFWG developed this HF strategy using the following approach:

- Identifying the scope of the current problem to fully understand how the changing demographics will impact the incidence and prevalence of HF patients in the future;
- Gathering clinical evidence and identifying best practices for the diagnosis and treatment of HF patients. Where gaps existed in the literature, recommendations were made on the basis of expert consensus opinion; and
- Engaging in consultative processes, soliciting stakeholder feedback, and drafting a plan to address existing gaps known to exist in the delivery of HF care.

### 2 Introduction To Heart Failure

#### 2.1 Definition of Heart Failure

HF is a complex and progressive clinical syndrome where the heart cannot pump blood sufficient to meet the body’s demands, resulting in poor exercise tolerance, and reductions in quality of life and survival (Arnold et al., 2006). Even during stable periods, HF patients may experience severe shortness of breath, fatigue, swelling in their legs and cognitive impairment. Although by definition HF is a clinical syndrome, it is also frequently described as a disease, particularly in the context of disease management tools and goals for HF patients.

#### 2.2 Causes of Heart Failure

HF can be caused by any condition that affects the ability of the heart to pump blood. The most common causes include coronary artery disease (CAD), hypertension, valvular disease, and non-ischemic cardiomyopathy. There are many underlying factors that put people at greater risk for developing HF, such as diabetes mellitus, high cholesterol, alcohol, and cigarette smoking.

#### 2.3 The Stages/Progression of Heart Failure

HF is a chronic disease that, left untreated, will progress to an end-stage condition (Figure 1.) (Hunt et al., 2005). Specific symptoms and clinical findings define each stage:

- **Stage A**: Patients have risk factors for the development of HF such as CAD, hypertension or diabetes mellitus but do not demonstrate impaired left ventricular function, hypertrophy, cardiac chamber enlargement, and are asymptomatic.
- **Stage B**: Patients have evidence of left ventricular hypertrophy and/or left ventricular dysfunction, however are asymptomatic.
- **Stage C**: Patients have evidence of left ventricular hypertrophy and/or left ventricular dysfunction and have either current symptoms of HF or have experienced symptoms of HF in the past.
- **Stage D**: Patients have evidence of left ventricular dysfunction and severe symptoms of HF.

![Figure 1: Disease Progression Pathway for Heart Failure](Source: Hunt et al., 2005)
The stages of HF are progressive and, for the most part, uni-directional. The development of structural heart disease or the existence at any time of symptoms of HF precludes individuals from reverting back to Stage A or B. Patients who develop Stage C or D disease are particularly vulnerable and at high risk of death or hospitalization. Once symptoms of HF have developed, patients may fluctuate between Stage C and D, which necessitates the use of the New York Heart Association (NYHA) Class to measure the level of functional impairment (Table 1). Depending on symptom control, patients may fluctuate between the NYHA classes representing periods of exacerbation and the need for acute care in the context of a chronic disease.

Table 1. New York Heart Association (NYHA) Classification

<table>
<thead>
<tr>
<th>NYHA Class</th>
<th>Functional Capacity</th>
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<tbody>
<tr>
<td>I</td>
<td>Patients with cardiac disease but resulting in no limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitations, or shortness of breath.</td>
</tr>
<tr>
<td>II</td>
<td>Patients with cardiac disease resulting in slight limitation of physical activity. They are comfortable at rest. Ordinary physical activity results in fatigue, palpitations, or shortness of breath.</td>
</tr>
<tr>
<td>III</td>
<td>Patients with cardiac disease resulting in marked limitation of physical activity. They are comfortable at rest. Less than ordinary activity causes fatigue, palpitations, or shortness of breath.</td>
</tr>
<tr>
<td>IV</td>
<td>Patients with cardiac disease resulting in the inability to carry on any physical activity without discomfort. Symptoms of HF may be present even at rest. If any physical activity is undertaken, discomfort increases.</td>
</tr>
</tbody>
</table>

This cycle of clinical instability, acute events and hospitalizations can be repeated many times before the end of life. End-of-life is less predictable than with other chronic diseases where the course is typically much more linear. These facts, when taken together, reinforce the need to treat end-stage HF as a terminal illness and underscore the importance of including advance care planning and considering palliative care early in the management plan for HF patients (McKelvie et al., 2011).

Figure 2: The Heart Failure Cycle

Despite advances in pharmacological and device-based therapies, HF patients have a poor prognosis, and HF remains a terminal illness, with an annual mortality rate between 5% and 50% (Arnold et al., 2006). In a recent study from Ontario, HF patients were observed to have a 10-year mortality rate of 99% (Chun et al., 2012). The median survival time of these patients was 1.75 years, demonstrating that one-half had died within two years and highlighting the clinical instability of these patients. Recently, the Public Health Agency of Canada published a paper that indicated patients hospitalized for HF had an in-hospital mortality rate of 13.3%; nearly triple the rate for all other causes (Dai et al., 2012).
2.5 Incidence and Prevalence of Heart Failure

Over 50,000 Canadians are diagnosed with HF each year (Dai et al., 2012) and the estimated crude prevalence of HF was 264,060 as reported by the Canadian Community Health Survey 2000/2001 (Chow et al., 2005). In 2011 there were 20,285 hospitalizations for HF in Ontario (Discharge Abstract Database, Ontario 2011). (Please see Appendix B for a summary of the Hospitalization Crude Rates by LHIN between 2006 and 2011). The age distribution of the HF population is distinct from other cardiac diseases. Table 2 shows that HF patients are older as compared to patients with other cardiac diseases.

Table 2: Age Distribution of Types of Heart Disease in Hospital

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Valve Disease</th>
<th>Arrhythmia</th>
<th>Heart Failure</th>
<th>Ischaemic Heart Disease</th>
<th>All Diseases of the Heart</th>
</tr>
</thead>
<tbody>
<tr>
<td>65-69</td>
<td>12.44%</td>
<td>10.79%</td>
<td>8.39%</td>
<td>12.92%</td>
<td>11.41%</td>
</tr>
<tr>
<td>70-74</td>
<td>13.80%</td>
<td>11.65%</td>
<td>10.97%</td>
<td>12.90%</td>
<td>11.37%</td>
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<tr>
<td>75-79</td>
<td>16.62%</td>
<td>13.96%</td>
<td>14.70%</td>
<td>11.80%</td>
<td>12.82%</td>
</tr>
<tr>
<td>80-84</td>
<td>16.09%</td>
<td>15.74%</td>
<td>19.54%</td>
<td>10.30%</td>
<td>13.27%</td>
</tr>
<tr>
<td>85-89</td>
<td>9.50%</td>
<td>11.59%</td>
<td>19.16%</td>
<td>7.30%</td>
<td>10.61%</td>
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<tr>
<td>90+</td>
<td>3.41%</td>
<td>6.25%</td>
<td>12.96%</td>
<td>3.77%</td>
<td>6.11%</td>
</tr>
<tr>
<td>Average Age</td>
<td>70</td>
<td>70</td>
<td>77</td>
<td>67</td>
<td>70</td>
</tr>
</tbody>
</table>

Data Source: Discharge Abstract Database, IntelliHEALTH Ontario, 2011

A recent publication from the Institute for Clinical Evaluative Sciences (ICES) showed that HF patients in Ontario are on average 76.5 years old, divided almost equally between males and females, and heavily burdened with comorbidities, both cardiac and non-cardiac in nature (Yeung et al., 2012). Although this report suggested that the incidence of HF has actually declined by more than 30% between 1997 and 2007, it is crucial to recognize that population growth is outstripping the rate of decline and ultimately resulting in an increase in the absolute number of HF cases.

The single greatest determinant of future HF cases is the pattern of population growth, which is illustrated in the population pyramid for Ontario for the two periods 2011 and 2036 (Figure 3). The upper outer bands are the increase in our population structure starting at age 65 years—these outer bands are the future at-risk HF population. As the proportion of people over 65 increases in our population, the number of HF patients will subsequently increase, and so will the demand for acute and chronic disease management for these complex cases. The planning for HF disease management must account for this pattern and growth and develop the capacity to care for an aging cardiac population.
3 Heart Failure Population In Ontario

3.1 Heart Failure Patients Have Multiple Chronic Comorbidities

Several of the risk factors that contribute to cardiovascular diseases (including HF) are common amongst many of the chronic illnesses that Ontarians are living with (Figure 4). During the development of the QBP Clinical Handbook for Congestive Heart Failure by HQO, data from the Discharge Abstract Database revealed multiple pre-admission and post-admission comorbidities that affect the management of HF patients. These comorbidities include additional cardiac disorders, respiratory disorders, several types of cancer, diabetes mellitus, kidney disease, and mental health issues (including dementia and depression) (HQO and MOHLTC, 2012). As can be seen by Figure 4 many of these comorbidities have risk factors that are in common with those that result in HF. Therefore a strategy that aims at reducing these risk factors could have a far-reaching impact on reducing chronic illness in Ontario.

Figure 4: Chronic Disease Risk Factors are Common to Many Conditions

3.2 Heart Failure Patients are Elderly and Frail

Older HF patients have higher mortality and hospitalization rates than younger persons with HF, largely due to concomitant frailty, disability, and cognitive impairment (Harkness et al., 2012). Frailty is a state of increased physiologic vulnerability that is often associated with chronic disease and arises from the accumulation of multiple deficits across multiple physiological systems (Bergman et al, 2007). Features may include weakness, weight loss, reduced activity, falls, and cognitive impairment, and affected individuals are at progressively increased risk of poor outcomes such as loss of independence, health service utilization, and ultimately death (Bergman et al, 2007). A recent prospective study in Minnesota assessed 448 older persons with HF, and found that frailty, based on a validated clinical assessment, was associated with a 92% increased risk of ED visits and a 65% increase in the risk of hospitalization (McNallan et al., 2013).

An Ontario-based cross-sectional study of the Ontario Home Care Reporting System assessed 39,247 home care clients with HF, representing almost 15% of all home care clients between 2004 and 2007 (Foebel et al., 2011). This sample illustrates the complexity of ageing HF patients, who were on average aged 83.5 ± 7.7 years, and who reported an exceptionally high proportion of impairments, symptoms, comorbidities, daily medications and hospitalizations, as shown in Table 3. In addition, 37% were hospitalized at least once in the 90 days prior to the home care assessment compared to only 26% of clients without HF. These findings illustrate the complexity associated with ageing HF patients, and reflect their inherent frailty and vulnerability to poor outcomes.

Table 3: Characteristics of Ontario Home Care Clients with Heart Failure, 2004-2007 (n=39,247)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>% Home care clients with characteristic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any cognitive impairment</td>
<td>52</td>
</tr>
<tr>
<td>Impaired in activities of daily living</td>
<td>38</td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>37</td>
</tr>
<tr>
<td>Daily pain</td>
<td>49</td>
</tr>
<tr>
<td>Had fallen in previous 90 days</td>
<td>32</td>
</tr>
<tr>
<td>Had five or more comorbidities</td>
<td>45</td>
</tr>
<tr>
<td>Receiving nine or more routine medications</td>
<td>58</td>
</tr>
<tr>
<td>Hospitalized once or more in previous 90 days</td>
<td>37</td>
</tr>
</tbody>
</table>

Source: McNallan et al., 2013.
3.3 Heart Failure Patients Live Across the Province

Analysis of current data indicates that patient outcomes vary across the province. A successful HF strategy would help to better understand these variations, while helping to ensure consistent access to evidence-based standards of care province-wide. Literature suggests that there are incongruities in access to HF clinics, and cardiologists across the province (HQO and MOHLTC, 2012). As well there are tremendous variations in readmission, in hospital mortality, ALC, and hospitalization rates across LHINs and hospitals. These inconsistencies result in substantial costs to the healthcare system and less than optimal outcomes for HF patients (HQO and MOHLTC, 2012; Lee et al., 2004b).

Ontario is subdivided into 379 census sub-divisions (CSD) by Statistics Canada, and based on a 2008 review, the MOHLTC recognizes 216 communities as being northern and/or rural in recognition of the unique characteristics of these communities. Some of these inconsistencies in HF care and outcomes may be explained by the unique characteristics of communities in the northern and/or rural part of Ontario such as:

- Relatively fewer services available to the population, including access to primary care;
- Travel to centres with services is frustrated by a lack of infrastructure and long distances;
- The socio-economic profile is generally lower than in urban areas; and
- Risk factors for cardiovascular disease (e.g., smoking rates) are typically higher in rural and remote communities.

For example, Northern Ontario encompasses 87% of Ontario’s land mass, and only six percent of the population, of which over one-half live in the five cities of Sudbury, Thunder Bay, Sault Ste. Marie, North Bay, and Timmins. The current specialty-focused model of HF care requires a critical mass to warrant the investment in human resources and infrastructure to deliver specialized programs and services. The population in parts of northern Ontario is small and dispersed, hence does not provide the needed critical mass for specialized HF management programs. As a result, access to primary and specialist services is limited in some areas.

4 Best Practices In Heart Failure Management

HF is a complex condition to manage, placing significant demands on the patient, their families and caregivers, the health care system and the HCP who provide their care. HF patients often need frequent follow up (every two to four weeks), especially in patients with more severe HF. Effective HF management has been a target of organizational and quality improvement interventions aimed at increasing adherence to evidence-based guidelines, improving patient outcomes, and increasing the efficiency of care delivery. As a result, there is clear evidence available on how to optimally manage HF from a clinical and organizational standpoint.

4.1 Chronic Disease Management

Numerous studies since the 1990s have found that HF disease management programs are of benefit for HF patients, especially those with more severe HF symptoms (McAllister et al., 2004). Though variability in clinic composition have made it difficult to define the ideal structure of disease management programs for HF patients, the Canadian Heart Failure Network recommends that minimum staffing should include a nurse, a physician, and administrative and clerical support (Howlett et al., 2010). There is strong evidence to suggest that programs that contain the core elements (Table 4) of the Chronic Disease Model (CDM) (Wagner et al, 1996) are essential to improve quality of care and patient outcomes. The CDM has been applied in diverse settings among HF patients (Scott, 2008; Brand et al., 2007; Braunstein et al., 2003) and with frail, complex seniors (Okie, 2012; Scott, 2008; Coleman et al., 2006; Singh & Ham, 2006; Rothman & Wagner, 2003).

In 2007, the MOHLTC released Ontario’s CDFM framework, which builds upon the CDM (MOHLTC, 2007). This CDFM framework provides a “roadmap for effective chronic disease management while addressing the distinct needs of clients with chronic conditions, as it aims to provide multifaceted, planned, pro-active seamless care in which the clients are full participants in managing their care and are supported to do this at all points by the system” (MOHLTC, 2007).
Table 4: Core Elements of the Chronic Disease Model

<table>
<thead>
<tr>
<th>Essential element</th>
<th>Description</th>
</tr>
</thead>
</table>
| 1. Community Resources and Policies | • Community programs, linkages to community care patient services, hospital outpatient services  
• Ensure care integration and care coordination across the health system, services and programs as well as multiple health conditions |
| 2. Health Care Organization | • Support improved access to care and services  
• Provide equitable funding across community-based and multidisciplinary resources and ensure infrastructure support for integration  
• Structure, goals, and values of an organization  
• Reimbursement environment |
| 3. Self-care Support | • Collaborative practice with patient/family to acquire skills and confidence with self-care, recognize early changes in symptoms early to prevent disease exacerbations and avoid acute care use  
• Provide self-care tools, routine assessments, planned visits |
| 4. Delivery System Design | • Multidisciplinary practice teams with division of labor to promote comprehensive and holistic care  
• Non-physician health care providers trained in chronic disease management |
| 5. Decision Support | • Provide evidence-based information and tools to patients, caregivers, and health care providers  
• Integrate evidence-based clinical practice guidelines into daily practice |
| 6. Clinical Information Systems | • Facilitate patient education, monitoring and follow-up, information sharing, accountability, and quality assurance  
• Reminder systems to help teams comply with practice guidelines  
• Feedback to health care providers about individual performance on targeted clinical outcomes  
• Registries for planning individual patient care and conducting population-based care |

Source: Adapted from Ministry of Health and Long-Term Care, 2007 and Harkness et al., 2012

4.2 Evidence-based Guidelines

Over the last 30 years, many effective evidence-based HF therapies have been developed, and it is important for HCPs to be aware of these therapies so they can routinely offer them to their patients. Guidelines are available for the management of HF patients, and these should be observed by specialists as well as PCPs and health care team members in order to reduce the variability associated with the management of HF (McKelvie et al., 2013).

Guidelines for clinical management of HF patients highlight the importance of regular monitoring of the patient’s condition and tailored therapy that is refined as the patient’s condition changes. There is excellent evidence that pharmacologic therapy, device implantation and lifestyle changes can have significant impacts on the morbidity and mortality and improve the quality of life for this patient population.

Please refer to Appendix C for further information regarding evidence-based HF treatment strategies.

There is also evidence that effective management of HF can result in significantly reduced utilization of scarce health care system resources (e.g., fewer hospitalizations). An organized approach to managing these patients across the province can lead to better patient outcomes and to more appropriate utilization of health care resources.

4.3 Focus on Self-care

Self-care is defined as “the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition” (Newman et al., 2004). Interventions that promote the development and adoption of self-care skills, such as pre-discharge education, standardized evidence-based education materials, and transitional care programs for HF patients, have been shown to reduce the risk of rehospitalisation and associated costs (Casley and Grantham, 2011; Gwadry-Sridhar et al., 2004; Naylor et al., 2004). Consideration of patient needs, concerns, and other comorbidities (e.g. cognitive impairment) is essential in tailoring optimal self-care strategies (McCausley, Bixby, and Naylor, 2006; Riegel et al., 2011).

HF management requires multiple strategies and older HF patients often require a caregiver to assist them to effectively manage their condition. Furthermore, some degree of cognitive impairment is quite common in the HF population and needs to be taken into consideration when management recommendations are provided to these patients.
4.4 Focus on Advance Care Planning

Given the high mortality and unpredictable course of HF, the Canadian Cardiovascular Strategy (CCS) HF guidelines recommend “that clinicians looking after patients with HF should initiate and facilitate regular discussions with patients and family regarding advance care planning” (McKelvie et al., 2011). Early identification and ongoing involvement of a substitute decision-maker is also highly desirable (McKelvie et al., 2011). The CCS guidelines further emphasize that optimal palliative care implies the control of patient symptoms throughout the entire course of HF regardless of prognosis, and that this care “should be based on a thorough assessment of needs and symptoms, rather than on an individual estimate of remaining life expectancy” (McKelvie et al., 2011). Implementation of these recommendations can be facilitated by standardized assessment of HF patients and closer integration with palliative care services in the community.

4.5 Primary Care and Interprofessional Collaboration

The role of the PCP is to diagnose HF and, once diagnosed, to treat the condition. Treatment should involve patient self-care education and support, medical management of the HF, concurrent management of any co-morbid conditions, monitoring of the patient’s condition, and referral to a HF specialist if needed.

Ideally, the PCP should provide care within the context of a medical home with the support of an interdisciplinary team that may include nurses, social workers, dieticians, and pharmacists. The College of Family Physicians of Canada (2011) defines The Patient’s Medical Home (PMH) as a “hub for the timely provision and coordination of a comprehensive menu of health and medical services patients need”. The PMH is a home base for the continuous interaction between patients and their personal PCPs who network with a multidisciplinary team to provide and coordinate a comprehensive range of medical and health services required by the patient.

Patients present with variable degrees of complexity, which necessitates the need for stratification according to their individual risk of a poor outcome. The intensity of interventions is then tailored accordingly. Depending on the severity of the disease, care may be provided by a cardiologist, general internist, or PCP with training in HF management. Given the limited availability of specialist resources, capacity should be built within primary care to utilize interprofessional resources more effectively and efficiently. In particular, the availability of nurses specifically trained in HF care may enhance the ability of the PCP to manage HF patients (Mavaddat and Mant, 2010).

Collaborative care between specialists and PCPs can improve quality and outcomes of care for patients and their caregivers. For example many HF patients may also have geriatric syndromes and/or frailty; thus, collaborative care with geriatrics may also improve outcomes. Activating access to palliative care specialists to plan for end-of-life care ensures patients have access to critical resources and family supports during this time.

4.6 Specialist Support

Though specialists are generally not in a position to assume all of the characteristics of primary care service, their support and expertise is essential to the care of complex and frail seniors, including the provision of many services (Okie, 2012; Starfield, 2011; Starfield, 2010; Starfield, 2009; Brand et al., 2007; Coleman et al, 2006; Rothman and Wagner, 2003), including:

- Direct, integrated and coordinated and proactive consultation and co-management;
- Capacity-building and clinical skills development, with dual emphasis on HF and geriatric medicine skills;
- Development and refinement of protocols, guidelines and other decision-support tools;
- Leadership and advocacy for system redesign;
- Quality improvement; and
- Leadership to promote a system of care that ensures the delivery of effective interventions to all patients within defined populations who need them. All Ontario residents with HF must have access to optimal HF care.

The relative paucity of specialists (Ross et al., 2006b) in HF and geriatric medicine (Hogan et al., 2012) is exacerbated by the expansive geography of Ontario, many areas of which have limited access to these specialists. Though conclusive evidence on the effectiveness of telemedicine is lacking (Gurné et al., 2012; Anker et al., 2011), use of this technology in the provision of integrated HF care should be considered and carefully evaluated further.

4.7 Intermediate-level Care

A possible approach to coordinating primary and specialty care is a stepped-care framework in which an intermediate level of care is established as shown in Table 5 (Brand et al., 2007). Under this framework, rooted in the CDEP program and based in primary care, the bulk of care to stable HF patients is provided by primary care. Patients experiencing clinical instability are referred to an intermediate level of care, which can be supervised by a local PCP or specialist with recognized expertise in HF, and supported by an appropriately trained nurse and interprofessional resources (Brand et al., 2007). Patients who stabilize can be referred back to the PCP, whereas those requiring more intensive care can be referred to a tertiary level of care with specialized expertise in the management of highly complex HF patients.
Implicit in this framework is a need for agreed-upon criteria for referral and risk stratification, and a role for more specialized levels not only related to direct patient care but which also includes capacity building and mentorship. Care process redesign is clearly required to implement this framework, as well as a more collaborative and interprofessional ethos on behalf of physicians, appropriate remuneration methods, and mechanisms for seamless and efficient transitions and information sharing between each level (Brand, 2007; Scott, 2008). Evaluation of a similarly structured program of care for primary care-based memory clinics has shown a high quality of care, enhanced knowledge about cognitive disorders at all levels of care, and more efficient utilization of and access to specialists (Lee & Heckman, 2012; Lee et al., 2004a).

Table 5: Heart Failure Patient Stratification

<table>
<thead>
<tr>
<th>Level of Care</th>
<th>Patient status</th>
<th>Care provision</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Low complexity NYHA I-II</td>
<td>Optimal prescription of pharmacological and non-pharmacological therapy, patient and caregiver self-care education and support.</td>
</tr>
<tr>
<td>2</td>
<td>Intermediate complexity NYHA II-III Unable to stabilize at Level 1</td>
<td>Consultation by Level 2 HF team. Patient stabilization, review of therapies and recommendations for changes. Discharge back to Level 1 when stable.</td>
</tr>
<tr>
<td>3</td>
<td>High complexity NYHA III-IV Unable to stabilize at Level 2</td>
<td>Consultation with and involvement of Level 3 specialized HF team until patient stabilizes sufficiently for transfer to Level 2 care.</td>
</tr>
</tbody>
</table>

Source: Adapted from Brand et al., 2007 NYHA- New York Heart Association Classification

4.8 Transitional care

Transitional care programs are time-limited interventions designed to facilitate safe and timely transfers of high-risk patients from one level of care to another (Naylor et al., 2013; Cawley and Grantham, 2011; Coleman et al., 2006; Cunliffe et al., 2004; McCauley et al., 2006; Miller et al., 2005; Naylor et al., 2004).

Key transitional program components include:

- Standardized and comprehensive assessment;
- Development of an evidence-based care plan focused on patient and caregiver self-care and medication reconciliation;
- Promotion of client and caregiver self-care and system navigation capacity;
- Care initiated in hospital and potentially extending up to several months beyond discharge, with frequent home visits and telephone contact; and
- Care delivery by an advance practice nurse working with the PCP.

Transitional care programs have been evaluated in several settings and populations, including older patients with HF. These programs have been shown to reduce healthcare costs, complications, errors, length of stay, and readmissions. An increase in length of time between hospital discharge and readmission, as well as improved patient access to available community resources and services are also achieved with these programs. Moreover, communication between patients and physicians improved as well as quality of life, functional status, overall health status, and satisfaction with care for seniors (Naylor et al., 2013; Stauffer et al., 2011; Voss et al., 2011; Inglis et al., 2010; Coleman et al., 2006; McCauley et al., 2006; Cunliffe et al., 2004; Naylor et al., 2004).

4.9 Wait Time Benchmarks

Provincial wait time benchmarks have been established and are monitored for access to diagnostic and advanced cardiovascular procedures. Despite the demonstrated benefits of early outpatient assessment for patients with HF, there appears to be substantial disparity in access to HF clinics, and specialists across the province. For patients who are referred to HF clinics and specialists, wait times are not transparent. The CCS has published recommended benchmarks for specialist consults (Knudtson et al., 2006) and HF (Ross et al., 2006b) as shown in Table 6. However, there is no standardized process for measurement of these access targets.

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5 The NYHA Classification is used to describe the extent of physical activity limitations due to HF symptoms. Class IV has the most severe limitations.
Table 6: Wait Time Benchmarks for Evaluation of Heart Failure Patients by a Health Care Provider

<table>
<thead>
<tr>
<th>Triage category</th>
<th>Access target</th>
<th>Clinical scenarios</th>
<th>Health Care Provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emergent (very high risk)</td>
<td>&lt; 24 hours</td>
<td>Acute severe myocarditis</td>
<td>HF Specialist, Cardiologist</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cardiogenic shock</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Transplant evaluation – acutely unstable patient</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>First episode of acute pulmonary edema</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Acute cardiac valvular regurgitation</td>
<td></td>
</tr>
<tr>
<td>Urgent (high risk)</td>
<td>&lt; 2 weeks</td>
<td>Progressive HF</td>
<td>HF Specialist, Disease Management Program, Cardiologist</td>
</tr>
<tr>
<td></td>
<td></td>
<td>New diagnosis of HF – unstable, decompensated</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Post myocardial HF</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>New progression to AHA/ACC Stage D</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Post hospitalization discharge HF</td>
<td></td>
</tr>
<tr>
<td>Semiurgent</td>
<td>&lt; 4 weeks</td>
<td>AHA/ACC Stage C</td>
<td>HF Specialist, Disease Management Program, Cardiologist</td>
</tr>
<tr>
<td></td>
<td></td>
<td>New diagnosis of HF – stable, compensated</td>
<td></td>
</tr>
<tr>
<td>Scheduled</td>
<td>&lt; 6 weeks</td>
<td>Chronic HF management</td>
<td>PCP, internist, Disease Management Program or HF Specialist</td>
</tr>
<tr>
<td></td>
<td>&lt; 12 weeks</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: Ross et al., 2006b

4.10 Measurement of Readmission Rates

Hospital readmissions are monitored because they are believed to be a reliable measure of the system’s ability to provide appropriate care, as well as of patient symptom burden. For example, a high readmission rate could mean that one or more of the following situations occurred:

- The patient was discharged too early;
- The patient was discharged without adequate home supports or education about living safely in the home (e.g., what danger signs to look for, where and when to call for help, when to resume normal activities, what side effects to watch for from their medication); or
- The patient was not adequately monitored while living at home, and the condition worsened without timely medical intervention.

These findings highlight both the need to improve HF management in the community to reduce the HF admission rates, as well as for a patient-centered approach to manage comorbidities that can also lead to hospital admissions in these patients. It is important to note that in certain situations admissions or even readmissions can be appropriate care for HF patients, particularly if it contributes to decreased Length of Stay (LOS) and better patient outcomes.
5 Current State of Heart Failure Management in Ontario

5.1 Primary Care Providers

PCPs should play a key role in diagnosing and managing HF. Primary care delivery in the province of Ontario is undergoing an important transition. Presently several different models for primary care exist, varying by funding model and number and type of care providers. Community Health Centres (CHCs), Family Health Teams (FHTs), and Family Health Groups (FHGs), just to name a few, are growing rapidly, with nearly 9 million Ontarians rostered within one of these primary care models (Glazier et al., 2012). These primary care organizations have the potential to give HF patients more timely and coordinated access to an interdisciplinary approach to the management of chronic diseases, including HF.

About 3 million patients remain registered with small and solo practitioners who often do not have the capacity or resources to serve the complex needs of HF patients and despite improvements in access to primary care, it is estimated that nearly 1 million Ontarians still do not have a PCP. Without a PCP to diagnose, manage and monitor their condition, these patients have limited access to care, and have to rely on walk-in clinics, ED visits or a hospital admission for care. Some patients with complex conditions encounter barriers to finding a PCP, if practitioners feel they do not have the skills or resources to manage these patients, or practice risk selection due to financial disincentives when capitation payments do not adequately account for the patient’s clinical needs and complexity.

Access to primary care varies widely across the province; the LHIN a patient lives in, and whether they live in a rural or urban setting affects the quality and quantity of primary care available. This lack of access can make it very challenging for patients with HF to access specialized services (e.g., HF clinic or end-of-life care) and to receive the ongoing preventative care they require avoiding exacerbations and maintaining optimal quality of life.

The recent introduction of Health Links has the potential to support and improve the care of complex HF patients in the community. Health Links makes primary care a central tenet of the health care system and will encourage greater collaboration between local HCP (including family care practitioners and specialists), hospitals, long-term care, home care, and other community supports (MOHLTC, 2012).

5.2 In-home Supports

HF patients often require and benefit from home care services. Community Care Access Centres (CCACs) connect people with the health and support services they need to help them stay in their homes as long as possible, prevent hospital admission, transition safely home from hospital, and explore long-term care options. CCACs provide care coordination, in-home multidisciplinary clinical care, information, referral and system navigation services, and connect patients to primary care services through the Health Care Connect Program. CCACs collaborate with hospitals, physicians and a wide range of community partners to provide care for specific patient populations including those with HF.

CCACs support HF patients to remain at home, in conjunction with primary and secondary care providers who direct the patient’s clinical care. Home care services for HF patients include:

- Clinical support such as nursing assessment;
- Ongoing supportive care such as rehabilitation and personal care services; and
- End-of-life supportive care when required.

In 2011/12, CCACs supported 637,000 patients in Ontario. Of those, 24,000 had a diagnosis of HF, 94% of whom were 65 years of age or older. A recent Ontario-based cross-sectional study of home care clients with HF illustrates the complexity of aging HF patients, their frailty, and vulnerability to poor outcomes (Foebel et al., 2011).

Patients can self-refer for home care services or be referred by physicians, hospitals, family, friends, or community members. Care coordinators assess patients using the standardized Resident Assessment Instrument (interRAI) and responses on the Home Care (RAI-HC) tool to develop the patient’s home care plan. The RAI-HC focuses on the person’s functioning and quality of life by assessing needs, strengths, and preferences, and facilitates referrals when appropriate. When used over time, it provides the basis for an outcome-based assessment of the person’s response to care or services. (Please see Appendix D for a further description of the interRAI).

Care coordinators provide ongoing clinical coordination based on patient need. The sharing of the RAI-HC information in a usable format with other care providers would facilitate greater care coordination of older patients with HF, though at present, this is not uniform practice across the CCACs in the province. In-home clinical services for HF patients are directed and provided by contracted service providers. Home care services can include nursing, physical, speech and occupational therapy, dietetics and personal support services.
While there may be consistency of service delivery within any one CCAC, there is variation in the level of home care support for HF patients between CCACs. Some CCACs have developed relationships with hospital HF programs to deliver clinical care, consistent patient education and CDPM tools; others have developed specific programs such as Tele Home Monitoring that provide monitoring, support, and intervention to maintain HF patients at home. Some CCACs are developing tools such as care pathways with a focus on improved self-care and provide self-management support. A recent survey of CCAC practices revealed:

- About one-half of CCACs provide in home administration of intravenous diuretics for patients with fluid overload and worsening HF symptoms;
- CCACs are working with health care partners to support local innovations in the care of HF patients (e.g., Telehomecare, Virtual Ward);
- CCACs work with Regional Cardiac Centres and other partners to develop consistent patient education and CDPM tools to support HF patients; and
- CCACs are engaged in research initiatives to improve clinical care for HF patients.

Recognizing the opportunity to improve consistency of care, CCACs are working hard to develop care standards across the province. A recent example is the implementation of a Rapid Response Nurse Program to support patient transition from hospital to home. Improving care at this transition point aims to reduce hospital readmission for at-risk patients. The first target population for this initiative is patients with a diagnosis of HF. As part of this initiative, the Rapid Response Nurses receive education about HF. In 2013, to support this initiative, the Ontario Association of Community Care Access Centres (OACCAC) is developing consistent outcome-based pathways for HF patients.

### 5.5 Heart Failure Specialists

In Ontario, there are large differences in access and use of specialty care by physicians across the province. In the Ontario population of patients aged 45 and older who were newly diagnosed with HF in 2005/06 (n=33,006), less than half (47%) had seen a cardiologist at least once within a year of being identified as having HF (Bierman et al., 2009). An additional 24% had seen an internist or geriatrician during the course of the year and 25% were under the sole care of a PCP (Bierman et al., 2009). Access to subspecialty HF care is even more limited because such care is located primarily in tertiary or quaternary care referral centres (Lee et al., 2004b). Women, older Ontarians, those with low incomes, or those who lived in rural areas were less likely to have seen a cardiologist (Bierman et al., 2009).

Referral systems are particularly important during the transition from hospital to home because this is a vulnerable period when potentially serious events may occur. An examination of HF patients discharged from the ED in Ontario found that nearly one in five patients was not evaluated by a cardiologist or their PCP within 30 days of discharge (Lee et al., 2010). The best outcomes were observed in patients who received shared care by a cardiologist and their PCP within 30 days of discharge.

### 5.4 Heart Failure Clinics

The Toronto Health Economics and Technology Assessment (THETA) Collaborative recently conducted a field evaluation of HF clinics (Wijeysundera et al., 2013; Wijeysundera et al., 2010). For the purpose of this evaluation, a HF clinic was defined as “a clinic that consists at a minimum of a physician (family physician, internist, or cardiologist) and a nurse, one of whom has specialized training and/or interest in HF.”

The evaluation identified 34 HF clinics in Ontario, with clinics in all but two LHINs (Central West and Erie St. Clair). The organization, size and scope of the clinics varied significantly:

- Staffing models varied across clinics, with from one to eight physicians and one to three nurses; some also included dietitians, pharmacists, physiotherapists and counselors;
- Eighty-seven percent had an affiliation with a cardiac rehabilitation program, and 65% were actively involved in management of another chronic disease (e.g., diabetes mellitus);
- All were ambulatory clinics, with 81% located in a hospital setting, and 26% were part of an academic institution;
- The number of new consults each year ranged from 25 to 128.

With no dedicated funding from the MOHLTC for HF clinics in Ontario, the operating budgets for these clinics must be carved out of other funding areas. It is important to note that in the context of their field study, the THETA researchers were not able to identify the complete denominator of HF resources across Ontario. In addition, no single standard model of HF care exists in Ontario, with significant heterogeneity in terms of staffing, resources, funding and infrastructure. There is also no formal mechanism to integrate and coordinate care provided by HF clinics with primary care.

When the study was published, only 10% of HF patients were seen at specialized HF clinics following discharge for a HF hospitalization, and while newer data are not readily available it is known that there is still insufficient access to HF clinics across the province, with substantial variation between LHINs.

While PCPs could refer patients to these HF clinics, it is likely that the majority of patients are referred by cardiovascular specialists and that knowledge of such resources may be variable among PCPs. In addition, HF clinics do not have uniform criteria for acceptance of new patients. The absence of detailed wait time data from the time of initial diagnosis to referral for consultation by specialists or HF subspecialists means that firm conclusions about wait times for HF cannot be drawn. However, informal surveying of HF clinics would suggest the wait time for consultation by the HF clinic could be approximately six to eight weeks; this is clearly longer than what has previously been recommended (Ross et al., 2006b).

At centres where there is anticipated to be a long waiting time to be seen at a HF clinic, transitional care clinics that can perform an initial post discharge assessment within seven days may be beneficial. This does not presently occur and is a gap in the system that needs to be closed.
5.5 Long-term Care
The prevalence of HF in long-term care (LTC) facilities is approximately 20% (Daamen et al., 2010). One-year mortality from HF in LTC exceeds 50% (Foebel et al., 2013; Boxer et al., 2012; CIHI 2009; van Dijk et al., 2005; Allen et al., 2011; Wang et al., 1998). HF accounts for a significant proportion of transfers of LTC residents to acute care, where one in seven will die, and the average survival of those sent back to LTC is measured in months (Foebel et al., 2013; Boxer et al., 2012; CIHI, 2009; Heckman et al., 2004; Wang et al., 1998). Almost one-third of HF hospitalizations from LTC are readmissions (Jacobs, 2011).

A recent population-based study in Ontario LTC homes showed that HF accounted for 16% of ED visits over a six-month period (Gruneir et al., 2010). The impact of ED visits by LTC residents is substantial and includes costly ambulance transport and long waits for impatient beds (CIHI, 2009). Over 90% of hospitalized LTC residents are admitted through the ED, with average hospital stays of 6 days that are complicated by delirium and functional decline (CIHI, 2009; Inouye et al., 2007; Creditor, 1993). Some residents face delays of up to 10 days before returning to their LTC home (CIHI, 2009). It has been suggested that many acute care visits could be prevented if appropriate HF care processes were in place in LTC (Gruneir et al., 2010; Rizza et al., 2007; Finn et al., 2006; Coburn et al., 2002; Bowman et al., 2001; Finucane et al., 2000).

There is concern that residents in LTC facilities are less likely than patients in the community to receive recommended therapies and care for HF may be suboptimal (Newhouse et al., 2012; Zingmond et al., 2009; Heckman et al., 2004). Concerns have been expressed regarding multiple comorbidities, adverse drug reactions, generalizability and relevance of trials and diagnostic uncertainty (Hancock et al., 2013; Heckman et al., 2004; Fuat et al., 2003). Recent data from Ontario LTC homes suggest that the use of antipsychotics and antidepressants are associated with poorer outcomes among residents with HF (Foebel et al., 2013). Importantly an autopsy study found that 30% of deaths from HF had been misdiagnosed (Gross et al., 1998). Improved HF care in LTC settings may reduce the need for acute care hospitalizations in these patients. In addition, many LTC patients have multiple comorbidities and/or geriatric syndromes such as dementia and frailty. Attention to end of life planning is an important component of care for these patients. To date, no sustainable HF management programs have been developed for the Ontario LTC sector.

5.6 End-of-Life Care
HF patients may experience many symptoms that can affect quality of life, including fatigue, pain, breathlessness, anxiety, nausea, confusion and depression. Not all of these symptoms are necessarily recognized by HCP as a symptom of HF, and are either not treated or not treated sufficiently. Indeed, one study (Gibbs et al., 2002) has estimated that approximately 4% of HF patients receive palliative care. Unlike end-of-life in cancer patients, which represents a more readily defined phase of illness, the end-of-life phase in HF patients is far more difficult to predict (Goodlin, 2009). As a result, PCPs may be reluctant to refer patients for palliative care or to a hospice. Consequently, end-of-life planning and care should be incorporated into ongoing CDM as early as possible. In addition, PCPs may benefit from training in discussing end-of-life issues.

In 2008, the Heart and Stroke Foundation of Ontario (HSFO) (HSFO, 2010) conducted informal interviews with health care providers and found that:

- There is no cohesive strategy for the care of end-stage HF patients;
- Communication between outpatient clinics, specialists and inpatient units tends to be suboptimal; and
- Few outpatient clinics or inpatient units have any linkages with palliative care programs.

5.7 Emergency Visits and Acute Admissions
The current organization of HF management in Ontario results in high rates of potentially avoidable ED visits and hospital readmissions. Lack of access to PCP, specialists, and HF clinics leave patients no other option but to access the ED. Collaboration between HCP and improved access to resources, including preventative care and end-of-life care would result in a reduction of unnecessary ED visits and acute admissions to hospital for HF related causes.

Data from 2005/06 indicate that HF was the cause of 1.9% of all hospitalizations in Canada and was listed as a comorbidity or primary diagnosis in 4.9% of hospitalizations (Dai et al., 2012). Despite the slight downward trend in crude rates of HF, hospitalizations from HF continue to rise (Figure 5). HF patients account for over 20,000 hospitalizations each year in Ontario, and HF remains the leading cause of hospitalization for the elderly in Canada (Dai et al., 2012). With the growth of the aging population these numbers are expected to rise dramatically over the next two decades (McNallan et al., 2013; Johansen et al., 2003).

Figure 5: Crude Rates of Heart Failure and Hospitalizations, Ontario, 2006-2011

In 2011, the Heart and Stroke Foundation of Canada (HSFC) (HSFC, 2011) conducted a population-based study in Ontario LTC homes to understand the reasons for hospitalizations and assess the potential impact of a sustainable HF management program. The study found that nearly 50% of hospitalizations were avoidable, with high rates of potentially avoidable ED visits and hospital readmissions. This highlights the importance of improving HF management in LTC facilities to reduce unnecessary hospitalizations and improve patient outcomes.
In 2011, there were 20,285 HF hospital admissions in Ontario, and these rates varied significantly across LHINs. The Project for an Ontario Women’s Health Evidence-based Report (POWER) Study (Bierman et al., 2009) reported that the age-standardized HF hospitalization rates in 2006-07 were 217 per 100,000 adults. The overwhelming majority of HF hospitalizations were among adults aged 65 and older, with the highest rates of admission occurring among those aged 80 and older (Bierman et al., 2009).

In addition to having a high number of admissions, HF patients also stay in hospital longer than average. The LOS for HF patients in 2005/06 was approximately 12 days, nearly double the LOS for all other causes (Dai et al., 2012). It has been estimated that hospitalizations account for 70% of the costs associated with management of HF patients (McMurray, 2010). Recent data from Ontario show that cardiac patients as a whole contributed to 42,000 ALC days of which HF patients contributed to nearly half in Ontario in 2011 (see Table 7). Patients with HF account for 29% of the acute LOS days and 49% of the ALC days reported for these cardiac patient groups.

Table 7: Acute and ALC Length of Stay for Select Cardiac Groups, Ontario, 2011

<table>
<thead>
<tr>
<th></th>
<th>Acute LOS</th>
<th>ALC LOS</th>
<th>Total LOS</th>
<th>% of ALC LOS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart failure</td>
<td>159,713</td>
<td>20,504</td>
<td>180,217</td>
<td>46.8%</td>
</tr>
<tr>
<td>Acute myocardial infarction</td>
<td>118,032</td>
<td>9,078</td>
<td>127,110</td>
<td>21.6%</td>
</tr>
<tr>
<td>Arrhythmias</td>
<td>78,080</td>
<td>5,575</td>
<td>83,655</td>
<td>13.3%</td>
</tr>
<tr>
<td>Other forms of heart disease</td>
<td>31,247</td>
<td>2,003</td>
<td>33,250</td>
<td>4.8%</td>
</tr>
<tr>
<td>Chronic ischemic heart disease</td>
<td>82,408</td>
<td>1,927</td>
<td>84,335</td>
<td>4.6%</td>
</tr>
<tr>
<td>Valve disease</td>
<td>34,734</td>
<td>1,226</td>
<td>35,960</td>
<td>2.9%</td>
</tr>
<tr>
<td>Other acute ischemic heart disease</td>
<td>10,581</td>
<td>791</td>
<td>11,372</td>
<td>1.9%</td>
</tr>
<tr>
<td>Angina</td>
<td>24,626</td>
<td>650</td>
<td>25,276</td>
<td>1.5%</td>
</tr>
<tr>
<td>Rheumatic heart disease</td>
<td>8,659</td>
<td>271</td>
<td>8,930</td>
<td>0.6%</td>
</tr>
<tr>
<td></td>
<td>548,080</td>
<td>42,025</td>
<td>590,105</td>
<td>100%</td>
</tr>
</tbody>
</table>

ALC = Alternative Level of Care; LOS = Length of Stay (days)  
Data Source: Discharge Abstract Database, IntelliHEALTH Ontario, 2011

HF patients are medically complex, typically with multiple co-morbidities and therefore the optimal medical management of these patients is intricate, and the system level management of these cases is complex. HCP must ensure services are coordinated to provide the right care, at the right place, at the right time.

An analysis of the disposition of HF patients post-discharge indicates the coordination of care for this vulnerable population is less than optimal. In Ontario between 2011 and 2012, there were 36,307 hospital discharges for adults ≥ 65 years of age and 26,348 (72%) of these discharges were back to the community (Discharge Abstract Database, Ontario 2012). From this cohort, only 29% received home care services (Table 8). Even in the eldest subgroup (age 85+ years), only 36% received home care support at hospital discharge. Although further analysis is needed to establish best practices for HF discharge planning, these high percentages for discharge with no home care supports for the elderly conflict with established medical opinion and the proven link between coordinated discharge planning and better outcomes for patients.

Table 8: Referral to home care services for people 65 years and older discharged to the community following hospital admission with heart failure in Ontario, 2011 and 2012

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>65-74 n (%)</th>
<th>75-84 n (%)</th>
<th>85+ n (%)</th>
<th>Total n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No support services</td>
<td>5,166 (77%)</td>
<td>7,205 (66%)</td>
<td>4,512 (51%)</td>
<td>16,883 (64%)</td>
</tr>
<tr>
<td>Home care services</td>
<td>1,385 (21%)</td>
<td>3,099 (29%)</td>
<td>3,170 (36%)</td>
<td>7,654 (29%)</td>
</tr>
<tr>
<td>Assisted living complex</td>
<td>135 (2%)</td>
<td>553 (5%)</td>
<td>1,123 (13%)</td>
<td>1,811 (7%)</td>
</tr>
<tr>
<td>Total hospital discharges to the community</td>
<td>6,686 (100%)</td>
<td>10,857 (100%)</td>
<td>8,805 (100%)</td>
<td>26,348 (100%)</td>
</tr>
</tbody>
</table>

Data Source: Discharge Abstract Database, IntelliHEALTH Ontario, 2012

The POWER Study found high potentially avoidable rates of ED visits and hospital readmissions after a HF hospitalization (Bierman et al., 2009). Within 30 days of discharge, 30% of patients hospitalized for HF visited ED and 20% were readmitted to hospital. Within one year, 75% had visited an ED and 59% had been readmitted. About one third of all hospital readmissions within 30 days and within one year were for non-CVD related causes. Implementation of effective CDPM Programs integrated across settings of care could reduce unnecessary ED use and hospital admissions, relieving the burden on hospitals and contributing to health system sustainability (Heckman et al., 2007; Bierman et al., 2009).
**6 Challenges with the Current Management of Heart Failure**

While there are discrete pockets of innovation across the province in which HF care is being delivered effectively, on the whole, the system of HF care in the province of Ontario is unstructured, fragmented, and variable. (Please refer to Appendix E for a summary of some of these innovations). With no cohesive provincial approach to the management of this complex syndrome, patients often fall through the cracks during transitions between care providers, leading to suboptimal care and resulting in potentially avoidable ED use and hospitalizations, and diminished quality of life. There are many gaps within the system related to quality of care, accessibility, communication, and timeliness of care. Although there are a number of published guidelines that comprehensively outline the best evidence-based care for HF patients, they do not take into consideration the challenges involved when implementing best practice. These challenges need to be identified and addressed before there can be any realistic expectation of implementing best practices throughout Ontario.

### 6.1 Complex Course of Heart Failure

The trajectory of HF is complex and unpredictable, and varies widely between patients (Goodlin, 2009). Often, patients will experience a cycle of crises and recoveries over a prolonged period of time. As seen in Figure 6, this cycle of clinical instability, acute events and hospitalizations can be repeated many times before the end of life. Ultimately, between 30% and 40% of patients suddenly and unexpectedly die from a cardiac arrest (HSFO, 2010). The prognostic uncertainty for patients with HF adds an additional layer of challenge in providing optimal care to this patient population. An ideal HF system for Ontario must ensure that quality care is delivered throughout all phases of the HF cycle.

Figure 6: Heart Failure Trajectory

- **Phase ➀** - Initial symptoms of HF develop and HF treatment is initiated
- **Phase ➁** - Plateau of variable length reached with initial medical management, or following mechanical support or heart transplant
- **Phase ➂** - Functional status declines with variable slope; intermittent exacerbations of HF that respond to rescue efforts
- **Phase ➃** - Stage D HF, with refractory symptoms and limited function
- **Phase ➄** - End of life

Dotted lines represent sudden cardiac death that can occur anytime during the trajectory.

Source: Goodlin, 2009

### 6.2 Knowledge Gaps Among Health Care Providers

A recent report prepared for the Waterloo Wellington LHIN identified that the limited opportunities for training in geriatrics has led to a deficit in the basic knowledge needed for the care of seniors across all health care sectors. As well, the management, review, and reconciliation of medications are not always well managed in primary care settings (Heckman et al., 2011). Although the report does not speak specifically to the management of HF patients, the CCN-HFWG felt that these comments applied equally to the management of HF in Ontario.

Successful HF management in primary care requires that HCPs receive appropriate training (Agvall et al., 2012; Jaarsma et al., 2012; Rosland et al., 2011; Persson et al., 2010). A curriculum for HF should be comprehensive and multifactorial (Peters-Klimm et al., 2012; Fuat et al., 2003), and should address the following areas of concern:
Clinical skills: Accurate diagnosis of HF in primary care is difficult, particularly in the setting of mild symptoms, older patients with non-specific signs and symptoms, and concomitant chronic obstructive pulmonary disease (Olofsson et al., 2007; Rutten et al., 2005). Compounding these difficulties is the ongoing erosion of proficiency with clinical skills and lack of exposure to chronic disease management during medical training (Conn and O’Keefe, 2009). However, a limited number of clinically derived items from the history and physical examination and the use of validated diagnostic scoring systems can help PCPs diagnose HF more accurately (McKelvie et al., 2012; Olofsson et al., 2007; Rutten et al., 2005; Skarner et al., 2002; Wang et al., 1998). Familiarity with the atypical presentations of HF among frail seniors (e.g. delirium, functional decline, falls, and incontinence) is essential (Heckman et al., 2013; Arnold et al., 2006).

Procedural knowledge: Lack of certainty about clinical practice guidelines and concerns about prescribing specific therapies have been identified as barriers to HF management in primary care, particularly for older, frail and complex patients (Fuat, 2003). Provision of evidence-based education series and clinical decision support tools, particularly if delivered using clinical case scenarios, can improve HF management by PCPs (Agrall et al., 2012; Cacian et al., 2012; Crawley and Grantham, 2011; Persson, 2010). Leveraging Ontario-wide sources of reliable and validated data, such as the interRAI HC used by CCACs and the interRAI CHA used by Community Support Services, including PCP training to understand and effectively use this information and associated care protocols in managing frailty in older persons with HF, is essential (Hirdes, 2006).

6.3 Absence of Standard Tools and Resources
The current system of care relies on inconsistent series of tools and resources to diagnose, treat, and manage HF. A cursory scan of current providers reveals tremendous variation in the tools and guidelines that are being used within and across LHINs, undoubtedly contributing to variation in patient outcomes. When new research about best practices is released, providers must revise these tools and resources to ensure that their patients are receiving the latest in evidence-based treatments. Even worse, providers may be unaware of the changes or may lack the health human resources to revise their tools and resources, and will therefore continue to provide outdated management to patients, leading to suboptimal outcomes. While these tools and resources may appear sufficient to address local needs on a day-to-day basis, the lack of standardization across the health care sector perpetuates system fragmentation by creating barriers to information sharing leading to inefficiency and repetition of assessments.

6.4 Lack of Measurement
Quality measurement is essential to guide, monitor, and assess the effectiveness of interventions aimed at improving HF care. In 2003, the Canadian Cardiovascular Outcomes Research Team and the Canadian Cardiovascular Society (CCS) co-released quality indicators for HF care in 2003, with an updated release by the CCS in September 2013 (CCS, 2013). Since that time, HQO and the MOHLTC have suggested key performance and outcome indicators for HF. There is agreement on what should be measured and consensus on the value of measurement, but still there is no comprehensive system in place to measure wait times for access to specialized HF care, or to aggregate process and outcome indicators to determine how well HF care is being provided across the province of Ontario. Please see Appendix F for a list of other organizations that have developed quality indicators for health care delivery and Appendix G for a summary of the primary challenges for selecting quality indicators for the management of HF.

In acute care settings, administrative data used for quality indicators cannot distinguish between HF with low or preserved ejection fraction so assessment of performance is limited. Furthermore, data on counseling for risk factor modification, medication, adherence, or self-management skills is not collected routinely, drug data is not universally available for those under age 65, and so the quality of medication management cannot be assessed for those who may have the most difficulty accessing medications. HF is a chronic disease and most HF care is provided in ambulatory settings. However, data is not available to assess HF care in ambulatory care settings. Functional status and quality of life are important for HF patients and optimal management may improve these outcomes, but data is unavailable on control of symptoms related to the specific condition such as chest pain or shortness of breath (Bierman et al., 2009).

6.5 Lack of System Integration
The Canadian health care system is poorly integrated and ill-suited to address the needs of an aging population (Johri et al., 2003). Health care for Canadian seniors has been described as fragmented with negative incentives, lack of accountability, inappropriate and costly use of acute and long-term care resources, and significant gaps in services (Bergman, 1997). Challenges include multiple entry-points, service delivery influenced less by patient need and more by available services, piecemeal care planning, redundant assessments and limited use of standardized tools, inappropriate use of costly services, long wait times for services and inadequate transmission of information (Hebert et al., 2003). Studies have similarly illustrated the poor coordination of health, social and palliative services for patients with advanced chronic HF compared to those with cancer (Mavaddat and Mant, 2010). Various approaches to care integration have been developed to improve health services for older and complex patients, including programs to improve coordination between hospitals and home care, the provision of fully integrated services within one organizational structure, and others based within home care services (Suter et al., 2009; Williams et al., 2009; MacAdam, 2008; Vedel et al., 2008; Kodner, 2006; Ouwens et al., 2005). The most recent of these approaches is Health Links, a program created by the MOHLTC to improve access for the highest users of the healthcare system. Evaluative studies have demonstrated the feasibility of implementing integrated systems of health care, which have shown reductions in functional decline, caregiver burden, hospital admissions and ED visits, either without increasing costs and actually reducing them (MacAdam et al., 2008; Hebert et al., 2003; Jozi et al., 2003; Kane et al., 2002; Landi et al., 2001; MacAdam, 2000; Shannon and Van Reenen, 1998).
6.6 Summary of Challenges with Current Management of Heart Failure

Understanding the differences between how care is currently delivered and what is needed to optimize care for HF patients can help us develop and implement models of care that meet their needs and improve quality as well as efficiency of services. A summary of the current gaps in HF management are illustrated below in Figure 7.

**Figure 7: Summary of Challenges with Current Management of Heart Failure**

1. Variations in access to services across the province and lack of information sharing.
2. Only 4% of HF patients receive palliative care.
3. Small and solo practices may not have the capacity to meet needs of HF patients with complex needs.
4. Some HF patients do not have a primary care practitioner.
5. Wait times are not measured, but are believed to be unacceptably long.
6. Referral criteria are not consistent across the province.
7. Not funded by MOHLTC; models of care vary across the province.
8. High proportion of ED visits and readmissions within 30 days of discharge.
9. Three-month readmission rates range from 23% to 50%.
10. One in five patients not evaluated by a cardiologist or PCP within 30 days of discharge.
11. LTC residents high users of EDs and have suboptimal access to recommended therapies.

A Provincial Approach to Heart Failure Management

The ideal, patient centered system to manage HF must be firmly rooted in a primary care sector that is highly integrated with specialty services. This should include community-based teams of allied health professionals, including home care, and community supports for patients (including specialized geriatric services and palliative care), and well defined transition points for HF patients as they move through the system. Considerations for patients with unique needs, such as the frail elderly, those with multiple comorbidities, and end of life/palliation must be accounted for in the model of care. The ideal HF system should be based on a CDPM framework that fosters the development of self-care strategies and supports HF patients and care givers in an overall model of self-management.

A highly collaborative clinical practice model that enables access to differentiated levels of HF care is a critical component to ensure limited resources are effectively deployed, building capacity within primary care, with close links to specialty care and appropriate community supports. Evidence-based guidelines are available for the management of HF patients, and these should be observed by specialists as well as PCPs to reduce the variability associated with the clinical management of HF. Effective HF management requires multiple strategies including pharmacologic, lifestyle, and device therapy. In order to ensure that best practices are consistently deployed rendering the highest quality care for this fragile patient population, and to ensure appropriate utilization of health care resources, specific performance measurements must be embedded throughout the system in order to evaluate care.

7.1 Key Priority Areas

1. **Standardize** tools and resources for patients, caregivers, and clinicians
2. **Improve** organization of care
3. **Enable** measurement and improvement
7.2 Recommendations

These recommendations address gaps in the system and foster effective system level management of care, which includes planning for demographic change, improving the organization of care, ensuring access, and assessing the outcomes related to these modifications. The recommendations are organized into three key priority areas: 1) standardizing tools and resources for patients, caregivers, and clinicians; 2) improving organization of care; and 3) enabling measurement and improvement.

Table 9. Key CCN Priorities and Recommendations for HF Care in Ontario

<table>
<thead>
<tr>
<th>Key Priority Area</th>
<th>CCN Recommendation</th>
</tr>
</thead>
</table>
| Standardize Tools and Resources for Patients, Caregivers, and Clinicians | 1. General information on HF must be available to improve public awareness and knowledge of HF.  
2. Standardized tools for self-care management should be developed and implemented.  
3. Self-help groups should be established to support HF patients and caregivers.  
4. Standardized tools and resources for optimal management of HF patients must be made available to HF Clinicians across the province, in particular unique patient groups (e.g., frail elderly, and end of life) will require additional standard assessments and resources (e.g., system navigation, palliation) to support care and transition stages. |
| Improve Organization of Care | 5. Specialized HF training, education, and resources to support standard clinical skills and competency should be provided for all clinicians through a provincial community of practice/mentorship programs.  
6. Ontario HF risk stratification and referral tools must be adopted by providers in acute and community care settings to standardize care.  
7. HF patients should receive appropriate follow-up intensity based on their clinical stage of HF and identified needs.  
8. Inventory of HF resources by LHIN should be available, so that there is a clearly defined regional network of HF care, comprised of FCP and Specialists to facilitate direct, integrated, and coordinated consultation and co-management of HF patients.  
9. Multidisciplinary teams and supports (CCACs and palliative care) must be available by LHIN to support HF management strategies. |
| Enable Measurement and Improvement | 10. A system to monitor and report on HF related care processes and quality indicators should be incorporated into the existing Ontario Cardiac Registry. This will enable linkages with existing cardiac data related to revascularization and other procedures as well as cardiac device implants that many patients with HF will require. In addition, opportunities exist to enhance and upgrade current investments (e.g., primary care incentives). |

7.3 Standardize Tools and Resources for Patients, Caregivers, and Clinicians

The first component of the strategy involves the development of a comprehensive repository of evidence-based tools and resources available to patients, caregivers, clinicians, and the general public.

An online patient portal will facilitate access to patient level information and tools to support a self-management model of care. These resources will include informational videos, webinars, and self-care management tools. Resources will contain information about various aspects of HF, including best practices for living with the condition. Additional resources will include links to local resources.

According to the CDPM framework, patients, who are knowledgeable about their disease, treatments, and how to avoid complications, have generally a better sense of well-being, as well as better outcomes. The establishment of self-help groups will help to connect those patients currently living with HF who have been recently diagnosed with the condition. Patients successfully living with HF are a valuable resource, and can offer peer support to other patients.

Resources for HCPs will include referral forms, clinical care pathways, and decision-based algorithms that will assist providers in optimizing care based on risk stratification. These resources will be based on evidence and best practices, with attention to ensuring the documentation is regularly reviewed, and updated as required. Standardization of these tools will help to establish protocols to expedite transitions to community supports and specialized HF clinics. The established protocols will also outline a more streamlined approach to management of HF patients who can quickly deteriorate and require urgent care.

7.4 Improve Organization of Care

At any point in time, the majority of patients with HF are relatively stable. They can be monitored by provider teams with relatively low resource intensity. One of the key enabling factors in the delivery of effective chronic HF care is the availability of local HF clinics. This is best achieved through a multidisciplinary team setting, often physician-led, but implemented through knowledgeable nurses or allied health care worker(s) with specialized HF knowledge. This multidisciplinary team composition has been identified as one of the key components of success for a number of HF clinics (McAlister et al., 2004; Kasper et al., 2002; McDonald et al., 2002; Stewart & Horowitz, 2002). Nevertheless, Ontario is a large and heterogeneous province, and so it is important not to be overly prescriptive regarding location and staffing of the clinic — there is no “one-size-fits-all” model for a successful HF clinic, which should rather maximize leverage of local resources.
To deliver access to differentiated levels of HF care, province-wide identification of existing HF services and resources is the first step. Care providers will be classified as either “hubs” of HF expertise or as “spoke” providers who could benefit from capacity building and greater access to a provider with greater knowledge of managing this complex disease. It is also important to identify where formal and informal networks of care exist, and where there is a need to re-organize or augment services. This will help to enable patients to move fluidly between care providers, while also facilitating the creation of mentorship relationships between “hubs” and “spokes.” CCN will develop and map out a coordinated plan for the distribution and availability of differentiated providers of HF care in different geographic regions or LHINs. Given the resource constraints on our healthcare system and challenges with scarce health human resources, these “hubs” and “spokes” will vary across the province (See Figure 8 for a suggestion of how this model of care may look in a region in Ontario). For example, many FHT’s have Diabetes Management Programs, which include the services of a Registered Dietitian, Nurse or Nurse Practitioner, and a Pharmacist. With approximately 40% of HF patients also suffering from diabetes (Ahluwalia et al., 2011; Metra et al., 2011; MOHLTC, 2007), there is an opportunity to augment existing Diabetes Management Programs with HF tools and resources instead of starting completely from scratch.

The Hub and Spoke Model represents a continuum of care, whereby the patients move between the levels of care as guided by the level of HF complexity. When a patient experiences worsening symptoms, timely referral to a HF specialist (e.g. “hub”) for assessment and stabilization can help to avoid further deterioration requiring hospitalization. When patients become unstable however, the level of care required increases substantially. Patients with severe acute decompensation will require hospitalization, where a more dedicated team of HF experts will facilitate the timely introduction and titration of evidence-based therapy, and the appropriate investigations to address the underlying cause for acute decompensation. Timely and appropriate access to centres offering specialized diagnostics and therapeutic options is imperative.

Importantly, by providing a more integrated solution to care provision, the Hub and Spoke Model will help establish close working relationships among care providers currently operating in isolation, and thus foster opportunities for greater knowledge translation and exchange and capacity development.
Table 10: Heart Failure Patient Stratification

<table>
<thead>
<tr>
<th>Level of Care</th>
<th>Patient status</th>
<th>Care provision</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Low complexity: NYHA I-II</td>
<td>Optimal prescription of pharmacological and non-pharmacological therapy, patient and caregiver self-care education and support.</td>
</tr>
<tr>
<td>2</td>
<td>Intermediate complexity: NYHA II-III Unable to stabilize at Level 1</td>
<td>Consultation by Level 2 HF team. Patient stabilization, review of therapies and recommendations for changes. Discharge to Level 1 when stable.</td>
</tr>
<tr>
<td>3</td>
<td>High complexity: NYHA III-IV Unable to stabilize at Level 2</td>
<td>Consultation with and involvement of Level 3 specialized HF team until patient stabilizes sufficiently for transfer to Level 2 care.</td>
</tr>
</tbody>
</table>

Source: Adapted from Brand et al., 2007

Evidence has identified that timeliness of access to health providers is one of the key determinants of patient outcomes following discharge from hospital for HF. In the US, the American College of Cardiology has launched a campaign mandating patients with HF be seen within seven to 14 days following discharge. Although not all patients will require evaluation in a high intensity specialty HF clinic, it is important to have the ability to provide: 1) medication management including reconciliation, monitoring of side effects, and up-titrate HF medications as required; 2) patient assessment of fluid status; and 3) self-care education and support. The patient’s ongoing risk for adverse outcomes and disease complexity should guide the intensity of care provided.

The time of hospital discharge may represent an opportune time to ensure referral of patients to cardiovascular specialists or regional HF clinics if required. Patients could potentially be referred upon discharge from the ED or after an in-patient hospital stay. Hospitals or EDs with local availability to such providers may continue to use their normal referral channels, but institutions with limited access may benefit from an electronic referral system. Such referral systems could potentially provide the locations of nearby HF centres and anticipated wait times for a patient to be evaluated by a medical team.

At centres where there is anticipated to be a long waiting time to be seen at a HF clinic, transitional care clinics or programs that can perform an initial post-discharge assessment within seven days may be beneficial. There is a need for a standardized risk assessment tool for patients with HF to allocate the patient to an appropriate level of care within a pre-specified time interval. For example, a patient will need to be seen in an appropriate setting within 7-14 days following a hospital discharge for acute decompensated HF. In each community, it will be important to have the Health Links in place between the hospital and community to allow an effective transition of care. More importantly, the availability of local primary care HF management hubs will create opportunities to divert patients presenting with de novo HF and who are otherwise stable, thus circumventing the need to unnecessarily access the ED.

7.5 Enable Measurement and Improvement

Ideally, ongoing measurement can be achieved by the development of a province-wide HF registry that will be built on the existing infrastructure at CCN. This system will enable comprehensive data collection so patient access and outcomes can be measured; allow for the development of a provincial quality assurance program to define, monitor and report on performance metrics; and will facilitate the creation of a provincial coordinated triage system to link patients with appropriate providers within a recommended wait time.

HF is a chronic disease that is associated with significant morbidity and mortality. Ongoing management and monitoring of patients’ clinical outcomes will help to determine opportunities for improvement in the delivery of care. These indicators will include patient satisfaction and symptom stability, and system measures such as hospitalization, and ED visits.

It is important that patients with HF, particularly after an episode of deterioration or in the process of becoming clinically unstable, can be assessed and followed in a timely fashion by the appropriate team. The risk-based triage referral system coordinates and monitors system referrals to link patients with the most suitable provider. This would allow for the development of standardized HF care across the province. Additionally, formal lines of communication would enable a more remote community to link in with a higher level of care in a more reliable fashion. There should also be appropriate quality indicators developed for monitoring the timeliness and quality of access to appropriate care. With regards to the quality indicators it will be important to take into consideration whether the patient has HF with reduced ejection fraction or HF with preserved ejection fraction. This is because although these patients both have clinical HF, the management approach would be slightly different between a patient with HF reduced ejection fraction and one with HF preserved ejection fraction.
The strategy outlined above is the result of an extensive literature review and the efforts of a multisectoral and multidisciplinary group from across the province. The successful implementation of this strategy will require additional literature reviews, an in-depth evaluation of current practices, stakeholder engagement, buy-in from key players at all levels of health care administration and delivery, and a realistic actionable approach to changing and improving the system.

8.1 Preparing for change
This first phase will involve information gathering and will lay the foundation for stakeholder engagement in subsequent phases. Building on the findings of the CCN HF WG, CCN will develop an in-depth understanding of the current state of HF management in the province of Ontario.

To address the lack of integration of services, an inventory of the current state of HF providers in Ontario is underway at CCN. The ultimate goal is to ensure equal access to standardized HF care for patients as well as easy access to mentorship and HF expertise for care providers across the province. Building on the 34 HF clinics identified in the 2011 THETA Report (Wijeysundera et. al., 2011) the inventory will be a synthesis of HCPs identified through snowball sampling, professional associations, and the LHINs. These providers will subsequently receive electronic surveys and telephone interviews to validate and better understand current practice, the potential to take on additional patients, and possible opportunities to augment existing service delivery. Service providers will include PCPs with knowledge or expertise in HF, groups of providers (either FHTs or CHCs) with knowledge or expertise in HF, specialty HF clinics, specialists (including cardiologists, internists, geriatricians), and hospitals.

Developing a set of standardized tools and resources for clinicians, patients, and caregivers will require an extensive review of the literature, feedback from patients and caregivers, and surveying of current care providers to determine if any unique and innovative strategies are being utilized to provide optimal care to HF patients. These findings will be synthesized and presented to a subcommittee of the CCN-HFWG where it will be determined if any new tools or resources must be created. The final product will be a selection of evidence-based standardized tools and resources that will be made available to the general public, including patients, caregivers, and HF providers in the province of Ontario.

Many of these tools will be well known and widely accepted, such as the 2012 Canadian Cardiovascular Society Heart Failure Management Guidelines (McKelvie et al., 2013). However, recently developed tools will also be investigated, including the DIVERT Scale (Costa, 2013) which is currently being trialed in parts of Ontario. This risk profiling tool utilizes an algorithm that builds off existing data already collected by CCACs through the RAI HC. (Please refer to Appendix H for a description of DIVERT scale). The tool estimates the likelihood of unplanned ED use, from two weeks to six months after the initial home care assessment, among home care patients as a means of identifying the urgency with which patients must be seen after discharge. This enables care providers to utilize appropriate preventative interventions. The benefits of full implementation of the DIVERT scale across Ontario would be substantial and readily implementable via minor software changes to existing RAI HC implementations.

To support the need for measurement and quality improvement in the delivery of HF care, a subcommittee of the CCN HF WG has been established to assess key messages from existing HF literature and best practices that will serve as a platform for the creation of the Ontario Heart Failure Registry.

8.2 Implementing Change
The second phase will build on the information gathered in phase 1, and will result in the development of a Heart Failure Website to make tools and resources widely available, and the Ontario Heart Failure Registry to allow for the ongoing tracking and evaluation of the delivery of HF care in the province of Ontario.

1) The CCN Heart Failure Website will have three key areas: 1) Patient and caregiver tools and resources; 2) Provider tools and resources; and 3) a publication of existing HF resources. To raise awareness of HF and to increase the availability of evidence-based resources and self-management tools, CCN will create a “Patient and Caregiver Portal” that will empower patients and caregivers by providing them with patient level information and tools to support a self-management model of care. Patient and caregiver resources will contain informational videos and fact-sheets in a variety of languages, including resources related to advanced care planning. Interactive webinars will be held – which will allow patients in rural and remote communities to access peer support, which is integral to managing HF. The self-management tools will feature a journal7, where patients can log daily weights, keep a food record, document their mood, and keep track of upcoming appointments or interventions. At the patient’s request, this journal can be shared with multiple HCPs to enable monitoring of compliance with medication, adherence to diet plans, and tracking of health outcomes. Additional tools and resources will be added based on the findings from the environmental scan in phase 1.

A tool kit of standardized tools and resources will be made available on the CCN website through a “Heart Failure Provider Portal.” These resources include referral forms, clinical pathways, standard order sets, and decision-based algorithms that will assist providers in optimizing care based on risk stratification. These resources will be evidence based and focus on best practices.

Standardization of these tools using established protocols will expedite care and transitions to community supports and specialized HF clinics. The triage and risk stratification tools will permit clinicians to manage patients who deteriorate clinically and facilitate urgent referral and access pathways to higher levels of care. Additionally, the website will support providers with standardized surveys and questions that can be utilized to measure patient reports experiences and outcomes.

7 The journal will initially be available for patients to print and/or fill out online based on comfort with technology. An app supported on both iOS and Android platforms will subsequently be rolled out.
The CCN-HFWG will categorize HF providers based on resource intensity and complexity of services and will map clinics geographically by LHIN. This approach will enable the identification of gaps in services at both the geographic and provider/system level. This gap analysis will enable the CCN-HFWG to make recommendations at the LHIN level to augment regional/local resources. This will help to ensure the effective and efficient use of resources across the province as new providers are created and/or existing providers are restructured to take advantage of the full scope of practice of interprofessional care providers. This process will generate a comprehensive list of all “hubs” of information, expertise, and advanced diagnostics for “spoke” providers in the surrounding area. The locations and contact information of these “hubs” will be made available to patients and health care providers on the CCN website to help to facilitate access to coordinated HF care in the province.

2) The Ontario HF Registry will be created and incorporated into the existing cardiac registry managed by CCN.

Fundamental to the success of the HF Strategy is the ability to continuously monitor and report on quality indicators. CCN has experience working with cardiac service providers to standardize referral processes, as well as reporting on metrics of care relative to access and quality. In addition, CCN maintains the Ontario cardiac registry and is well positioned to include additional minimum data set/metrics relevant to HF care. A subcommittee of CCN-HFWG will work with the Information Technology team at CCN to undertake the creation of a data dictionary that will be integrated into the existing cardiac database at CCN.

8.3 Spreading and Sustaining Change

In many ways this phase has already begun. The CCN-HFWG has engaged with key stakeholders throughout the course of preparing the Ontario Heart Failure Strategy. The ultimate goal of this phase is the successful launch of the CCN Heart Failure Website and the Ontario Heart Failure Registry.

This phase will officially begin with the inaugural annual “Provincial Heart Failure Strategy Forum” (which will be held February 2014). This conference will bring together the HF community from across the province, and will foster new connections and relationships among providers. This will be an opportunity for CCN to share the Ontario HF Strategy with the entire HF community and to announce the impending launch of the Website and Registry. Attendees will have the option to be added to a distribution list that will provide updates on Website and Registry progress.

The registry will be rolled out in phases across the province, with CCN conducting Webinars to train end users on data entry. The success of the registry requires compliance with data entry by all care providers who manage patients with HF. This will in part be achieved by digitizing the HF management flow sheet and using that data to populate the registry. Presently, the flow sheet and related OHIP HF Management incentive are underutilized by primary care providers, and so there is an opportunity to increase compliance by enabling increasing user-friendliness of the form, allowing easier access to the form, and raising awareness of the monetary incentive available for managing this complex disease. The heterogeneity of HF providers (ranging from solo primary care providers to specialists in academic health science centres) will necessitate more than just a monetary incentive. An active stakeholder engagement strategy that includes collaboration with the LHINs and key stakeholders will be crucial to the success of the Ontario Heart Failure Registry moving forward.

The launch of the CCN HF Website will be promoted through a variety of media, including advertisements in print and online publications that will reach PCPs, FHTs, specialists, and allied health professionals. The “HF Provider Portal” will facilitate networking through webinars and CMES. CCN will distribute a press release to the media to help increase public awareness of HF and the creation of the new website. Promotion of the website to the patients and caregivers currently coping with HF will occur in part by care providers informing them of its creation. In addition to allowing information to trickle down from care providers, links to the patient and caregiver portal will be placed on the websites of partner organizations, such as the Heart and Stroke Foundation of Ontario. The geographical map of HF Clinic locations will provide real-time current information to clinicians enabling them to access HF resources in their community. Collaboration with the LHINs will ensure that the list of HF services remains current as new providers are added and/or existing providers restructure to change the scope of their service delivery.

8.4 Evaluating Change

CCN is well positioned to achieve this implementation plan with the CCN-HFWG consisting of fully engaged clinical experts in HF management across the continuum of care.

Informal feedback on the HF registry will be tracked over a six-month period and formal evaluation of the database will occur at the end of the six months. Revisions and refinements will be made as required to improve the usability, flow, and meaningfulness of the data.

Six months after launching the CCN HF Website there will be a formal evaluation resulting in the refinement of tools and resources. CCN will continue to evaluate and update resources on a monthly basis to ensure they remain current and relevant to HF practice in the province of Ontario.
8.5 Implementation Approach

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<th>Phase</th>
<th>Timeline</th>
<th>Objectives</th>
<th>Deliverables</th>
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<tr>
<td>Preparing for Change</td>
<td>3 months</td>
<td>Obtain feedback, advice and guidance from stakeholders while gathering resources and best practices</td>
<td>• Obtained survey distributed events coming in on a rolling basis.</td>
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<td>Implementing Change</td>
<td>4 months</td>
<td>Design and develop tools (patient, provider and system level)</td>
<td>• Developed new tools and resources as needed.</td>
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<td>Spreading &amp; Sustaining</td>
<td>7 months</td>
<td>Evaluate uptake of recommendations, document, and tools</td>
<td>• Completed inventory of HF providers (survey and telephone interviews).</td>
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<td>• Reviewed existing tools and resources for clinicians, patients, and caregivers.</td>
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<td>• Patient/caregiver feedback</td>
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<td>• Identified gaps and created new tools and resources as needed.</td>
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<td>• Review HF best practices of measurement and indicators.</td>
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<td>• Creation of Patient and Caregiver Portal</td>
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<td>• Creation of HF Provider Portal</td>
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<td>• Geographical mapping of HF service providers (identify any gaps in service)</td>
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<td>• Differentiated levels of care</td>
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<td>• Created HF Data Dictionary</td>
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<td>• Built Ontario HF Registry (extension of existing Cardiac Registry at CCN)</td>
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<td>• Organized HF Forum</td>
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<td>• Host HF Forum</td>
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<td>• Implemented an Hub and Spoke system to provide differentiated levels of HF care; therefore</td>
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<td>building capacity into the healthcare system to care for these patients, using resources</td>
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<td>that for the most part are presently available in the healthcare system;</td>
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<td>• A future HF system to be based on the CDPM framework;</td>
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<td>• A provincial coordinated triage system to link patients with appropriate providers within a</td>
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<td>recommended wait time;</td>
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<td>• Comprehensive data collection so patient access and outcomes can be measured; and</td>
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<td>• Provincial quality assurance program to define, monitor and report on performance metrics.</td>
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9 Summary and Conclusions

The CCN-HFWG has articulated three key priority areas for improving HF care in Ontario:

1. Standardize tools and resources for patients, caregivers, and clinicians;
2. Improve organization of care; and
3. Enable measurement and improvement

Many of the recommendations outlined in this document have been known to patients and care providers as the optimal solutions to managing HF care for decades. The goal is to create a comprehensive provincial strategy that will standardize and improve care consistently across the province. As a provincial body with expertise in cardiac care, CCN is poised to execute these recommendations through collaboration with key stakeholders.

Achievements that will result from implementing the recommendations include:

- Supporting patients and families in self-care strategies;
- Assisting HF care providers in delivering high quality of care, based on best practices throughout all phases of the HF cycle;
- Creating a “Hub and Spoke” system to provide differentiated levels of HF care; therefore building capacity into the healthcare system to care for these patients, using resources that for the most part are presently available in the healthcare system;
- A future HF system to be based on the CDPM framework;
- A provincial coordinated triage system to link patients with appropriate providers within a recommended wait time;
- Comprehensive data collection so patient access and outcomes can be measured; and
- Provincial quality assurance program to define, monitor and report on performance metrics.
Once implemented using various practical approaches, the CCN-HFWG’s recommendations will result in:

- Better use of hospital resources by reducing unnecessary ED visits and hospitalizations, and by building capacity in the community to care for the growing HF population; and
- Better patient outcomes by reducing morbidity and mortality while improving quality of life as patients receive the right care, in the right place, and at the right time within the recommended wait times.

This strategy is aligned with and is positioned to support many provincial initiatives currently underway, including operationalizing Health Links, Quality-Based Procedures, and Healthy Change: Ontario’s Action Plan for Health Care.

Appendix A: CCN Heart Failure Working Group Membership

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*previous working group members
Appendix B: Crude HF Hospitalization Rates by LHIN, 2006 to 2011

Heart Failure Hospitalization Crude Rates by LHIN
2006-2011
Ontario Ministry of Health and Long Term Care
IntelliHEALTH ONTARIO Data Last Refreshed [October/2012]

Data Source: Discharge Abstract Database, Ontario, 2011
Appendix C: Treatment of Heart Failure

i) Pharmacologic Management of Heart Failure

The main pharmacologic therapies for HF are:

- Angiotensin converting enzyme inhibitors (ACEi);
- Beta-blockers;
- Mineralocorticoid receptor antagonists (MRA); and
- Angiotensin receptor blockers (ARB).

These drugs are used in various combinations to manage HF (McKelvie et al., 2013).

ACEI Therapy

Injury to the heart muscle results in activation of the renin-angiotensin-aldosterone system (RAAS), which can cause further injury and adverse effects on the blood vessels, kidneys, muscles, bone marrow, lungs and liver, and create a vicious cycle resulting in a worsening in the condition of the HF patient (Shah & Mann, 2011; McMurray, 2010).

The use of ACEI therapy to interrupt this cycle has been demonstrated to be very effective (Flather et al., 2000) at reducing mortality and morbidity in symptomatic and asymptomatic patients with reduced LVEF (Flather et al., 2000). Importantly, ACEI has been found to decrease the incidence of HF in patients who are at risk for developing HF (Dagenais et al., 2006). The studies have also demonstrated that the use of ACEI improves symptoms (Abdulla et al., 2006). Long-term follow-up of the patients in ACEI studies has demonstrated that the early administration of ACEI results in sustained benefit over many years (Buch et al., 2005; Jong et al., 2003; Hall et al., 1997). ACEI have been firmly established as therapy to be used in all HF patients with reduced LVEF regardless of symptoms (McKelvie et al., 2013).

Beta-blocker Therapy

Myocardial injury results in activation of the sympathetic nervous system; this activation results in further progression and worsening of HF (Shah & Mann, 2011; McMurray, 2010). Beta-blockers counteract the effects of the sympathetic nervous system.

Three major trials have demonstrated the benefit of beta-blockade in addition to ACEI for HF patients (Packer et al., 2001; CIBIS II, 1999; MERIT, 1999). The beta-blocker trials have demonstrated significant reduction in mortality in the order of 30% (Packer et al., 2001; CIBIS II, 1999; MERIT, 1999). Importantly, a significant approximately 35% reduction of HF hospitalizations has been observed with beta-blocker therapy (Packer et al., 2001; CIBIS II, 1999; MERIT, 1999). Patients in these studies also experienced an improvement in symptoms (Packer et al., 2001, MERIT, 1999).

Beta-blocker therapy is recognized as essential to the management of HF and, unless contraindicated, should be used in all HF patients (McKelvie et al., 2013).

MRA Therapy

Aldosterone, through its stimulation of mineralocorticoid receptors, plays an important role in the progression of HF (Funder, 2009; Delcayre & Svyngedauw, 2002). Aldosterone levels remain elevated despite treatment with ACEI, beta-blocker, and ARB therapy (Fung et al., 2003; Sato & Saruta, 2003; Strathears, 2004; McKelvie et al., 1999). This provides the rational for the use of a MRA in HF.

Three major trials have examined the effect of MRA in HF patients with reduced LVEF (Zannad et al., 2010; Pitt et al., 2003; Pitt et al., 1999). These studies have demonstrated, in the full spectrum of HF patients from post myocardial infarction with reduced LVEF to stable minimally symptomatic HF patients through to severely symptomatic patients, a significant up to 30% reduction in mortality and up to 40% reduction in morbidity (Zannad et al., 2010; Pitt et al., 2003; Pitt et al., 1999).

The data for MRA therapy are now very convincing and consistent regarding benefit. MRA are effective in the full spectrum of HF patients from advanced to the more minimally symptomatic patients. The Canadian Cardiovascular Society (CCS) 2012 HF Guidelines now recommend that HF patients symptomatic on ACEI and beta-blocker treatment be started on MRA therapy (McKelvie et al., 2013).

ARB Therapy

ARBs have been studied in HF patients with reduced LVEF in addition to ACEI therapy and as an alternative in patients intolerant of ACEI (McKelvie et al., 2013). Studies have demonstrated that when an ARB is used in addition to ACEI, there is a significant (approximately 20%) reduction in HF hospitalizations (Cohn et al., 2001; McMurray et al., 2003), and a 16% reduction in cardiovascular mortality (McMurray et al., 2003). In ACEI intolerant HF patients with reduced LVEF, the use of an ARB has been demonstrated to modestly improve clinical outcomes (Granger et al., 2003).

According to the 2012 CCS HF Guidelines, ARB can be used either in patients with chronic HF or in those following an acute MI with HF or reduced LVEF who cannot tolerate an ACEI (McKelvie et al., 2013). Despite these recommendations, an ARB is no longer considered the first choice recommendation in HF patients with reduced LVEF who remain symptomatic despite optimal ACEI and beta-blocker treatment. The reason for this is that the data supporting the use of a MRA as add on therapy is much more robust than the data for ARB.

Other Pharmacologic Therapies

Other pharmacologic measures can be used for the management of HF (McKelvie et al., 2013), although the evidence for these therapies is less robust regarding the reduction of mortality and morbidity:

8 Aldosterone is a hormone that increases the reabsorption of ions and water in the kidney, thereby increasing blood volume and, therefore, increasing blood pressure. Importantly, aldosterone increases the amount of fibrous tissue in the heart leading to reduced function of the heart muscle.
• Diuretics are commonly used to treat HF because this therapy effectively relieves symptoms of shortness of breath (dyspnea) and swelling (edema). Although there has not been a single large randomized trial assessing benefits, one meta-analysis concluded that diuretics reduce the risk of worsening HF and death, and improve exercise capacity (Paris et al., 2002).

• Digoxin can be used to manage HF patients who are in sinus rhythm (i.e., have a regular heartbeat) (McKelvie et al., 2013). A systematic review of small trials has suggested some benefits to reduce symptoms of HF, although the trials in the review were performed prior to the widespread use of beta-blockers (Foord et al., 2004). The main benefit of digoxin is to reduce HF hospitalizations (The Digitalis Investigation Group, 1997).

• The combination of hydralazine/nitrate therapy has been used in the management of HF (McKelvie et al., 2013). Evidence for the use of this therapy is more limited; however, a trial with African-American patients suggested the combination therapy, in addition to optimal standard therapy, reduces mortality and HF hospitalizations, and improves quality of life (Taylor et al., 2004).

Heart Failure Patients with Preserved Ejection Fraction (HFPEF)

HFPEF is a condition where the patient has typical clinical findings of HF but the LVEF is not reduced (Owan and Redfield, 2005; Hogg et al., 2004). This condition is more prevalent in the elderly and women, and in patients with a history of hypertension.

The reported mortality rate for these patients is lower than that of heart failure patients with reduced ejection fraction, although it is still unacceptably high (MAGGIC 2012; Hogg et al., 2004); however, studies have generally shown the morbidity, especially HF hospitalizations, is similar to HFPEF patients (Hogg et al., 2004).

There are limited data regarding evidence-based therapies for HFPEF patients, with most recent randomized controlled trials evaluating ACEi and ARB showing neutral or marginal benefits (Massie et al., 2008; Cleland et al., 2006; Murray et al., 2003; Yusuf et al., 2003). The main approach to therapy is to control the potentially contributing risk factors for the syndrome such as hypertension and reduced blood flow to the coronary blood vessels (Hogg & McMurray, 2006). Diuretics are typically used to control symptoms of congestion, and beta-blockers and rate-lowering calcium channel blockers to control heart rate, if required (Hung et al., 2002). ACEi and ARB may be used if there are other indications not related to HF (Hogg & McMurray, 2006).

ii) Device Therapy

Device therapy usually consists of either an implantable cardioverter-defibrillator (ICD), a cardiac resynchronization therapy (CRT) device, or the combination of both of these devices (McKelvie et al., 2013). An ICD should be considered in HF patients with LVEF ≤35% regardless of symptoms (Howlett et al., 2009; Bardy et al., 2005; Moss et al., 1996). CRT has been found to improve symptoms as well as reduce mortality and morbidity even in patients with more minimal symptoms of HF (Tang et al., 2010; Howlett et al., 2009; Moss et al., 2009; Cleland et al., 2005; Bristow et al., 2004).

Another type of device that is used less commonly is a ventricular assist device (VAD) (McKelvie et al., 2011). The VAD may be used to mechanically support the left ventricle, right ventricle or both ventricles depending on the clinical presentation. VADS are considered for patients with advanced HF or rapidly progressing HF who do not respond to standard treatment. They are most frequently used to support the HF patient until the patient can receive a cardiac transplant. Less often, a VAD is used for long-term support of a patient who is ineligible for transplant but otherwise has a good life expectancy.

iii) Other Therapies

Despite the importance of pharmacologic and device therapies for the management of HF, other forms of therapy are equally important. Methods of HF management should also include ongoing follow up, education and self-care skill teaching (Canadian Cardiovascular Society Data Dictionary, 2013). Recommendations are required about dietary salt and fluid restriction, monitoring of weight, appropriate exercise, and palliative care/advance care planning.

Patients should be advised regarding a low salt diet or for more advanced findings of congestion, a no-salt diet (Arnold et al., 2006). Advice should be given to all patients about restricting fluid intake to about two liters per day. Those individuals with more severe symptoms of congestion should have a more stringent fluid restriction (Arnold et al., 2006). It is very important patients be instructed to weigh themselves each morning (Arnold et al., 2006). This simple measure is an excellent strategy for identifying worsening HF symptoms and to prompt patients to seek medical intervention, perhaps avoiding hospitalization.

Patients should be advised about the role of regular physical activity in preventing further deconditioning and improving health related quality of life (Flynn et al., 2009; Arnold et al., 2006). Although less well established, there may also be reductions in clinical events (O’Connor et al., 2009; Arnold et al., 2006) especially in those patients who most regularly exercise (Keteyian et al., 2012). These improvements are additive to the benefits of ACEi and beta-blockers.

HF is a progressive syndrome with a high mortality rate similar to or greater than most cancers (Stewart et al., 2001). Thus, advance care planning and palliative care are important components of HF management (McKelvie et al., 2011):

• The goal of advance care planning is to ensure that if a patient with a serious illness cannot no longer communicate treatment preferences, there is sufficient information available to provide care consistent with the patient’s goals and values (McKelvie et al., 2011).

• Palliative care is the promotion of physical and psychosocial health, regardless of diagnosis or prognosis and, thus, is appropriate anywhere along the HF continuum (McKelvie et al., 2011). Importantly, it is applicable in conjunction with other therapies that are intended to prolong life (McKelvie et al., 2011).
Appendix D: interRAI

While implemented across eight Canadian provinces and one territory, interRAI instruments are most extensively used in several Ontario health care sectors, including home care, community support services, long term care, mental health settings, and palliative care. The Canadian Institute for Health Information is the repository for interRAI data collected from LTC, complex continuing care, home care and mental health. This existing infrastructure would facilitate quality assurance initiatives as well as system evaluation though linkages with other large administrative databases. Though the implementation of these instruments in Ontario has largely focused on administrative use, appropriate and targeted investments to adjust existing interRAI processes, including optimizing software configurations and paying attention to clinical workflows and clinician training, would allow the full clinical capacity of these tools to be harnessed and facilitate substantial improvements in the effectiveness and efficiency of clinical care of frail seniors across the health care system.

Appendix E: Current Innovations in Heart Failure Management

i) Care Paths for Heart Failure Patients

All CCACs are committed to introducing care pathways for HF patients by the end of 2012/13. The Hamilton Niagara Haldimand Brant Community Care Access Centre (HNHB CCAC) has implemented a Rapid Response Transitional Team (RRTT) with all hospitals in the HNHB LHIN. The goal of RRTT program is to prevent avoidable admission to hospital for existing CCAC clients, and facilitate earlier hospital discharge. The program may play a key role in reducing hospital readmission and reducing the ALC rate.

At risk, complex patients are identified by hospital staff and CCAC care coordinators. Patients referred to the RRTT program are assessed within 24 hours of discharge by registered nurses (RN) who have access to Health Care Connect, accessing the patient’s hospital records when required. The RN reviews the patient’s hospital discharge plan, completes medication reconciliation, and ensures the patient has relevant follow-up. Nurse practitioners on the team provide clinical support to more complex patients, collaborating with PCPs, cardiologists, and HF Clinic staff as required. Approximately 800 patients were supported by the RRTT program from March to December 2012. Approximately 40% of RRTT patients have HF or other cardiac diagnosis. The CCAC is in the process of developing care pathways for HF patients.

The HNHB CCAC collaborates with the cardiology program at Hamilton Health Sciences to provide evidence-based care for HF patients and conduct research. HF patients at risk of readmission are referred to the RRTT program for follow-up. The RRTT team can connect back to inpatient and HF clinic for clinical advice to support these clients as they transition back to their own PCP.

HNHB CCAC collaborates in a Best Practices Discharge Bundles project with two hospitals, Hamilton Health Sciences and the Brant Community Health Care System, to reduce the hospital readmission rate for patients with HF and COPD. Dedicated hospital staff members screen patients for readmission risk and have implemented ‘teach back’ strategies to ensure patients understand their health condition and the follow-up that is required. At the time of discharge, the patient has written medication reconciliation and a follow-up PCP appointment. Patients identified at high risk of readmission are referred to the RRTT program. It is expected that the Bundled Transitions approach will be spread to all other hospitals across HNHB LHIN.
ii) Telehomecare

The Thunder Bay Regional Health Sciences Centre has implemented a Telehomecare program in collaboration with an internal medicine clinic to complement the ongoing care of HF and COPD patients. This nurse-practitioner-led program is a regional program within the North West LHIN, and is led by the Ontario Telehealth Network, which is also responsible for outreach.

To participate in the program, patients must:

- Be 18 years of age or older;
- Have an established diagnosis of COPD or HF;
- Have been admitted to hospital or visited the ED at least once in the past year;
- Require regular monitoring of their condition by a health practitioner;
- Are capable of learning and understanding instructions; and
- Live in a residential setting with a telephone line.

The Telehomecare program is based on a new pathway for coordinated collaboration between patients and their multidisciplinary care team that enables, teaches, and supports patients to actively manage their condition. The programming is based on the Stanford model of self-care.

After an initial assessment, the Telehomecare nurse meets with the patient in the clinic to establish the care plan and install the remote monitoring unit. The unit transmits daily readings for the patient, and the health care team teaches and coaches the patient based on that data and the patient’s expressed goals. The service provides medical management with active titration of medication in addition to support within the patient’s home. Data are stored within the hospital’s electronic chart, which allows PCPs to access the data at any time.

The North West LHIN is developing a Provincial Reference Model for its Telehomecare initiative that can be rolled out to other LHINs in years two and three of the program, with a target of 40,000 patients enrolled within three years.

iii) Automated Calling

The University of Ottawa Heart Institute has implemented an automated calling program using interactive voice response (IVR) technology. This program initiates automated calls to patients at regular intervals post-discharge, using a predetermined series of questions. The technology allows the patients to respond to questions in their own voice, receive health information or request services or care. Responses are captured in a central database and are flagged if they require a call for reassessment or action.

One of these IVR applications is the HF Follow-up application, which was designed to meet the goals of promoting self-care education and decreasing readmissions. Patients are contacted every two weeks for three to six months. The IVR algorithm is made up of 16 questions detailed as follows:

- For five of the questions, the IVR application provides information content (e.g., common HF medications and self-care such as salt and fluid restrictions);
- Eight questions elicit potential callback flags so the nurse can further assess the patient;
- Three questions offer to mail out specific information such as how to make healthy food choices when eating at a restaurant.

As part of a larger project, 47 HF patients were followed by IVR for six months. Out of the 125 calls received, 58 were requests to the system to hear information on HF medications, and many patients made the request more than once. Seven medication adverse events or potential events were captured during the monitoring period. Four patients presented to the ED for non-cardiac (three) and HF (one) reasons. The latter had been prescribed a contraindicated medication. Four patients were admitted for cardiac reasons such as myocardial infarction. However, there were no avoidable admissions related to HF. Most patients (74%) found the IVR system to be very helpful, and most (94%) would use this service again.

All of these applications have improved efficiency by automating the calling, which is time intensive in follow up. The system recognizes patients who are doing well and allows the provider to focus on the small number of patients who need targeted intervention. Most elderly patients are comfortable using phone technology, and this is an inexpensive technology for providing follow up care.
Appendix F: Source Organizations for Guidelines and Quality Indicators

1. The Canadian Cardiovascular Society Guidelines for the Diagnosis and Management of Heart Failure (Arnold et al., 2006);
2. European Society of Cardiology Heart Failure Association (McMurray et al., 2012);
3. The American College of Cardiology Foundation (ACCF); American Heart Association (AHA); Physician Consortium for Performance Improvement (PCPI™); Performance Measurement Set (2012);
4. National Institute for Health and Clinical Excellence Evidence Update (2011);
5. National Heart Foundation of Australia; Multidisciplinary Care for People with Chronic Heart Failure (2010);
6. American Heart Association – Get with the Guidelines Heart Failure Registry (2011);
8. Institute for Clinical Systems Improvement: ICSI (2011);
9. Canadian Cardiovascular Society Data Definition: A CCS Consensus Document (2013);

Appendix G: Challenges in Selecting Quality Indicators

A review of current literature revealed that there is no perfect or generally accepted suite of quality indicators that can be applied to any network. Five primary challenges for selecting quality indicators for the management of HF include the following:

- The appropriateness of using an indicator can change over time. For example, the use of ACE/ARB medication may be an excellent evidence-based quality indicator; however, if 95% of the population is already using this medication, monitoring its use may not be helpful. As practice evolves, new innovations are accepted, and evidence accumulates, quality indicators will also change. (See Appendix C: Treatment of Heart Failure for a list of processes that are proven to have an impact on outcomes for HF patients)

- The purpose and perspective of quality indicators are also very important. Some quality indicators may measure a process that is expected to reduce mortality; however, at the same time, following that process may increase hospitalizations and, consequently, the cost of care. In selecting an indicator, the evaluator must be clear on what is being measured;

- Most common indicators are process of care measures, and assumptions are made regarding the relationship between the process and the outcome to be achieved. For example, beta-blocker usage generally has a positive effect on mortality; however, other medications may not have been sufficiently tested to allow for such a conclusion. There is also a growing focus on outcome measures such as functional status and quality of life;

- There are also challenges related to the sheer number of organizations involved in recommending guidelines or indicators, each with unique data definitions. In addition, it is often difficult to secure reliable and comprehensive data to be used in these indicators.

The ageing population in Ontario, which brings a marked increase in the number of residents living with chronic diseases like HF is causing a major shift in the focus of our health care priorities from hospital-based care to community-based care. This shift has led to a growing understanding that quality indicators must cover the full continuum of HF care including acute, transitional and outpatient care.

The challenge in identifying appropriate system indicators is the importance of recognizing the impact of a change in one part on other parts of the system. For example, as hospitals work to reduce hospitalizations, the burden on community-based providers is increased, potentially also resulting in delays in hospitalization, resulting in suboptimal care and worsening patient outcomes.
The recent 2010 CCS HF guidelines (Howlett et al., 2010) have suggested that the failure to demonstrate meaningful improvements in HF patient outcomes may be related to how the indicators have been developed (i.e., traditional emphasis on acute and outpatient care). The CCS suggested that a more comprehensive approach to HF management that incorporates transitional and end-of-life care, with an emphasis on the full continuum of HF care, is important. For example, the benefits of better in-hospital care may be undone by suboptimal transitional care or outpatient disease management, thus the need exists for indicators that cross the continuum of care.

Appendix H: The DIVERT Scale

Using a retrospective longitudinal design of 617,035 long-stay home care clients in Ontario and Manitoba, mean age 75.9 (IQR: 70.0-85.9) and assessed with the interRAI Home Care (RAI HC) instrument, a decision tree, now referred to as the DIVERT Scale, was created (Costa, 2013). This scale estimates the likelihood of unplanned ED use among home care patients as a means of risk identification, and to enable care providers to utilize appropriate preventative interventions. Validation of this tool revealed that risk of unplanned ED use is measurable and can be used to adequately predict decision support and will enable elaboration on provincial quality metrics by establishing cluster-based benchmarks. The benefits of full implementation of the DIVERT scale across Ontario would be substantial.
Glossary of Terms

<table>
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<tr>
<th>Term</th>
<th>Description</th>
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<tbody>
<tr>
<td>ACEi</td>
<td>Angiotensin-converting enzyme inhibitor: A type of medication used primarily for the treatment of hypertension and heart failure.</td>
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<td>CGA</td>
<td>Comprehensive Geriatric Assessment (e.g. interRAI)</td>
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<td>COPD</td>
<td>Chronic Obstructive Pulmonary Disease: A progressive chronic disease that makes it difficult to breath.</td>
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<td>CRT</td>
<td>Cardiac Resynchronization Therapy uses a special pacemaker to re-coordinate the action of the right and left ventricles in people with heart failure.</td>
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<td>CVD</td>
<td>Cardiovascular Disease: Diseases affecting the heart and blood vessels.</td>
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<td>HF</td>
<td>Heart failure is a complex and progressive syndrome (group of symptoms that characterize a condition) where the heart cannot pump sufficient blood to meet the body’s demands.</td>
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<td>ICD</td>
<td>Implantable Cardiac Defibrillator is a battery-powered device placed under the skin that keeps track of your heart rate. If an abnormal heart rhythm is detected the device will deliver an electric shock to restore a normal heart beat.</td>
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<tr>
<td>LVEF</td>
<td>Left Ventricular Ejection Fraction: the volumetric fraction of blood pumped out of the heart (left ventricle) with each heartbeat.</td>
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<td>MRA</td>
<td>Mineralocorticoid receptor antagonists: A type of medication that reduces morbidity and mortality in chronic heart failure with reduced ejection fraction.</td>
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<td>NYHA</td>
<td>The New York Heart Association classification is used to describe the extent of heart failure symptoms (e.g. shortness of breath or fatigue) on how much they limit physical activity. NYHA Class ranges from Class I (no limitations); Class II (mild); Class III (moderate); and Class IV (severe limitations; symptoms at rest).</td>
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<td>PCP</td>
<td>Primary Care Provider: typically a general practitioner (GP) or family physician (FP).</td>
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<td>RAAS</td>
<td>Renin-Angiotensin Aldosterone-System: A neurohormonal system that is activated in heart failure and causes progression of heart failure. Medications are used to block the RAAS and improve symptoms of heart failure, decrease hospitalization and mortality.</td>
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<tr>
<td>VAD</td>
<td>Ventricular Assist Device: a machine that is used to mechanically support the left ventricle, right ventricle, or both ventricles.</td>
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<td>Ventricle</td>
<td>The lower chambers of the heart. The right ventricle pumps blood to the lungs. The left ventricle pumps blood to the body through the aorta.</td>
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References


Starfield B. (2010). Primary Care, Specialist Care, and Chronic Care: Can They Interlock? *Chest*, 137(1): 8-10.


