British Heart Foundation / Marie Curie Cancer Care

Manualisation of models of Caring Together in NHS Greater Glasgow and Clyde

FINAL REPORT - February 2014

Matt-Mouley Bouamrane,
Kathryn Saunderson,
Frances Mair

Table of Contents

Acronyms & Abbreviations

ACP	Anticipatory Care Plan
AHF / CHF / HF	Advanced Heart Failure / Congestive Heart Failure / Heart Failure
BHF	British Heart Foundation
COPD	Chronic Obstructive Pulmonary Disease
CHP / CHCP	Community Health Partnership / Community Health & Care Partnership
CCT	Comprehensive Care Team
CT	Caring Together
DOG	Design and Operational Group
DS-ACP	Disease Specific Advance Care Planning
ePCS	Electronic Palliative Care Summary
GGC (NHS)	Greater Glasgow and Clyde
HAT	Holistic Assessment Tool
HFA	Heart Failure Association (of the European society of cardiology (ESC))
HFNS/HFSN	Heart Failure Nurse Specialist / Specialist Nurse
HFSA	Heart Failure Society of America
HFST	Heart Failure Support Team
Inv	Inverclyde (CT implementation site)
LTC	Long term Condition
LVSD	Left ventricular systolic dysfunction
MACP	Medical Anticipatory Care Plan
MDT	Multi-Disciplinary Team
NE	North East (CT implementation site)
NICE	National Institute for Health and Clinical Excellence
NPT	Normalisation Process Theory
NYHA	New York Heart Association
PC	Palliative Care
PCP	Primary Care Physician
PREFER	Palliative advanced homecare and heart FailurE care
RWJF	Robert Wood Johnson Foundation
SIGN	Scottish Intercollegiate Guidelines Network
SPPC	Scottish Partnership for Palliative Care
SW	South West (CT implementation site)

Executive Summary

Introduction

Heart failure is a terminal condition and we know that the management of advanced heart failure remains suboptimal. Those with advanced heart failure often experience a poor quality of life and feel unsupported, especially compared to those with cancer. Marie Curie Cancer Care and the British Heart Foundation in partnership with NHS Greater Glasgow and Clyde have invested in a 5-year programme, 'Caring Together', which aims to improve the quality of – and access to – coordinated care for those with advanced heart failure at the end of their life. The Caring Together Programme strives to improve end of life care for heart failure patients based on five core components. The core components were implemented in three different areas of NHS Greater Glasgow and Clyde producing three different models of care.

The Core Components of Caring Together	
I – Patient Identification and Referral	If a patient is registered with a GP within the 3 pilots area, • **has a diagnosis of AHF (NYHA III or IV)** • **has distressing or debilitating symptoms despite optimal medical therapy** • **has supportive or palliative care needs** that may include a combination of physical, social, emotional, spiritual or psychological needs
II – Holistic Assessment of CT patient	• cardiology review: (outpatient / in-patient as appropriate) • holistic assessment: review with patient of the physical, social, psychological and spiritual aspects of their needs in order to identify appropriate solutions
III – Care Management and Coordination	• patient is assigned a care manager (usually the HFNS), acting as the main point of contact for care management, information, advice and support
IV – Training & Education	• Training provided to stakeholders delivering services within the programme • Shared learning between specialties (palliative care / cardiology and service delivery settings, community / acute care)
V – Multi-disciplinary work and Joint Working	• Joint working and care coordination across teams (community, out-of-hours care and acute care) • care manager, coordinates care with the MDT and can action additional referrals if required • a care plan is devised with individual patients to fulfil personalised medical and palliative care needs and national guidelines.

The aims of the present study are:

1) define and manualise the models developed in the three areas;

2) identify components that could be transferred to other areas of the UK and other disease groups;

3) undertake a scoping review comparing the components with those of other initiatives in the UK and internationally.

Methods

We have conducted a scoping review of the literature in order to gain an understanding of the current state of the art in the provision of integrated palliative care models for advanced heart failure. This has focused on models where ongoing active treatment of the patient illness is conducted in parallel with a broader and holistic approach to care management, particularly in terms of a progressive, up-stream introduction of palliative care interventions, usually including symptom management and relief, psychological support for patients and their carers as well as advanced care planning.

This literature review was complemented by a comprehensive qualitative study of interviews with the key stake-holders who have been leading the implementation or delivering front-line service across the different sites in NHS Greater Glasgow and Clyde. The qualitative analysis helped us gain a deeper understanding of the model core components and the key steps in the patient pathway as reported by the programme stakeholders.

Data Analysis

Interviews were audio-taped and transcribed verbatim, with participant consent, and transcripts served as the data for analysis. We have used Normalisation Process Theory to identify components of the care models and assess the potential for their operationalisation in other geographical or care settings. Normalisation Process Theory is a sociological toolkit that is useful to understand the dynamics of implementing, embedding, and integrating a new service, technology or complex intervention into care delivery. It helps us disassemble the human processes that are at work when we encounter a new set of practices as is the case in the Caring Together programme. This makes it an ideal theory to help us conceptualise the likely transferability of different components of the programme to other locations.

Key Findings

While palliative care is considered in many of the guidelines on heart failure management there is little guidance on the actual arrangement of palliative care services or models themselves. There are a few common themes but how this guidance is implemented will vary according to the setting, available services and resources and patient populations.

Our scoping review identified sixteen studies that covered various aspects of integrated palliative care models for advanced heart failure; including twelve studies that described specific models of care in detail. Across interventions of this type the key common features relate to: *raising awareness of the problem and providing educational support for professionals; earlier and more effective identification of those with palliative care needs; an emphasis on improving knowledge and understanding of the condition; improving patient and caregiver support, addressing the full spectrum of physical, emotional, social and spiritual needs; a greater use of specific tools to facilitate identification and discussion of important issues likely to be of importance to patients and caregivers; improved individual case management with better continuity and coordination of care, so an emphasis on more holistic care; promoting better information and skills sharing across teams with greater collaboration across professional groups; improved out of hours care planning; greater collaboration between health and social care; a greater emphasis on advanced care planning; and in some, bereavement support.*

Most of these components feature in the Caring Together programme which, our qualitative work suggests is well on the way to achieving its original aims. A great deal of positive feedback was given about its impact and professionals seemed confident that the programme was beneficial. Positive comments covered a range of issues but particular areas of success related to: *awareness raising; effective tools and processes for documentation; strengthened relationships between different professional groups; improved communication both between professionals and also between professionals and patients;*

better support for caregivers; improved coordination of care; increased provision of holistic care; up-skilling of staff; and objective evidence of positive effects on duration of hospitalisation and achieving choice regarding preferred place of death. The importance of stakeholder involvement and effective "champions" was clear.

However, numerous challenges remain, not least how best to increase referrals to the programme and ensure equity of access to all those with advanced heart failure. While stakeholder engagement was good there remained deficiencies, for example, effective interaction with general practice was relatively limited despite extensive engagement efforts, and multimorbidity in advanced heart failure posed difficulties when working within systems where there remains a major focus on disease centred care.

Transferability of the Core Components

When considering transferability issues in relation to the Caring Together programme a key point is that the main elements identified in the review of the integrated palliative care models were similar to the core components of the CT programme, suggesting that the transferability and integration of these core components to other care settings is likely to be high.

Core component 1: Patient Identification and Referral

All of the models described in the review build upon the implementation of a robust mechanism for the identification of patients eligible to be included in the integrated care programme. Although there are some small variations across the referral criteria, most of them are very similar to the existing Caring Together referral criteria: advanced heart failure patients being defined as NYHA Class III/IV with deteriorating symptoms or significant functional impairment due to chronic heart failure despite optimum treatment, with 2 models including the surprise question ("would you be surprised if this patient died in the next year?"). Of particular relevance here are those models which have adopted proactive, systematic and multimodal identification systems – including for some the early identification of patients in primary care. This is therefore a key component in any future rollout of Caring Together but one that needs particularly careful attention in view of some of the challenging experiences described in relation to reach of the Greater Glasgow and Clyde Programme to date. Caring Together has been successful in recruiting many advanced heart failure patients who have consequently benefited from the Programme but there is evidence to suggest that not all advanced heart failure patients are gaining access to the Programme, for example, individuals with diastolic dysfunction are largely absent.

Core component 2: Holistic Assessment of Patient

All of the models described in our review, again in common with Caring Together, include a comprehensive assessment of health status of eligible patients included in the integrated care programmes. These in-depth assessments – often including family or carers – focused on elucidating current health status, existing symptoms and management needs, reviewing support needs – both physical and emotional – support availability and preparing an advanced-care/emergency response plan. The comprehensive assessment of patients is also taken as an opportunity for patient education about symptoms, self-management and disease trajectory. Cardiological review and holistic assessment is therefore an essential component of most models of care and we would suggest that, based on the review and our empirical data, that this component would have high transferability potential.

Core component 3: Care Management and Coordination

As with Caring Together, most of the identified models' central activity consists of proactively coordinating the care delivered by a variety of providers into a joined-up, coherent management plan with a particular emphasis on avoiding acute care admissions. In most cases, this task is allocated to a nurse – usually but not always – specialised in the management of heart failure. An interesting variant model was that of the *Comprehensive Care Team*, where the case-management was carried out by a social worker while also providing individual psychological support. A potential limitation of this however was the suggestion that as the result of the care coordinator being a social worker rather than a clinician, primary care providers may have been less inclined to follow the *Comprehensive Care Team* recommendations. The care management and coordination aspects of Caring Together were reported to be quite successful and in theory should have a high potential for transferability. However, the presence or not of underpinning systems to facilitate information sharing and the willingness or ability to invest in such infrastructures will be an issue that will affect transferability and is an important resource issue for consideration when choosing future implementation sites.

Core component 4: Training & Education

Again, as with Caring Together, several of the integrated models emphasised that shared-care and care coordination was best implemented within a programme of shared-learning and knowledge-transfer, both for patients (initially during assessment and subsequently through regular meetings either with health professionals or support groups) and care providers. Feedback about this aspect of Caring Together was positive and again the transferability of this component seems likely to be high. Although it is important to be clear that training and education need to be ongoing rather than seen as a one off investment and training does have resource implications.

Core component 5: Multi-disciplinary work and Joint Working

Most integrated models emphasised that multidisciplinary work was critical to the programme success and this usually involved both regular meetings and efficient communication and information sharing. As has been mentioned by stakeholder in relation to Caring Together, some studies have reported difficulties at times in sustaining engagement and participation from primary care partners. The transferability of this component will depend to some extent on the prevailing organisational cultures at any future implementation locations. It is a key aspect of the programme which should be advocated but clearly is most successful at sites where there are pre-existing links and relationships to build upon.

Additional Points

Identifying champions, although not a core component, was an important feature of the most successful models of care identified in our scoping review and has clearly been central to the success of the Caring Together programme. Identification of appropriate clinical champions will be important to drive the successful implementation of the Caring Together programme in other areas. Such champions need to be: individuals who would be deemed credible in their localities, so influential; but also to have enthusiasm and be able to sustain their involvement. Over reliance on a single champion has inherent risks and thus having a range of champions driving the service would be advisable.

Facilitation groups also proved to be crucial factor in facilitating the implementation of the Caring Together programme. The facilitation groups allowed for the service to be implemented in a way that considered the local needs and priorities and allowed implementation of the Caring Together programme into the existing structure and services. This local knowledge and tailoring of services to the local environment was key to the successful development of the models.

Similarly, good underpinning information systems are needed as they can assist in promoting effective patient identification and referral and improved information sharing and care coordination. Finally, the policy context both nationally and locally supported the implementation and integration of the Caring Together programme in Greater Glasgow and Clyde and this, along with management support, are other important factors contributing to the success of the programme. Such issues need to be considered at any future implementation site.

Conclusions

In Greater Glasgow and Clyde the Caring Together programme was rolled out as 3 distinct models, individualised and contextualised to meet local needs and circumstances. It is very clear that a "one size fits all approach" to the further extension of the programme across the UK NHS or elsewhere in the world would be very unlikely to be successful. Flexibility, as seen in Greater Glasgow and Clyde, will be a key attribute of any further Caring Together roll out. While the NHS, at first glance, would seem to be a homogenous service, in fact, as has been evident in Greater Glasgow and Clyde it is quite heterogeneous with each area often being quite unique in the way services are delivered. This is a crucial point to note when considering the transferability of different components of the Caring Together.

I- INTRODUCTION

Heart failure is a terminal condition with a greater number of expected life-years lost than many common cancers [1]. Although outcomes are improving the median survival following a first episode of heart failure is just 2.34 years in men and 1.79 years in women [2]. Such statistics provide a stark picture of a disease that is both an important public health problem and a devastating disease for many people. Much is known about the unmet needs of those with advanced heart failure (AHF) [3-7]. For example, those with AHF are known to experience a wide range of distressing symptoms, such as pain, anxiety and shortness of breath, that lead to poor quality of life [8-11]. It is also clear that both patients and carers frequently describe feeling inadequately unsupported by practitioners and health and social care systems [4, 12]. Palliative care services are also less available to those with AHF in comparison to those individuals with a cancer diagnosis; and importantly prognostication is reported as a major challenge [13, 14], with the trajectory of AHF being less predictable than, for example, most cancers, which are generally characterized by steep linear declines in wellbeing in the last months of life. Instead the journey of those with AHF is one of unpredictable decompensations and improvements, and decline to the terminal stages is much subtler and less clear cut [15-17]. This makes it difficult for health professionals to be sure when to switch to a palliative approach.

The importance of palliative care for those with AHF and the need to address end-of-life issues are now well established [18-21]. Nevertheless, recent systematic reviews of the literature show that major challenges to high quality care remain [6, 7]. For although the need for improved communication is widely advocated and generally accepted this does not seem to be translating into routine practice as conversations between those with AHF and health professionals appear to still focus mostly on disease management rather than end of life issues. Clinicians continue to wait for patients to bring up these issues, but since knowledge deficits are ubiquitous, this rarely happens and as a result, these important conversations never take place [12, 22]. Crucial conversations about important subjects such as implantable cardioverter defibrillator deactivation are simply not happening as a matter of routine [23]. Equally, a lack of continuity in the care provided to those with AHF remains evident and there remains inconsistency regarding when to change the emphasis of care from life prolonging to supportive [7, 12].

Aim of the Study

The aims of the present study are to:

1- define and manualise the models developed in the three areas
2- identify components that could be transferred to other areas of the UK and other disease groups
3- undertake a scoping review comparing the components with those of other initiatives in the UK and internationally

Overview of our Approach

We have conducted a scoping review of the literature in order to gain an understanding of the current state of the art in the provision of integrated palliative care models for AHF. This has focused on models where ongoing active treatment of the patient illness is conducted in parallel with a broader and holistic approach to care management, particularly in terms of a progressive, up-stream introduction of palliative care interventions, usually including symptom management and relief, psychological support for patients and their carers as well as advanced care planning.

This literature review was complemented by a comprehensive qualitative study of interviews with the key stake-holders who have been leading the implementation of the CT programme or delivering front-line CT services across the different sites in NHS GGC. The qualitative analysis helped us gain a deeper understanding of the core components of the models being rolled out across the city and the key steps in the patient pathway as reported by the programme stakeholders.

We have used Normalisation Process Theory (NPT) to identify components of the care models and asses the potential for their transfer and operationalisation in other geographical or care settings. NPT is a sociological toolkit that is useful to understand the dynamics of implementing, embedding, and integrating a new service, technology or complex intervention into care delivery [24, 25]. It helps us disassemble the human processes that are at work when we encounter a new set of practices as is the case in the CT programme. This makes it an ideal theory to help us conceptualise the likely transferability of different components of the programme to other locations.

II- Background

Local Policy Context and Guidance for the Management of Advanced Heart Failure

While national and international evidence based guidelines give varying levels of guidance on palliative care in heart failure, there are also a number of policy and local documents that have addressed the management of palliative care in AHF [19, 26-31]. While our scoping review, described in Section 5, summarises the literature regarding potential models of palliative care for use with those in AHF, the policy documents outlined below provide guidance regarding key features to be addressed when implementing palliative care for AHF at a local level. Key points from these policy documents and a brief outline of the guidance is provided below.

Palliative care in Scotland was addressed in a Scottish Government paper *'Living and Dying well: A national plan for palliative and end of life care in Scotland'* in 2008 [32]. This paper outlined an overarching plan for palliative and end of life care in Scotland with the intent of it being:

> *"a plan to ensure that good palliative and end of life care is available for all patients and families who need it in a consistent, comprehensive, appropriate and equitable manner across all care settings in Scotland."* (p2, [32]).

The action plan covers 5 main areas, each with suggested action points to develop the palliative and end-of-life care in Scotland:

1. *Assessment and review of palliative and end of life care needs*
2. *Planning and delivery of care of patients with palliative and end of life needs*

3. *Communication and coordination*
4. *Education, training and workforce development*
5. *Implementation and future developments*

The NHS improvement *'End of Life Care in Heart Failure: A Framework for Implementation'* was developed within the context of the 'End of life strategy' and focuses specifically on the needs of those with AHF [29]. It aimed to *"raise awareness of the supportive and palliative needs of people living or dying with progressive heart failure, to facilitate the commissioning of services specifically tailored to meet those needs".* The document expands on the 6-step end-of-life care strategy (Department of Health, 2008, [28]) – promoting high quality care for all adults at the end of life. The six key steps of the end-of-life care pathway are:

1. *Discussions as the end of life approaches*
2. *Assessment and care planning and review*
3. *Coordination of care*
4. *Delivery of high quality services in different settings*
5. *Care in the last days of life*
6. *Care after death*

The `End-of-Life Care in Heart Failure Framework' uses the generic model of end of life care and expands it with issues directly pertaining to HF for each of the six key steps [29]. It emphasises the importance of: *multidisciplinary working; implementation of effective mechanisms for information exchange; investment in communications skills training; proactively identifying those with AHF to help them benefit from established programmes* *such as the Gold Standards Framework; better integration between community and secondary care providers; the appointment of care coordinators to act as single point of access; multiagency strategic commissioning (to ensure effective utilisation of health and social care services); advanced care planning; and bereavement support*.

Under the heading of multidisciplinary working, the need for involvement of a *'broad range of social and health service sectors'* along with coordination of care is highlighted as essential to prevent 'fragmentation' of care [29]. The report also emphasises the importance of patient-centred care and thus that the importance of the various components will vary according to each patient’s circumstances and journey point through their illness. The report also recommends use of advanced-care planning, including a defined and recorded advanced-care plan, which should be accessible by all care providers and reviewed regularly.

A report by the British Heart Foundation (BHF) Scotland, the Scottish Partnership for Palliative Care (SPPC) and the Scottish Government, *'Living and Dying with Advanced Heart Failure: A Palliative Care Approach'* describes a detailed palliative care management approach for HF [26]. The report seeks to clarify palliative care principles when specifically applied to AHF. A need for a holistic and palliative care approach for HF is emphasised, with a suggestion that this is best achieved through: shared care, multi-professional teams and enhanced communication. The report also suggests that coordination of care by a named individual – such as a heart failure nurse specialist – is an important feature of the approach. Furthermore, the report suggests that:

> *"It is unlikely that the models and standards of care envisaged can be delivered without investment in some level of additional resources in additions to the reorganisation of existing services"* (p30, [26]).

Clearly, this is an important point for consideration when evaluating the CT programme and its potential transferability to other locations in the future. The report makes eight core recommendations for the delivery of optimal care in AHF (p30-32, [26]):

1. *That all patients with AHF should be provided with both optimum cardiac management and palliative care*
2. *Health care teams should adopt a holistic approach to the care of patients with heart failure, ensuring not only optimum management of physical symptoms, including those relating to co-morbidities, but also identifying and addressing practical, social, psychological, emotional and spiritual needs.*
3. *Members of health care teams should ensure that patients with AHF and their carers have sufficient opportunities to discuss, at their own pace and at times of their choosing, any issues that are important to them, including the management of the condition and its prognosis.*
4. *A model of shared care involving close collaboration between different healthcare teams should be implemented in the care of patients with AHF.*
5. *Arrangements for appropriate end of life care should be in place for all patients with AHF.*
6. *Educational and training opportunities should be provided for all health and social care professionals caring for people with heart failure to enable them to understand the patient's cardiac problems and to address their general palliative care needs.*
7. *Further palliative care research should be undertaken*
8. *The resource implications of this report and recommendations should be addressed*

The NHS Quality Improvement Scotland developed quality standards for heart disease in 2010 which identify clinical standards for the management of patients with heart disease [31]. Some of the standards applicable to patients with AHF include those relating to: *communication, multidisciplinary management and education and training of staff.* However one standard specifically emphasised is the need for: *'Supportive and palliative care for patients with heart disease'*. The standard suggests that patients who remain symptomatic when on optimal treatment should have access to supportive and palliative care. Support should address not only patients' physical needs but also in other areas, including spiritual, social and psychological needs. To conduct a proper needs assessment, the standard suggests the use of `triggers’: in this case, the *gold standards prognostic indicator guidance* [31]. In addition to the use of tools for assessing patient symptoms, the standard also recommends the documentation of a specific care plan, which should be regularly reviewed (e.g. every 3 months). Furthermore, the standard recommends that the care plans is shared with others involved in the care of patients, and particularly out-of-hours care providers [31].

The Scottish Government *`Better Heart Disease and Stroke Care Action Plan’* (2009), identifies palliative care in HF as being of critical priority [27]. It endorses and reiterates recommendations made by the Scottish Intercollegiate Guidelines Network (SIGN) guideline and the BHF/SPPC report [19, 26] on implementing a model of *shared-care* and *care co-ordination* by a named individual. In addition, it also recommends multidisciplinary outpatient follow up and community support for HF patients, stressing the importance of communication with out-of-hours care providers.

The development of a centre of excellence for AHF within Glasgow – as a joint collaborative venture by the British Heart Foundation, Marie Curie Cancer Care and NHS Greater Glasgow and Clyde (GGC) – was also acknowledged in the Scottish Government action plan as a positive and significant contribution in focusing resources in an area of strategic importance [27] . Furthermore, the Health Improvement Scotland report *'Heart disease improvement Programme'* (2011), highly commended the development of palliative services within NHS GGC through the `Caring Together’ programme [33].

III The Caring Together Programme

Marie Curie Cancer Care and the British Heart Foundation in partnership with NHS Greater Glasgow and Clyde (GGC) have invested in a five year programme called `Caring Together' (CT), which aims to improve the quality of care for those with AHF across GGC. As outlined in the previous section the programme supports the Scottish government's action plans for palliative care services, which call for a more equitable provision of end of life care services for patients with any advanced, progressive or incurable condition across all care settings.

There have been a number of reports relevant to the CT programme and its development and implementation. The British Heart Foundation heart failure palliative care project report: `The Glasgow and Clyde experience’ (2010) outlined a project to identify patients with HF that could benefit from palliative care, with the aim of developing care delivery to these patients within Glasgow and Clyde [34]. This report identified that supportive palliative care could be integrated into the existing heart failure nurse specialists’ role. Additionally, another report: Role of the British Heart Foundation heart failure palliative care specialist nurse: a retrospective evaluation identified that the implementation of a heart failure palliative care nurse specialist could improve the care that AHF patients received at the end of life [35].

Overview of the Caring Together (CT) Programme

The Caring Together programme aims to develop pioneering models of palliative care for patients in the advanced stages of heart failure in Greater Glasgow and Clyde.

In particular, the CT programme aims to [36-38]:

- *meet the needs of patients and carers*
- *complement the optimal management of heart failure*
- *promote equity of access to palliative care for heart failure patients*
- *acknowledge the patient's preferences in place of care, including home*
- *enable increased choice of place of care for patients*
- *improve coordination of care among stakeholders*

The programme implementation has thus focused on:

- developing integrated models of care for heart failure patients and providing improved access to palliative care services
- implementing core components of the model according to local needs and within service capacity
- improving access and standardising care processes for AHF patients
- raising awareness and availability of palliative care for heart failure patients
- improving communication between the stakeholders in primary and secondary care and ensuring continuity of care during the transition from hospital to community.

The Core Components of Caring Together	
I – Patient Identification and Referral	If a patient is registered with a GP within the 3 pilots area, • **has a diagnosis of AHF (NYHA III or IV)** • **has distressing or debilitating symptoms despite optimal medical therapy** • **has supportive or palliative care needs** that may include a combination of physical, social, emotional, spiritual or psychological needs
II – Holistic Assessment of CT patient	• cardiology review: (outpatient / in-patient as appropriate) • holistic assessment: review with patient of the physical, social, psychological and spiritual aspects of their needs in order to identify appropriate solutions
III – Care Management and Coordination	• patient is assigned a care manager (usually the HFNS), acting as the main point of contact for care management, information, advice and support
IV – Training & Education	• Training provided to stakeholders delivering services within the programme • Shared learning between specialties (palliative care / cardiology and service delivery settings, community / acute care)
V – Multi-disciplinary work and Joint Working	• Joint working and care coordination across teams (community, out-of-hours care and acute care) • care manager, coordinates care with the MDT and can action additional referrals if required • a care plan is devised with individual patients to fulfil personalised medical and palliative care needs and national guidelines.

The programme has been piloted in three areas of the NHS GGC health-board:

- North-East Glasgow (NE)
- South-West Glasgow (SW)
- Inverclyde (Inv)

Figure 1. NHS Greater Glasgow and Clyde Community Health Partnerships (http://www.chps.org.uk/content/)

Structure of Caring Together Programme

Caring Together is supported by a full time programme manager and full time administrator, both jointly funded by Marie Curie Cancer Care and the British Heart Foundation. The programme manager is responsible for day-to-day management of the programme activity. In addition, the programme has part-funded a consultant cardiologist with an interest in heart failure and palliative care - employed through NHS GGC - and a full time lead nurse/senior lecturer - employed through Glasgow Caledonian University. A programme board, composed of representatives of the partner organisations (Marie Curie Cancer Care, the British Heart Foundation, and NHS GGC) is responsible for the management of the programme in Glasgow and Clyde. Below we provide a copy of the full details of the core components and models of the programme which have previously been described in reports from each of the three facilitation groups [36-38].

Development of the Integrated Models

The three integrated models of care, being used across GGC, have been designed and developed with the full participation of the local stakeholders. The core components and other key aspects were developed by the Design and Operational Group (DOG). Local facilitation groups have taken the core components and facilitated the redesign of services to accommodate the components and integrate them into the local delivery.

The main work group of the programme was the Design and Operational group (DOG). The DOG was a multidisciplinary stakeholder group comprised of clinicians and key service providers within Glasgow and Clyde, who provided front-line knowledge and expertise as well as being champions for the programme. The DOG was responsible for the design of the core components of the models, guided service redesign in the three different localities, had oversight of the outputs of the programme, recommended service changes to the programme board and identified local issues and risks. In overall the DOG was responsible for the design and development of the models which meet the needs of the patients and carers.

Under the DOG were three local facilitation groups (NE Glasgow; Inverclyde; South West Glasgow) consisting of hospital, hospice and community care professionals involved in the management of patients with heart failure in each pilot area. The local facilitation groups, supported by the programme team were responsible for the development and implementation of the local models which would meet local demand and be provided within existing service capacity. The local facilitation groups were crucial in ensuring that the model for the pilot site met local needs.

Core Components of Caring Together

Clear and concise referral criteria and pathways

Patients are referred to Caring Together if they meet the following criteria:

- Have advanced heart failure (New York Heart Association classification categories III or IV)
- Have distressing or debilitating symptoms despite optimal medical therapy
- Have supportive or palliative care needs that may include a combination of physical, social, emotional, spiritual or psychological needs
- Are registered with a GP in North-east Glasgow, Inverclyde or South-west Glasgow

In order to promote consistency in the application of the referral criteria, the programme board approved (Sept 2013) the use of supplementary considerations for referral to Caring Together:

- Increasing age (>75) [frail and elderly]
- Co-morbidities (one or more)
- Increasing symptom burden/symptomatic
- Hospital admissions or requiring increased home visits in last year
- Assessment for transplant/advanced specialist intervention
- Surprise question *"would you be surprised if this patient died in the next year?"*

These supplementary considerations are not to broaden the referral criteria, but to support decisions on who should be referred, and to minimise misinterpretation which leads to exclusion of appropriate patients to CT.

A comprehensive assessment of identified patients

Patients who meet the referral criteria receive:

- a cardiological review in outpatient or in-patient settings as appropriate
- a holistic assessment which looks at the physical, social, psychological and spiritual aspects of their needs so that these needs can be addressed

The holistic assessment is supported by the Caring Together Holistic Assessment Tool (HAT). The HAT provides prompts and supports the holistic assessment of both patient and carer. The HAT includes validated tools such as the Edmonton Symptom Assessment Score (augmented with HF symptom specific questions), patient health questionnaire (PHQ-9), Generalised Anxiety Disorder Assessment (GAD-7) questionnaire and modified carer strain index. The HAT supports the care manager in identifying patient and carer needs, and monitoring any changes which may occur. The care manager can refer the patient and carer onto other services as appropriate e.g. rehabilitation, social services, benefits assessment, carer health assessment, specialist palliative care, hospice day services, palliative clinical nurse specialist or other clinical specialities.

Allocation of a care manager who leads and coordinates care

Each patient in Caring Together is assigned to a care manager, who will act as their main point of contact for information and support. The care manager, who could be their heart failure nurse, district nurse or GP, works closely with the wider multi-disciplinary team to ensure that the patients and their carers receive the care and support that they need.

An individualised anticipatory care management plan

Caring Together has developed a medical anticipatory care plan to meet patients' care needs and national guidelines. The care plan is completed by the patient's cardiologist and includes concise information on the patient's medical and palliative care needs, patients understanding of their condition and prognosis, and patient’s place of care and Do-Not-Attempt-Cardiopulmonary-Resuscitation preferences. The care plan is shared with the wider multidisciplinary team to ensure that all aware of the patient’s condition and preferences of care. The GP is a vital component of this as the information within the care plan allows completion of the electronic palliative care summary (ePCS), which is vital in the out-of-hours management of these patients.

Where a medical anticipatory care plan cannot be produced, Caring Together has implemented standardised letters which are used to communicate patient preferences and understanding to the wider multidisciplinary team including the GP (for ePCS completion).

Education and Training

A training needs analysis of key staff groups in the pilot sites was undertaken by CT during February and March 2011. The analysis identified levels of knowledge and understanding of heart failure and palliative care for these key staff groups. Successful consultation with the community, heart failure and care home lead nurses across the NE/SW and Inverclyde pilot sites has resulted in training of and awareness sessions being provided for over 200 clinicians and updates are continuing. Training sessions have been undertaken for a number of professional groups including: General Practitioners, Band 6 District Nurses, Palliative Care Resource Nurses, Heart Failure Specialised Nurses, Care Home Liaison Nurses and Long Term Conditions Benefits Assessors. Any additional professional development needs arising from these sessions has been addressed where possible by signposting to existing educational resources currently available across GG&C, NHS Education for Scotland (NES) and Department of Health.

An approach to multidisciplinary working and joint learning

The programme's multidisciplinary approach across the acute, community and out-of-hours care teams enables us to deliver consistent and coordinated services to patients and their carers in all care settings. We also support joint learning between palliative care and cardiology teams in the acute and community settings (see below).

Integrated Models in the three Pilot Sites

The local facilitation groups in each pilot site have taken the core components and designed and developed integrated models of care which are appropriate to the locality, meet local demand and can be provided within existing service capacity. The local facilitation group have been crucial in ensuring that the models for the pilot site meets local needs, both in terms of resources and patient and carers needs.

North East (NE) Glasgow

The NE Glasgow pilot site is an urban area that covers a population of 224,000. Hospital care is mainly provided by Glasgow Royal Infirmary and Stobhill Hospital and hospice care by the Marie Curie Hospice. Community care is provided by the North Sector of the Glasgow City CHP.

Outpatients that fit the CT criteria attend the Heart Function and Supportive Care Clinic at Glasgow Royal Infirmary, staffed by a consultant cardiologist (with an interest in heart failure and palliative care) and a heart failure palliative care nurse. The clinic operates weekly (7 out of 8 weeks), and usually sees 2 new patients and 3-4 returning patients. Patients are seen for cardiological assessment, optimisation of therapy where appropriate, assessment of palliative care needs and generalist palliative care interventions and support. The cardiologist is provided with the capacity to communicate progression of symptoms and the need for anticipatory care planning to the patient and carer.

The majority of patients are referred to the clinic by fellow consultants and heart failure specialist nurses. In general the cardiologist will not have met the patient prior to their first attendance at the clinic. The holistic assessment of patients is undertaken by the heart failure palliative care nurse using the Caring Together HAT to support, guide and record the assessment. Depending on the condition and understanding of the patient and carer, the assessment may not be completed within the clinic.

For LVSD (Left ventricular systolic dysfunction) patients, the appropriate heart failure specialist nurse will be identified as the care manager. The holistic assessment tool is passed to the care manager for completion and/or ongoing monitoring of the patient. For non-LVSD patients the heart failure palliative care nurse will continue to act as care manager.

The outcome of the outpatient consultation is communicated to the patient's general practitioner and district nurse (and other healthcare professionals as appropriate) via a template letter from the cardiologist (which includes information required for the completion of the electronic palliative care summary). Where appropriate, the cardiologist completes a medical anticipatory care plan which is copied to the GP and district nurse. The care manager will communicate changes in the patient condition to the GP and district nurse through template consultation letter (which can include information from the holistic assessment tool where appropriate). Where appropriate, patients and carers are provided with anticipatory care plans (NHS GGC anticipatory care tool - "Thinking ahead and making plans") for consideration and completion; the care manager can support and guide the patient and carer in the completion of the plan.

The cardiologist and heart failure palliative care nurse can directly (at the time of the clinic appointment) refer patients to the Long Term Conditions Benefit services for assessment of their benefits allowance and other social care needs.

For inpatients, a weekly multi-disciplinary team ward round in the cardiology ward at Glasgow Royal Infirmary has been established. The Multi-Disciplinary Team (MDT) is for patients admitted with a diagnosis of heart failure and is led by the same consultant cardiologist as the outpatient clinic. The aim of the MDT Ward Round is comprehensive assessment of patients holistic needs, optimisation of cardiological interventions where appropriate, referral to other services e.g. insertion of devices, palliative care and social services. Patients who are admitted to other wards e.g. Care of the Elderly will be discussed at the MDT Ward Round and if appropriate referred to Caring Together.

Inverclyde

The Inverclyde pilot site is a predominately rural area with a population of 81,000. Hospital Care is mainly provided by Inverclyde Royal Hospital and hospice care is provided by Ardgowan Hospice. Community care is provided by the Inverclyde Community Health and Care Partnership (CHCP).

Patients that fit the CT referral criteria are reviewed at outpatient palliative care appointments within the existing Heart Failure Clinic at The Royal Inverclyde Hospital. The clinic is staffed by a consultant cardiologist and a Heart Failure Specialist Nurse (HFSN). Operating monthly the clinic usually sees six palliative patients for joint cardiological assessment by the cardiologist and HFSN and optimisation of therapy where appropriate. Due to the small size of the hospital, and for the majority of cases the patients are known to the cardiologist prior to the palliative consultation and it is predominately the cardiologist and HFSN that place them for the palliative care consultations. The cardiologist does not address palliative issues. The HFSN, in the clinic, undertakes the assessment of palliative care needs (Caring Together Holistic Assessment Tool) and advises on generalist palliative care interventions and support. There is regular communication with palliative care colleagues in the Ardogwan Hospice and within the hospital and if necessary patients are referred to palliative care for specialist input/day therapies as appropriate. The Heart Failure Specialist Nurse (HFSN) in the clinic or their colleague take on the role of care manager subsequent to the consultation. The anticipatory care plan is raised and provided where appropriate. The patient is discussed at monthly MDT as appropriate where a palliative consultant and specialist palliative care nurse are present.

The Cardiology Ward Round identifies inpatients that may fit the criteria for CT and require assessment of holistic needs, optimisation of cardiological interventions and referral to other services. Inpatients are discussed at monthly MDT meetings which included palliative care consultant and specialist palliative care nurse.

South West (SW) Glasgow

The SW Glasgow pilot site is a predominately urban area with a population of 117,000. Hospital care is mainly provided by the Southern General Hospital (SGH) and hospice care is provided by the Prince and Princess of Wales Hospice. Community care is provided by the South Sector of the Glasgow City CHP.

Patients that fit the CT referral criteria are reviewed as outpatient's palliative care appointments within the existing Heart Failure Clinic at the Southern General Hospital. The clinic is staffed by a consultant cardiologist and a HFSN. Operating weekly the clinic usually sees 2-3 palliative patients for joint cardiological assessment by the cardiologist and HFSN and optimisation of therapy where appropriate. The majority (but not all) patients will be known to the cardiologist and/or the HFSN. The cardiologist does not address palliative issues. The HFSN, in the clinic, undertakes the assessment of palliative care needs (Caring Together Holistic Assessment Tool) and advises on generalist palliative care interventions and support. Patients are referred to palliative care for specialist input/day therapies as appropriate. The HFSN in the clinic or their colleague take on the role of care manager subsequent to the consultation. The anticipatory care plan is raised and provided where appropriate.

The Cardiology Ward Round identifies inpatients who fit the CT criteria and require assessment of holistic needs, optimisation of cardiological interventions where appropriate, and referral to other services.

Refining the Models

Following the approval of the models and associated tools by the CT programme Board in June 2011, the three pilot sites implemented the first iteration of their model. The sites identified patients that fit the criteria of CT, completed assessments, assigned care managers and are co-ordinating the care of these patients. The first iteration of the three models in the pilot sites ran to November 2011. An action research partner supported the programme in the refinement of the models and tools in each of the three pilot sites. This iterative assessment identified issues, barriers, good practice and amendments to processes and tools that required refinement. The models and tools were amended as necessary by the programme and facilitation groups for the second iteration from March 2012 to November 2012, when a second iterative assessment was undertaken. The final versions of the models were implemented by the programme team and facilitation groups in April 2013.

Caring Together: Background Summary

The CT programme has identified core components with clear aims and objectives. These core components have been implemented in different ways across GGC. Thus, three different models of CT have been rolled out in order to ensure models that were fit to meet the needs of the local health care context. Such an approach was necessary to increase the likelihood of acceptance of the programme and to promote integration and embedding of the models into everyday practice across the area which, although representing just one health board, serves circa 1.8 million people.

IV- Methods

IV.1 – Literature Review

The purpose of our scoping review is to assess the state of the art in the development of dedicated integrated palliative care pathways for heart failure and in particular, the reported impacts on service provision, clinical processes and the quality of life of patients and carers. Having identified the key components we can then compare these to the core components of the CT programme.

The research questions can be broken down into the following subcategories of objectives:

Objectives of Scoping Review

Objective 1: To identify and describe the range of palliative care interventions for patients with advanced heart failure.

Objective 2: To describe barriers and facilitators to implementation in practice.

Objective 3: To describe eligibility criteria and referral protocols to the palliative care interventions.

Objective 4: To describe who had responsibility for care management and how communication and information-sharing among the multi-disciplinary care team was conducted?

Objective 5: To explore how intervention effectiveness was assessed? What outcome measures were used? For example, in relation to impacts on the Quality of Life of patients and carers or on health care utilisation?

Objective 6: What benefits or disbenefits resulted from the interventions?

Objective 7: What were the effects, if any, on health service provision, clinical processes and continuity and coordination of care?

Objective 8: To compare the key components of palliative care models identified in the literature with those of the CT programme.

The full search strategy is enclosed with this report as Annex I.

The following databases were searched:

Database	Interface / URL
MEDLINE In-Process & Other Non-Indexed Citations and MEDLINE	OvidSP

Inclusion Criteria

Types of studies: primary studies (quantitative, qualitative or mixed-methods) describing interventions designed to develop integrated care pathways for advanced heart-failure.

For a study to be included there had to be evidence of at least one of the following:

- Reporting on the development and/or implementation of palliative care pathway AND involvement of patients with advanced – heart failure (even if the pathway is not exclusively developed for this population but the population is specifically assessed in the study).

Exclusion:

- Reviews and meta-analyses
- Studies of palliative care pathways not involving heart-failure patients
- Studies of heart-failure management or treatment not included as part of a coordinated palliative care pathways

Types of participants:

- Service providers
- Patients
- Carers

Data Extraction & Analysis

Data extraction was performed using a standardised data instrument (Annex II) to collect information along the 7 objectives (where they were applicable).

IV.2 – Method for Qualitative Study and Analysis

- We conducted n=23 interviews with a range of stakeholders of the CT implementation between September 2013 and January 2014. Ethics approval for qualitative data collection was sought and granted in September 2013 by the University of Glasgow College of Medicine, Veterinary and Life Sciences (MVLS) and is enclosed as Annex III.
- A semi-structured interview questionnaire, based on the NPT framework was been developed and piloted in September 2013 with the Caring Together Programme Manager and Lead Nurse and is enclosed as Annex IV.
- The Caring Together Programme Manager and Lead Nurse provided one researcher (MMB) with a list of key stakeholders. All stakeholders on the list were contacted with an invitation to take part in this study. A participant information sheet was sent along to all potential study participants with the option to take part in either a face-to-face interview or by telephone and is enclosed as Annex V.
- If stakeholders responded positively to the invitation to take part in the study, a interview was scheduled with one of 2 researchers (MMB or KS), preferably face-to-face or by telephone, according to the preference of the interviewee.
- From then on, we used a `snow-ball' approach to identify further stakeholders. This means that once we had completed an interview, we asked each participant to suggest who else – in their opinion – we should contact for further information about the programme implementation.

The interviews aimed to collect respondents' views around the following core questions:

- *Aims and motivation of the CT according to the participant's perspective*
- *Which of these aims were achieved and how? Which were not and why?*
- *What were the facilitators and barriers to implementation*
- *What aspects of the programme had transformed service delivery*
- *What were the perceived benefits and disbenefits of the programme*

- *Who were the main stakeholders in the programme implementation and delivery, according to the participant's perspective*
- *How is the CT implemented in the service and operationalised on a day-to-day basis. This included more detailed questions on the programme core components: referral to the programme, holistic assessment, care management and coordination and advanced care planning.*
- *How did the stakeholders communicate, shared information and coordinated care. What processes and systems did they use for this?*
- *What were the skills and training needed to allow a successful programme implementation?*
- *What were the lessons learned?*
- *What recommendations would the participant make to others wishing to implement the CT in another geographical or service setting?*

The interviews were semi-structured and open-ended in order to allow the interviewer or interviewee to elaborate on unanticipated and potentially valuable information with additional questions, and probe for further explanation [39].

We used Normalisation Process Theory (NPT) as a conceptual framework to interpret the perceived benefits or disbenefits of the programme and the factors which were identified as facilitating or hindering the programme implementation.

NPT is concerned with the social organisation of the work (implementation) of making practices routine elements of everyday life (embedding) and of sustaining embedded practices in their social contexts (integration) and was developed particularly in response to the evidence, which suggested that embedding and integrating innovative health interventions can be difficult to achieve in practice [24, 25].

Several dimensions of the NPT framework are particularly well suited for a study of this nature. First, it considers implementation processes as crucial factors affecting an intervention in a given context or – in other words – that a myriad of complex factors can

affect the outcomes of an intervention. As an example, a teleconsultation intervention could fail in a specific setting because technological toolkits are unreliable, the network infrastructure does now allow it to operate adequately or the rationale for replacing the existing service is unclear or actively resisted by the very agents supposed to operationalise the new system. In a different environment, using robust and reliable technology, championed by influential local stakeholders and with clear practical health and / or financial benefits, the same intervention could be successful (for example, using a tele-consultation to decide whether an oil-rig worker needs to be airlifted or not to hospital).
Thus, NPT considers a complex intervention – such as the introduction of new services or a technology implementation – as a dynamic social process, shaped by the collective action of stakeholders through their *`agency'*, i.e. the ability for health professionals to shape events on the ground through one's own actions, which is of particular importance for a programme which seeks to bring new ways of delivering care such as the CT.

Importantly, NPT considers the organisational context in which the stakeholders' agency operates as being a key factor affecting the ultimate normalisation – or not – of new services and systems. NPT thus provides a useful theoretical lens through which one can understand how new systems and services (such as electronic health records and integrated care pathways) can be successfully deployed, what are the factors that contribute to the normalisation of new ways of working or – on the other hand – what were the factors which may have contributed to the failure or rejection of new systems and services.

The 4 key constructs of the NPT framework are presented in the following table:

Overview of Normalisation Process Theory (NPT):

NPT was developed in response to the evidence, which suggested that the implementation, embedding and integration of complex interventions and new ways of working are difficult to achieve in practice.

NPT aims to explain the routine embedding of practices by reference to the role of four generative mechanisms: ***coherence; cognitive participation; collective action and reflexive monitoring.***

- **Coherence:**

  refers to the work of making a complex intervention hold together and cohere to its context, how people "make sense" or not of the new ways of working.

- **Cognitive participation:**

  is the work of engaging and legitimising a complex intervention, exploring whether participants buy into and/or sustain the intervention.

- **Collective action:**

  examines how innovations help or hinder professionals in performing various aspects of their work, issues of resource allocation, infrastructure and policy, how workload and training needs are affected and how the new practices affect confidence in the safety or security of new ways of working.

- **Reflexive monitoring:**

  is the work of understanding and evaluating a complex intervention in practice, and how individuals or groups come to decide whether the new ways of working are worth sustaining.

Table 1. Normalisation Process Theory 4 generic constructs

Data Analysis

All interviews were audiotaped with respondents' consent and transcribed to form the data for analysis which was examined using a framework approach [39], using an NPT informed framework (included as Annex VI). Quality control of analysis was ensured through the use of data clinics to discuss coding and through double checking of coded data. Our framework was flexible and we sought data that fell outside the framework to ensure the comprehensiveness of our analyses.

V-Scoping Literature Review

This scoping review is divided into 2 separate parts:

I- a review of guidelines on the care management of patients with AHF, and a

II- a scoping review reported of integrated models of care for AHF.

V.1 - Heart failure palliative care guidelines review.

There are a number of published evidence based guidelines relating to heart failure from around the world. This section reviews current European, North American and Canadian heart failure guidelines specifically in respect to their guidance on palliative care and end of life care arrangements and models. Information specifically relating to the delivery and models of palliative care have been included rather than information on clinical management.

The guidelines vary on the extent of their palliative recommendations. Most have sections dedicated to palliative or end-of-life care in heart failure [19, 40-44] with additional update [45] and position statements [20] giving further detailed palliative guidance also. The majority of the guidelines reviewed in this section are from 2009 onwards representing the most up to date guidelines available for review. The Canadian Cardiovascular Society conference recommendations were from 2006 [44] but there was an additional 2011 update with specific section on palliative care [45]. Additionally included was a scientific statement from the American Heart Association on decision making in advanced heart failure [46] which – although not a guideline – makes recommendations on decision making in advanced heart failure.

Eligibility and Referral to Palliative Care

It is acknowledged that prognostication in heart failure can be challenging. The importance of end of life care and palliative care is mentioned by many guidelines as part of heart failure management. Prognostication can be one of the causes of difficulties when identifying patients suitable for palliative care and those who are approaching end of life care. Due to the different illness trajectory of heart failure as compared to other conditions, such as cancer, there may be different points in the disease course where it is appropriate to consider end of life planning and care, as acknowledged in the position statement from the Heart Failure Association (HFA) of the European society of cardiology (ESC) [20]. The scientific statement from the American Heart Association (AHA) notes the importance of clinical trajectory in guiding decisions and ensuring that they are made at the appropriate time [46].

The Canadian Cardiovascular Society update recommends that there should be regular discussion of advanced care planning with patients and their families, and that palliative care should be provided not on a basis of remaining life expectancy but on an assessment of needs and symptoms [45]. Many of the other guidelines discuss advanced care plans and advanced directives as way of planning future and end of life care [20, 41, 42, 45]. The AHA scientific statement further highlights this issue by saying that on hospital admission it is better to review advanced care plans which have been discussed prior to admission rather than trying to introduce them on admission and that it should be the clinician that is responsible for initiating discussions and formulating a customised plan for end of life care [46].

The initial identification of patients who may be suitable for palliative care is challenging and there have been a number of different criteria suggested to guide decision making in this sphere. For example the European Society of Cardiology (ESC) guidelines suggest factors that can be considered to identify patients for end of life care, such as clinical judgement, NYHA class, frequent admissions and quality of life [42]. Another important aspect of identifying patients would be based on clinical judgement. The Heart Failure Society of America (HFSA) recommend that identification of patients who are at the end-of life should be in collaboration with clinicians who are experienced in heart failure but also suggests a number of clinical features to identify those with advanced persistent heart failure [42]. The American College of Cardiology Foundation (ACCF) guidance suggests that heart failure or palliative teams are the most appropriate people to help families and patients decide when the time is right for palliative care [43].

This would seem to suggest that an approach using both clinical judgement and patient specific factors would be the best way of identifying patients for end of life care. This would be balanced with patient's wishes and expectations.

There is some disparity in guidance as to when palliative care should be discussed with patients. The Scottish Intercollegiate Guidelines Network (SIGN) guidelines recommend adoption of a palliative care approach early in chronic heart failure [19]. The National Institute for health and Care Excellence (NICE) guidelines also suggest that palliative needs be considered at the `earliest opportunity’ [40] and a major recommendation within the HFA position statement is that disease course including advanced directives be discussed at an early stage of disease [20]. In concordance with this the AHA scientific statement suggest that referral to palliative care should be considered at a time while 'disease-modifying therapies' continue [46].

However there is no consensus on when these discussions surrounding end of life should take place. In seeming contradiction to the above guidance the HFSA guideline suggests that these discussions be held until later in the HF disease process:

"Discussions of end-of-life care can occur when the patient has progressed to a state of severe, refractory HF" [41] (p494).

However the HFSA guidance goes on to suggest that discussions should take place early enough in the disease course that the patient is still capable of being involved in the discussion [41] which again emphasises the role that patients should play in these discussions and decisions about their end of life care.

Although there is apparent discordance between guidelines regarding the ideal timing for discussion of palliative care with patients they all suggest it be discussed early enough that the patient can be involved in the discussion. The majority of these guidelines do suggest that it be discussed earlier in the disease course which would allow forward planning and may lead to earlier identification and referral of patients. Ultimately it appears that current guidance suggests that the timing of such discussions is a decision to be made between clinical teams, patients and families. Unfortunately, the evidence to date from the literature suggests palliative care issues are often not discussed with patients suggesting perhaps that the current vagueness and lack of consensus of clinical guidelines in relation to this may be contributing to rather than resolving uncertainty about the timing of such discussions.

Range of Palliative interventions

Although end stage management and palliative care are covered in these guidelines, there is little specific information on the range of possible palliative care models or interventions and how they should be implemented. For example, the NICE guidance on heart failure recommends that patients and families or carers have professionals within the team looking after their heart failure that have palliative care skills [40]. However, there is limited guidance on who within the team should have these skills or how they should be coordinated.

Only a few of the guidelines give specific details on this issue. The position statement from the HFA of the European Society of Cardiology outlines two possible models for the arrangement of palliative care in advanced heart failure [20]:

> 1. *"Heart failure specialist care aligned with palliative care consultancy... the patient is cared for primarily by the HF specialists, be it the HF interdisciplinary care team or the cardiologist. General palliative care is provided by the general practitioner or general community nurses, with specialist palliative care input by the palliative care physician or specialist teams as required"* [20] (p440).
> 2. *"Heart failure-oriented palliative care services.... in which palliative care services assume responsibility for the basic care of the patient and their family, and HF specialists serve as consultants for specific issues relating to the treatment of HF"* [20] (p441).

This gives two possible models that could be implemented depending on the existing organisation and structure of the background health care system and the available resources. They acknowledge that no one model will be transferrable between all health care systems [20].

The Canadian Cardiovascular Society recommend the use of an "interdisciplinary CCM [Chronic Care Model]" [45] (p328) for arranging palliative care services which is a patient centred chronic disease model of care [47] with 6 core elements:

- Community Resources and policies
- Health systems organisation of health care
- Self management support
- Decision support
- Delivery system design
- Clinical information systems

While no other guidance gives details of specific models there is guidance that there should be coordination and integration of care for example the HFSA guidance recommends that there should be integration and coordination of care between primary care heart failure specialist services and other outside agencies [41]. This would imply that there is need for a structured collaborative approach toward to the provision or models of palliative care.

Responsibility for care

All of the guidelines discuss the 'team' involved in the palliative management of patients with heart failure. The two models outlined above from the HFA of the European Society of Cardiology position statement regarding the optimal arrangements for palliative care suggest two possible different groups of specialists being responsible for the management and coordination of care [20]. The SIGN guidelines suggest the delivery of "low to moderate complexity" palliative care being delivered by the patients usual care providers which could refer to any member of the team involved in the patients care in primary or secondary care, and may depend on who the patient routinely sees for their heart failure management or the locally available services for each individual patient [19]. This may fit with the first model for palliative care suggested by the HFA position statement where palliative care is suggested to be provided by the general practitioner and community nurses [20].

Coordinating care

Co-ordinating care is an important aspect in management of end stage heart failure. The role of coordinator of care and liaison between professionals may be assumed by different members of the team and may vary in different health care systems [20]. The HFA guidance also makes reference that palliative care is "applicable to all care settings and is not dependent on a specific health-care team" [20] (p436). Many of the guidelines highlight the importance of coordination of care [41] or a shared care approach and this would suggest that there needs to be someone within the team with an overall view of the patients care - coordinating care and seeking the specialist advice from others where needed. To this end it the HFA position statement suggests that there should be development of "formal professional alignments" and a collaborative working arrangement [20].

Ultimately this guidance would emphasise that palliative and end of life care can be provided by any member of the patients care team. The organisation of this will depend on local health care systems and availability or services and existing collaborations between specialists and teams. There is no direct guidance on who should have overall responsibility for care and coordination, but there does need to be this collaborative approach to provide the best possible end of life care and will need a member of the team to take on responsibility for care coordination and liaison.

Barriers and Facilitators

As already touched upon there will be a number of barriers and facilitators to the successful implementation of palliative care in advanced heart failure. The above sections have touched on these issues. As there is limited guidance on the models of palliative care there is subsequently limited guidance on facilitators and barriers to implementation of palliative care in heart failure. The reason for the relative paucity of clear guidance on possible care models could be due to a lack of high quality evidence based research available on the different health care models being utilised.

Summary: review of Guidelines for Palliative Care for Heart Failure

While palliative care is considered in many of the guidelines on heart failure management there is little guidance on the actual arrangement of palliative care services or models themselves. There are also conflicts identified in the available guidance. There is disagreement over at what point palliative care should be considered for patients and when it is appropriate to initiate palliative care. There are different suggested models in some of the guidelines but no firm model of care unanimously suggested. There are a few common themes as noted in the above sections but how this guidance is implemented will vary according to the setting, professionals involved in care, available services and resources and patient populations. The lack of consistent guidance and a shared vision of the best approaches for the management of advanced heart failure may contribute to ongoing deficiencies in management of this patient population.

V-2 Overview of Integrated Palliative Care Programmes for Advanced Heart Failure

Following on from this review of guidelines on the care management of patients with AHF, we reviewed studies describing the implementations or evaluation of integrated palliative care models for AHF. The purpose of this scoping review was to assess the range and scope integrated palliative care pathways for heart failure and in particular, the reported impacts on service provision, clinical processes and the quality of life of patients and carers.

Search Results

The searches performed identified 1498 records. No duplicates were identified for removal.

Resource	**Records identified**
MEDLINE In-Process & Other Non-Indexed Citations and MEDLINE	1498
TOTAL	**1498**
TOTAL after deduplication	**1498**

Sixty-eight abstracts were selected for full screening and of these, n=16 studies were selected in our scoping review (Appendix VII). Those sixteen studies covered various aspects of integrated palliative care models for AHF; including twelve studies that described specific models of care in detail, which we now present in chronological order of implementation or reporting in the literature.

PhoenixCare demonstration program (1999-2001)[1]

Overview of PhoenixCare

In response to a perceived need for patient access to palliative care and supportive services prior to hospice eligibility (i.e. funded by Medicare for the final 6 months of life), the Robert Wood Johnson Foundation[2] (RWJF) initiated in 1999 a national initiative in the U.S. to support novel care delivery models that extended palliative care upstream in the course of illness, in parallel with life-extending care. *`Promoting Excellence in End-Of-Life Care'*[3] *funded* 22 demonstration projects with the aim of identifying successful approaches and models. The Hospice of the Valley[4] (Phoenix, Arizona, U.S.) received a 3-year grant (1999-2001) to develop the PhoenixCare project, a demonstration programme of coordinated home-based and palliative care services for individuals with advanced chronic illnesses, still undergoing active treatment within a managed care setting [48]. This pilot aimed to improve the quality of life and physical and mental functioning of patients, while striving to be either more cost-effective – or at least cost neutral – compared to traditional care. Participants needed to have either a diagnosis of CHF or COPD, with a life expectancy of up to 2 years.

The program delivered home-based care and support services, focusing on:

- *disease and symptom management,*
- *patient and caregiver education on disease management,*
- *social and psychological support*

An important element of the rationale behind the project implementation as a home-based programme lay in the fact that many individuals with life-limiting illnesses reside at home rather than in care facilities.

PhoenixCare Model

---

[1] **NOTE: the dates associated with a specific programme in the subtitles are those reported in the referring study, and are here provided for reference purposes only. The dates typically cover the period during which a programme or intervention was evaluated and the valuation reported in the literature. The dates should therefore NOT be interpreted as indicating that the intervention ended after the said period or indeed that the programme has now been discontinued.**

[2] Robert Wood Johnson Foundation: http://www.rwjf.org/en/about-rwjf.html

[3] http://www.rwjf.org/en/research-publications/find-rwjf-research/2009/10/promoting-excellence-in-end-of-life-care.html

[4] http://www.hov.org/

Registered nurse case managers played a leadership role in coordinating the PhoenixCare services in liaison with the patient's primary care doctor, managed-care[5] organisations case managers and with community agencies. Each nurse case managers, provided service to a caseload of 30 to 35 patients. As PhoenixCare participants are approaching death yet still under treatment, the nurse case managers coordinate palliation and treatment services in parallel.

The PhoenixCare model is summarised in the following table:

The PhoenixCare Model [48]	
Focus 1. Self-management of illness and knowledge of resources	*`the program aimed to increase patient self-management of illness and knowledge of health-related resources by providing information and education to patients and caregivers'*
Focus 2. Preparation for end of life	*The program aimed to improve patients' readiness for end of life by promoting the acquisition of appropriate legal documents and discussion of legal documents with others.*
Focus 3. Physical and mental functioning	*The program aimed to enhance the physical and mental functioning of clients (sic) through intensive case management by PhoenixCare staff, as well as patient education for self-management of illness.*
Focus 4. Utilization of medical services	*The program aimed to shift from utilisation of high cost emergency medical services and inpatient acute hospitalisation to proactive management of disease in outpatient settings, through intensive management and patient education on self-management of disease.*

Specific care protocols each covered three distinct phases of the patient journey:

- *admission and initial case management of medically unstable patients,*
- *management of stable patients following stabilisation, and*
- *support of unstable patients experiencing an exacerbation episode.*

The stabilisation phase includes monitoring of medication compliance, educational activities and assessment of new symptoms and support needs. During exacerbation episodes, the nurse case managers took an active role in assessing medical status, implementing a

---

[5] http://www.nlm.nih.gov/medlineplus/managedcare.html

symptom control intervention, communicating with the attending physician and managed care organisation and making counselling referrals if required.

PhoenixCare Protocols [48]	
1. Disease and symptom protocol at admission	▪ assess current health status, ▪ identify immediate symptom management needs, ▪ establish communication with the managed care organisation contact and attending physician, ▪ develop an emergency response plan ▪ coordinate the plan with attending physician.
2. Educational services	▪ develop advance care plans, ▪ provide education to patient and family about the disease, ▪ provide education about patient self-monitoring and self-management of disease.
3. Support services	▪ assess psychological and spiritual needs, ▪ assist with access to community resources that might provide custodial care, transportation, and help with finances

Evaluation of PhoenixCare

Aiken et al. conducted an evaluation of PhoenixCare using a randomised trial. The control condition was the usual care provided by the managed care organisations. There were 67 CHF and 33 COPD PhoenixCare participants and 62 CHF and 28 COPD controls. An intake interview was conducted followed by 3-months intervals follow-up interviews and outcome measures assessed focused on the following 4 main categories:

1. Patient self-management of illness and knowledge of resources
2. Preparation for end of life
3. Physical and mental functioning
4. Medical system utilisation

Participants enrolled from July 1, 1999 through March 31, 2001 and all data collection ceased on September 30, 2001. Of the 101 PhoenixCare participants, 62%, 55%, and 43% provided time 3, time 6, and time 9 interviews, respectively. Of the 91 control participants, corresponding percentages were 54%, 38%, and 33% at time 3, 6, and 9, respectively. Patients had 44 contacts on average through the Phoenixcare intervention.

- intervention participants reported a sense of having greater information for self-management of illness, a greater appreciation of resources available to help with their illness (outcomes assessment, Focus 1). In the early months of intervention only, they reported better preparedness for daily experiences, an effect which later reversed at time 6.
- intervention participants showed a higher rate of having a living will or advance directive than did controls, (71% compliance in PhoenixCare vs. 65% in control) (outcomes assessment, Focus 2).
- PhoenixCare intervention was associated with maintained or improved Physical Functioning and General Health, (outcomes assessment, Focus 3).
- The level of medical utilisation remained overall unchanged during the intervention for both intervention and control participants, (outcomes assessment, Focus 4).

The evaluation thus suggested positive outcomes for the participants in the PhoenixCare intervention in comparison to the control group. Intervention patients reported having received more information about both management of illness and about resources than did controls. After the first three months (time 3), the intervention patients reported being less likely to have experienced health related events for which they were unprepared (though this effect reversed at time 6). Intervention patients were more likely to have prepared a will or advance directive by time 3. PhoenixCare patients reported higher symptom distress time at time 6. At 9 months, intervention patients reported better Physical Functioning and General Health than the control group. With regards utilisation of Emergency Medical Services, there was no reduction in standalone emergency department visits associated with PhoenixCare.

The study authors' suggested potential alternative explanations as to how PhoenixCare may have beneficially impacted patients outcomes: (i) the intervention provided an excess of usual care by complementing the managed-care organisations treatment and / or (ii) the high skill set of PhoenixCare staff – with experience in both chronic disease management and end-of-life care and with specialised training in delivering the PhoenixCare palliative care protocols – led to enhanced patient care management.

St. George Heart Failure integrated care model (1999-2002)

In 1999, a collaborative partnership between palliative care, cardiology, and respiratory clinicians was established at St. George Hospital (Sydney, Australia), with the aim of improving the care of patients with terminal, non-malignant illnesses [49]. Based on a review of the literature, retrospective case-note analysis and consultation with stakeholders, an integrated care pathway was developed to provide a systematic care plan for management of terminally-ill patients. The model includes both a collaborative, palliative care approach in parallel with a community-based HF management program and was motivated by the practical difficulties involved with having palliative care specialists seeing all patients with end-stage non-malignant diseases. Through a systematic framework for education, training, skill enhancement and knowledge-sharing and access to multi-disciplinary expertise, other clinicians involved in the care of the terminally ill patients were introduced to palliative care management approach. The aims of the integrated collaborative partnership included:

- *evaluating the perceptions of palliative care among acute care nurses;*
- *identifying potential knowledge deficits and educational needs;*
- *identifying and exploring ethical dilemmas;*
- *identifying barriers and facilitators to the delivery of palliative care in non-malignant clinical conditions;*
- *develop a research agenda to inform practice and improve care for patients with end-stage HF*

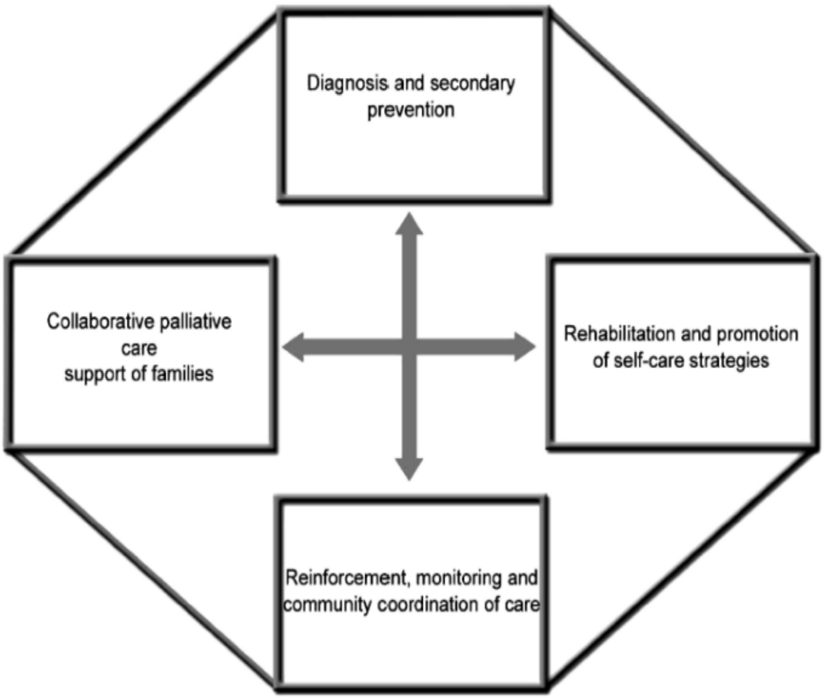

Figure 2. St. George Model of Heart Failure Care [49]

The authors suggested that the greatest facilitators of the model's success was the communication between teams – including the willingness of the palliative care service to provide education, mentorship, and expert consultancy – and the support of the St. George Division of General Practice – including endorsement of the model, education, communication and dissemination. Recently, the authors have also reported a practice guideline recommending how to implement palliative care services for terminally HF in primary care [50].

Barriers to implementation have included: the existing financial and administrative models, which do not necessarily promote the co-management of patients, the increasing need for supportive services in the community and waiting times for assessments.

The Comprehensive Care Team Trial (2003)

Rabow et al. conducted a 12 months controlled trial of a demonstration project called the Comprehensive Care Team (CCT): a multi-disciplinary outpatient palliative care service for patients with serious illness continuing to receive treatment for their underlying disease [51]. The primary goals of the project were to improve patient symptom management, psychological and spiritual well being, quality of life, and satisfaction with care. Secondary goals included improving advance care planning, reducing health care utilisation, and supporting family caregivers. The trial involved n=50 intervention patients and n=40 control patients, with a diagnosis of either cancer, CHF (n=17 intervention and n=14 control) or COPD. The CCT included a social worker, nurse, pharmacist, chaplain, psychologist, clinical artist, and three physicians and adopted a holistic approach to the care of patients (physical, emotional and spiritual). The CCT model included 7 core components (see table).

The study found that that patients with cancer, advanced CHF, or advanced COPD suffer significant symptoms burden towards the end of life. The CCT provided some improvements in the following outcomes: physical (dyspnea and sleep), psychological (anxiety), spiritual (spiritual well-being), and advance care planning (funeral planning). In addition, patients with access to CCT services made fewer primary care and urgent care visits, without an associated increase in specialty clinic visits, emergency department visits, number of hospitalisations, or number of days hospitalised.

There was no significant difference in mortality or location of death between the groups, or any evidence that intervention patients enrolled in hospice care more frequently. In general, these outpatients with advanced illness received palliation of symptoms while pursuing aggressive treatment of their disease.

There were no significant group differences in medical centre charges. CCT patients did not have improvements in pain, depression, or quality of life and the authors suggest that this may be attributed to the fact that the primary care physicians rarely implemented the CCT's pain and depression recommendations and that the primary care physicians’ (PCP) reluctance to treat pain and depression could present a barrier to holistic care improvement. An alternative explanation suggested is that PCPs did not follow CCT recommendations because patients underwent assessment by a social worker with physician review, rather than direct examination by a physician. However, the CCT consultation letter to PCPs was written and signed by a physician. Overall, the CCT was most effective in improving outcomes that the team could influence directly, via provision of services, education, and support. The CCT had little effect on outcomes that required action by PCPs. Outpatient palliative medicine teams might have greater efficacy if they are able to directly implement recommendations within clearly defined limits agreed to by the PCP.

Core Components of the Comprehensive Care Team [51]
1. Consultation with Primary Care Physician (PCP): - in-depth and follow-up patient assessments conducted by the social worker. - assessments presented to the entire CCT at regularly scheduled team meetings directed by one of the CCT physicians. - at 3 points (study entry, midway, and study completion), the CCT developed recommendations that were offered to the patient's PCP via a written letter and e-mail. Recommendations based on validated patient surveys and the social worker assessment were offered in the following 5 domains: physical symptoms, psychological well-being, social support, spiritual well-being, and advance care planning.
2. Individual case management: the social worker provided case management and offered psychological support in person and by telephone. The social worker also encouraged patients to address issues of advance care planning, including surrogate decision makers, prognosis, funeral arrangements, and wills.
3. **Family / care-giver support:** a nurse provided family caregiver training and support through formal classes and informal individual consultation.
4. **Medication Review:** a pharmacist performed a medical chart review of patient medications, looking in particular for drug-drug interactions and unnecessarily complex medication regimens.
5. **Spiritual and psychological support:** a chaplain offered each patient spiritual and psychological support.
6. Monthly Support groups: patients and their families were invited to monthly support groups that included discussions about symptom management and advance care planning, and art projects designed to explore emotions relating to illness and relationships.
7. Volunteer Patient Support: medical and pharmacy students provided volunteer patient support and advocacy through weekly telephone contacts with patients, monthly visits, and regular communication with the CCT about patient needs.

Pathways of Caring (2000-2003)

The Veterans Administration (VA) Greater Los Angeles Healthcare System implemented a 3-year demonstration project called *`Pathways of Caring'* aiming to improve end-of-life care for veterans diagnosed with inoperable lung cancer, AHF and chronic lung disease [52]. The project was primarily targeted towards four poor-prognosis conditions – unresectable non-small–cell lung cancer (NSCLC), advanced CHF, end-stage COPD, and advanced cirrhosis – but was designed to be applicable to other illnesses. The main goals of the program are:

1. *Identification of patients early after determination of a poor prognosis*
2. *Development of care goals based on the patient's values and preferences, and delivery of care that remains consistent with those goals*
3. *Comprehensive care throughout the patient's illness, addressing the full spectrum of physical, emotional, social, and spiritual needs*
4. *Continuity of care and coordination of services across providers and care settings*
5. *Support for families' caretaking and emotional needs*

During the program's 3 year duration, n=132 patients were enrolled (n=37 for CHF). The study authors suggest that the programme contributed to a *`significant shift of palliative care service delivery upstream'.* An analysis of 54 program patients who died and spent at least 1 month in Pathways demonstrated rates of advance directive completion including 56% for power of attorney for healthcare and 31% for written living wills. Fifty percent of these 54 patients enrolled in hospice (4 out of 11 for CHF). Forty-three percent of Pathways patients were able to die at home, and only 28% died in the hospital. In the final 30 days of life, program patients averaged 3.5 days in the hospital, including 0.4 days the ICU. Median hospice length of stay for hospice-enrolled program patients was 25 days, identical to national hospice statistics.

Pathways of Caring [52].

1. **Active case-finding and enrolment:**
   - After confirmation of program-appropriateness using eligibility criteria and contact with the primary provider, enrolled patient receives disease-specific information on disease pathophysiology, common symptoms and their management, emotional and spiritual issues and support strategies, and advance care planning.
   - The patient also receives detailed information on the program itself including its goals, system of care, 24-hour telephone contact numbers, and survey evaluation strategy.
2. **Interdisciplinary palliative assessment:**
   - enrolled patient and family member are scheduled for a 2-hour outpatient evaluation during the program's biweekly clinic. The evaluation is conducted in consecutive 20-minute appointments with each Pathways team member and includes: *basic symptom assessment, identification of social and financial issues, nutritional evaluation, assessment of emotional and spiritual resources, and advance care planning.*
   - each provider documents the assessment and plan, with targeted follow-up arranged based on individual patient needs.
   - document surrogate decision-maker and end-of-life treatment wishes, if elicited.
3. **Nurse case management:**
   - a nurse with advanced training in palliative care acts as the case manager, serving a range of functions including: symptom identification and management, patient education about condition and prognosis, coordination of care, and when appropriate, facilitation of transitions in care including hospice.
   - active patients are reviewed with the interdisciplinary team at biweekly team meetings with referrals to other Pathways providers as needed.
   - the case manager works closely with the patient's primary care physician and specialists, communicating via e-mail and telephone to monitor symptoms, schedule visits, and modify and reinforce treatment plans.
   - if a program patient is hospitalized, the case manager received an electronic notification & contact the inpatient team to assure communication of care goals and advance directive information.
4. **Palliative support services:**

   integrate with other palliative support services including home-based care, home hospice, and volunteer services.
5. **Family support services:**
   - case manager regularly monitored caregiver emotional and caregiving needs and mobilised support services as possible.
   - in addition to limited in-home support services, the program made available family counseling with the programme psychologist and spiritual counseling by the chaplain.
   - after a patient's death the case manager coordinated bereavement support.

Bradford Heart failure and Palliative Care services Partnership (2002-2005)

In 2002 the Bradford City, North, and South West Primary Care Trusts (PCTs) each appointed a Heart Failure Nurse Specialist (HFNS) to support patients in the community following a hospital admission for heart failure, with the aims of: improving the quality of life of patients and reducing hospital readmission rates through provision of psychosocial support, liaison between health and social care services and optimization of cardiac medication [53]. The 3 HFNS nurses post were pump-prime funded by the British Heart Foundation. The appointed nurses had extensive cardiology experience but lacked confidence in providing palliative care. They liaised with the local specialist palliative care service to gain relevant skills. Equally, palliative care staff lacked confidence to care for HF patients, so a shared-learning and knowledge transfer process was initiated between the two staff groups. The specialist palliative care services collaborating primarily with the HFNS nurses included a Marie Curie hospice and community palliative care team community (6 clinical nurse specialists, medical consultant, psychology, social work and ethnic liaison professionals). In 2003, successful bids were made to the PCTs and Big Lottery fund to develop care for non-cancer patients at the Bradford Marie Curie hospice, leading to the employment of a full-time psychologist and a 20% increase in Day Therapy capacity. The psychologist joined the existing psychology service in the hospice and community palliative care team but also had a specific remit to develop care for people with non-malignant disease, including heart failure. This allowed the establishment of a Heart Failure Support Group, run by the HFNSs in the hospice day therapy unit. The Support Group is run as a two-hour session on a fortnightly basis, exclusively for heart failure patients and their carers. The support group offers: an opportunity for social interaction between patients and carers, regular, informal emotional support from the psychologist, access to individual consultation with heart failure and palliative care nurses, psychologist, benefits advisor or palliative care consultant as necessary, education covering the disease process, medication, nutrition, psychological wellbeing, exercise, benefits advice, complementary therapies, group relaxation sessions.

Key Elements of Bradford HF / Palliative Care partnership [53].
▪ HFNSs were invited to attend the community palliative care team’s regular **multidisciplinary team meetings** (MDTs).
▪ Attendance of the HFNSs at **formal educational events** organized by the palliative care service and vice versa.
▪ **Practice-based education for primary care staff** delivered jointly by the HFNSs and a palliative care consultant.
▪ HFNSs adopted a **holistic supportive and palliative care assessment**, encouraging the patient to prioritize their problems, identify coping strategies and express preferences for care. The assessor acted as a key worker to personally address the problems if they had the relevant skills and resources, or to coordinate provision of support from elsewhere.
▪ **Collaboration over patient care** included: advisory care (telephone advice from palliative care consultants about specific symptom problems, joint case discussion at MDTs) and direct care (joint visiting with a Macmillan nurse, medical assessment at a hospice-based outpatient clinic, hospice admission for symptom control or terminal care)
▪ **Assessment, Information management and sharing:** Use of a standardized, formal assessment of patients' problems, coping strategies, values and care preferences. The HFNS and palliative care service perform continuous data collection, audit and evaluation, which are used to inform the NHS commissioners and charities involved in funding them. The palliative care services use a shared electronic clinical record system, which allows centralized reporting of activity data across the district. The HFNSs record key information on a database.

Memorial Medical Center Heart Failure Continuum of Care (2003-2008)

In 2003, the Memorial Medical Center (Springfield, Illinois, U.S.), a 534-bed acute care tertiary hospital developed a heart failure support program as part of a wider quality initiative program for HF [54]. The program is delivered by a dedicated heart failure support team (HFST) comprised of registered nurses and led by an advanced practice nurse and implements a three-step approach to acute care management of HF patients:

- **Step 1:** *Identifying all patients with heart failure*
- **Step 2:** *Verifying the heart failure diagnosis*
- **Step 3:** *Daily monitoring of the patient through discharge*

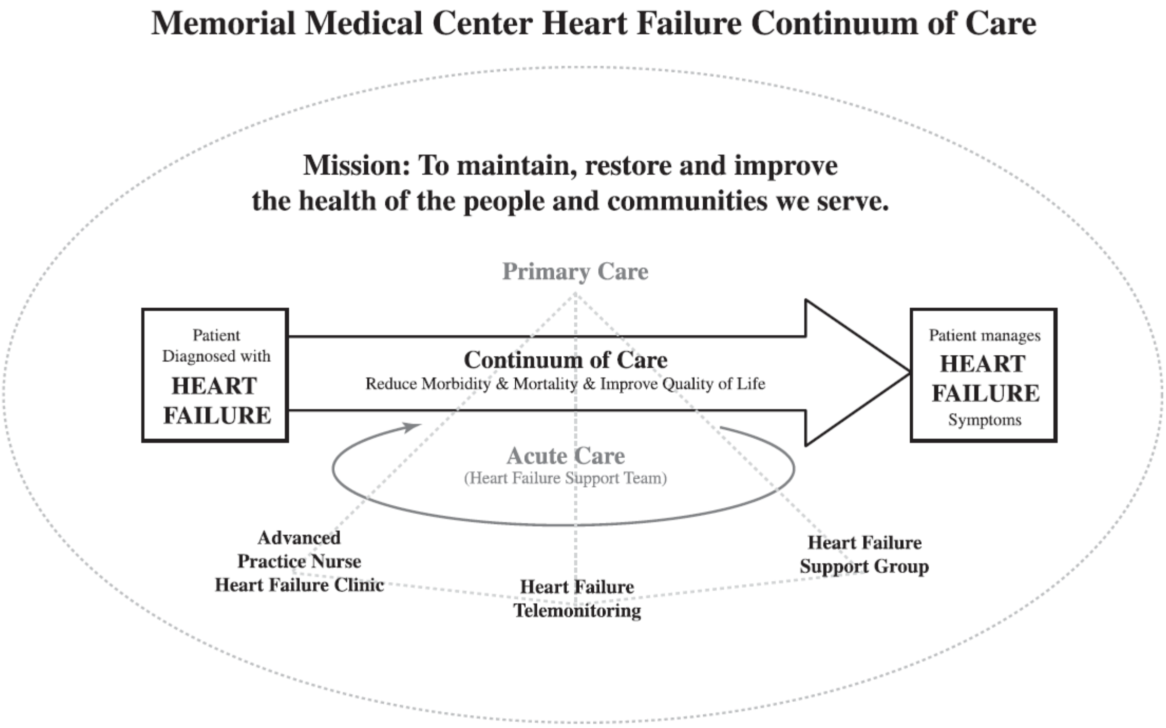

Figure 3. Memorial Medical Center Heart Failure Continuum of Care [54]

Step 1: *Identifying all patients with heart failure*

Prior to the program implementation, it was not possible to identify all the patients with HF within the hospital regardless of admission route or place of treatment. Searching for the admitting diagnosis on the hospital's electronic medical record was time consuming and did not necessarily allow identifying the patients with HF as a secondary diagnosis.

Consequently and as part of the HFST program development, the hospital Information Technology created an *`HFST List'*. This list generated a permanent link associating a patient with the HFST, triggering an automatic electronic referral to the HFST team for each patient medical encounter at the hospital. The computer tracking program allowed the HFST nurse to obtain direct referrals to the program for any patient with a current or past history of HF or with an ejection fraction of less than 40%. In addition, the identification of HF patients was further refined by daily communication between the HFST and the laboratory department, direct care and cardiac rehabilitation nursing staff, physicians, and cardiovascular patient registrars. Echocardiography logs as well as cardiac catheterization schedules were also reviewed daily. By using a comprehensive multimodal approach, the HFST nurse case managers played a key role in identifying patients with HF and could obtain an accurate patient list on a daily basis.

Step 2: ***Verifying the heart failure diagnosis***

Once a patient is added to the HFST list, a standardised documentation tool for heart failure quality indicators is initiated and permanently added to the patient's medical record, serving both as a communication tool and documentation of the HFST monitoring of patient care. Importantly, it identifies the ACC/AHA stage of HF and covers and documents teaching appropriate to the patient's illness progression, leading to a 10-fold increase (at time of reporting) in the number of patient contacts for education since the quality indicators inception in 2005. A *"Living with Heart Failure"* booklet was developed and provided to patients during their first visit to the HFST while continuing education is also provided during subsequent visits with the aim of slowing disease progression.

Step 3: ***Daily monitoring of the patient through discharge***

The final step in the model consists in regular monitoring of core measures prior to discharge (e.g. most current diagnostic value of ejection fraction measure, medication therapy status) as well as the HFST nurses requesting additional tests, and / or making further referrals (e.g. dietician or palliative care nurse) as needed. Outpatient support systems available for HF patients include tele-health, HF support group and an acute-care nurse practitioner.

The ability to maintain contact with HF patients both in and out of the hospital allows for continuity of care, continued education and monitoring.

The authors conclude that collaboration between and among physicians, nurses, case managers, and personnel from admitting, laboratory and information technology resulted in a multifaceted approach that consistently afforded timely identification of patients with heart failure. Once identified, patients received close, daily monitoring of important quality indicators that resulted in a reduction in variation and very high quality, consistent care.

The Supportive Care program (2006-2009)

The University of Colorado Hospital implemented in 2006 an outpatient HF palliative care program called *`the Supportive Care Program'* [55], operating as a half-day clinic, co-located in a HF clinic. Over the 3 ½ year time period of the study (Feb. 2006-July 2009), 50 unique patients were seen for a total of 228 visits. The majority of patients were referred by cardiologists and cardiac nurse practitioners, who were co-located with the palliative care physician, in the same half-day HF clinic. Patients were mostly male (72%) and had a median age of 51 years. At the initial Supportive Care Program visit, 70% had NYHA Class III-IV HF. The authors argued that outpatient HF palliative care differs from that of hospital-based inpatient or cancer palliative care: patients' 1-year mortality (14%) was relatively low, indicating much of this population was not near the end of life. None-the-less, the mental health needs of the HF cohort were substantial: depression and anxiety were prevalent. Patients frequently had fears and concerns about the future and occasionally had thoughts of hastening their death. Topics addressed in supportive care programme visits, included: advance care planning, psychological issues, social issues, spirituality, care coordination, consults and referrals. Advance care planning topics were addressed in 48% of patients. Of patients who had more than one palliative care visit, advance care planning was addressed in 65% compared with 33% in patients with one visit only.

The study authors suggested that palliative care needs in terms of care coordination, advance care planning, and psychosocial issues are such that they recommend that HF palliative care programs should include a nurse and social worker or psychologist. The nurse is also likely to be best placed to act as the HF care manager, particularly if trained and committed to both palliative and disease management goals.

Automated home telephone self-monitoring for Advanced Heart Failure (2007-2008)

Between January 2007 and January 2008, Kurtz et al. conducted a study of 138 patients with AHF under 3 treatment conditions: (i) usual care for HF (G1, n=50), (ii) multi-disciplinary team approach (G2, n=56), and home telephone self-monitoring (G3, n=32) [56]. Following discharge from hospital, patients in G1 received standard care management from their general practitioner and cardiologist, without any intervention from the HF MDT. The G2 patients were managed in a HF clinic by an MDT team comprising nurses, dieticians and doctors. During a 45-min consultation, patients were explained their treatment plan, received physical activity and dietary advice, provided with advice on potential treatment side-effects and how to monitor and manage their symptoms. The consultation was repeated up to six times per year during face-to-face visits, while patients could also phone the clinic for advice from their care manager (nurse). The patients G3 had only three planned visits to the clinic during the year but were asked to regularly call an automated system, to listen to an interactive question-answering system using their telephone keypad. Questions were about change of weight, dyspnoea and general health condition. Stable patients were asked to repeat the phone call once a week, minor worsening HF patients were asked to repeat the phone call after 3 days and suspected worsening patients HF (i.e. at high risk of hospitalisation according to the system) were either asked to arrange a medical visit or directly connected to the HF care manager. There was no significant difference in outcomes between G2 (MDT care) and G3 (telemonitoring) but there was significant disadvantage with usual care: n=22 adverse events (cardiovascular deaths and rehospitalisations for HF) for G1 in the period vs. n=14 for G2 and n=7 for G3 respectively. In addition, time to re-admission for HF increased in G2 (188 days), and G3 (198 days) compared to G1 (95 days). The study suggests that automated home-based telephone self-monitoring may be an effective method – with outcomes in par with active, face-to-face MDT HF monitoring – of reducing the risk of CV death or re-admission for heart failure in high-risk patients, with most of the benefits in fewer HF re-admissions rather than mortality reduction.

Heart Failure Care Framework, Boyd et al. (2009)

Boyd et al. conducted a study aiming to evaluate the key components of services for people with AHF from multiple perspectives [57]. The authors conducted serial interviews over 2 years with 36 patients with AHF, 30 family carers and 62 professionals in South-East Scotland to review various heart failure care models.

Participants confirmed the value of a key health professional coordinating care, holistic assessment and regular monitoring. A lack of time and resources due to competing priorities in primary care, failure to respond to the fluctuations of a heart failure illness trajectory, concerns about the balance between direct care from specialist nurses or a more advisory role and difficulty in judging when to move towards palliative care hindered consistent access to proactive care.

A heart failure care framework, with key stages and service responses, was developed to recommend how care might be delivered in line with UK policies on long-term conditions, palliative and end-of-life care. Patients with long-term conditions needing palliative care should be identified and managed using pragmatic criteria that include a proactive shift in care goals. A 3 stages framework for the management of AHF patients include: (1) disease management, (2) supportive and palliative care and finally, (3) terminal care.

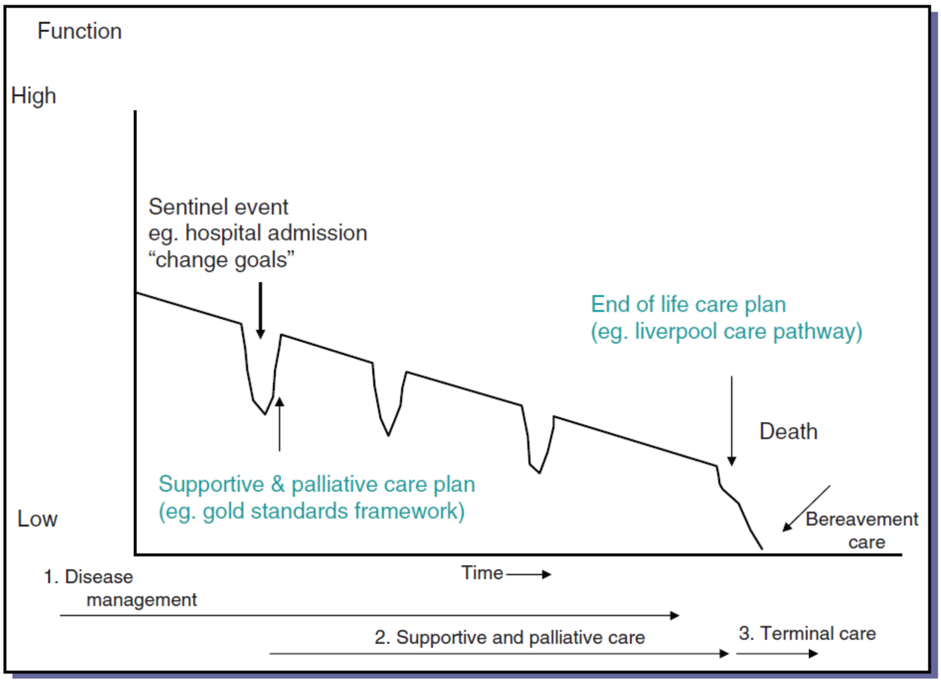

Figure 4. Boyd et al. three stages of progressive heart failure [57]

Three stages of care in Boyd et al. Heart Failure Care Framework [57]	
Stage 1: Chronic disease management phase: (NYHA Classes I-III)	- **Performance status:** good; no advanced co-morbidities.* - **Goals of care**: active monitoring, evidence based treatment to prolong survival, symptom control, patient and carer education, supported self-management. - **Information:** name of condition and what that means, course of the illness/treatment. - **Primary care team:** coordinates regular monitoring and review using local protocols derived from national guidelines; practice register/database for chronic illness triggers and monitors service provision. - **Hospital specialists** (cardiologists and/or geriatricians): diagnostic review, assessment and specialist treatment/advice for complex cases; specialist support to primary care team. - **Heart failure nurse specialists:** short-term interventions to aid patient self-management; support, advice and education for the primary care team.
Stage 2: Supportive and palliative care phase: (NYHA Classes III-IV)	- **Performance status:** deteriorating due to heart failure and/or advanced co-morbidities; disease specific prognostic indicators used as an aid to professional judgement. - **Goals of care:** tertiary prevention; maintaining optimal symptom control and quality of life. - Information: discuss changing condition, goals and preferences for future care; anticipatory care planning with patient and family. - **Primary care team:** move patient to Supportive Palliative Care register; identify a key professional; ensure regular holistic, multidisciplinary assessment of patient and carer health and social care needs; treatment and medication review in consultation with hospital specialists; plan for acute crises including liaison with out-of-hours services. - **Hospital specialists**: assessment and specialist treatment review for complex cases; specialist support to primary care team; planned admission and rapid triage if hospital inpatient or outpatient care needed; coordinated discharge planning. - **Heart failure nurse specialists**: specialist advice to primary care team on heart failure medicines management and monitoring; hospital/community liaison for patients needing secondary care. - **Palliative care specialists:** support for primary care team and hospital specialists; specialist advice or short term interventions for symptom control, complex communication and advance care planning.
Stage 3: Terminal care phase: (NYHA Class IV)	- **Performance status:** frail and largely bed bound despite maximal therapy; no reversible problems, or life threatening comorbidity. Dying period may range from days to weeks; clinical indicators: renal impairment, hypotension/tachycardia, persistent oedema, anaemia, hyponatraemia. - **Primary care team:** coordinate comprehensive health and social care package for patients who remain at home; plan for management of acute deteriorations; clarify resuscitation status; withdraw medication not for symptom control; carer support including bereavement care. - **Hospital specialists/specialist nurses:** advice/management of treatment withdrawal (e.g. defibrillators); optimize end-of-life care of patients dying in hospital (integrated care pathway). - **Palliative care specialists:** advice and support for end-of-life care in hospital and community; advice on complex symptom control in end-stage organ failure.

Key Components of effective heart Failure services according to Boyd et al. [57]
- A key health professional to coordinate care, provide personalized information and support self-management.
- Managed care using primary care registers/databases to organise and monitor service provision; electronic prompts for review dates.
- A patient-held management plan including an advance care plan to be drawn up and reviewed by the key professional, patient and carer.
- Holistic assessment and regular monitoring of the patient’s physical condition, functional ability, psychological and social needs.
- Implementation of clinical guidelines, disease protocols and care pathways for heart failure management, palliative and end of life care; access to specialist advice/assessment.
- Integrated care of patients with multiple co-morbidities; including medicines management.
- Identification of patients with palliative care needs and transition to supportive and palliative care as the illness progresses.
- Out of hours care planning: information and self-management strategies for patients and carers, anticipatory care planning, use of special notes to out-of-hours services including resuscitation status.
- Regular assessment and review of carer needs, including respite care and bereavement support.
- Joint health and social care planning for personal care and prompt provision of equipment and adaptations; assistance in applying for benefits.
- Access to allied health professionals such as pharmacists, dieticians, physiotherapists and occupational therapists.
- Information about voluntary sector support services (user groups, social support and carer support services) and educational resources.

Disease Specific Advance Care Planning for Heart Failure (2011)

Disease Specific Advance Care Planning (DS-ACP) aims to facilitate ACP in chronically and terminally ill patients [58]. The model uses a trained facilitator to guide communication on patient values, goals for treatment in worst-case scenarios, develop a disease specific documentation plan, identify resources needed and aims to facilitate the planning process and emphasise condition-specific treatment scenarios. The DS-ACP interview is an in-depth planning discussion for patients with advanced chronic illness, their chosen health care agent, and other family members as appropriate. A trained nonphysician facilitator, working in partnership with the patient's health care providers (e.g., physician, nurse practitioner), delivers the interview. The resulting conversation is designed to assist patients in understanding their disease trajectory and related life-sustaining treatment options and make informed and timely health care decisions. DS-ACP planning begins with the assumption that patients want their chronic illness to continue to be treated, but recognizes that complications may occur that result in outcomes the patient would find unacceptable. This planning process assists patients in defining the limits to continuing life-sustaining treatment under such outcomes.

Key Components DS-ACP
A proactive intervention scheduled in the outpatient setting when the patient is not in medical crisis.
Patient-centered interview techniques to explore patients' understanding of their illness, fears, concerns, and experiences. This information is used to (1) uncover gaps in knowledge about their disease and the need for referrals to others, such as the physician; (2) assist the patient in verbalizing goals and values about quality of life; (3) address issues that have prevented the patient from planning; and (4) develop trust in the facilitator and planning objectives.
Active inclusion of the patient's health care agent to open communication pathways between the patient and agent, assist the agent in understanding the role of substitute decision maker, and prepare the agent to make future decisions consistent with the patient's goals and values.
Planning focused on complications patients may anticipate specific to their disease trajectory and the related life-sustaining treatment decisions that may be needed.
Decision aide planning tool (i.e., the Statement of Treatment Preference form) to assist patients to clarify their goals for care in selected ''bad outcome'' situations after the patient has suffered a complication.

Schellinger et al conducted a study in a large health system consisting of 11 hospitals and over 70 primary care clinics in the U.S. [58]. n = 1894 patients were referred for DS-ACP, of which n=602 completed the process. The study found that 94.3% of those completing the DS-ACP process, had a health directive compared to 24.8% of noncompleters ($p < 0.001$). Of the patients who died by the end of the study period (n = 286), DS-ACP participants were more likely to have used hospice compared to nonparticipants (56% versus 37%, $p = 0.002$). The authors argued that their study demonstrated that the DS-ACP model, can be deployed in a large health care system.

Palliative advanced homecarRE and heart FailurE caRE (PREFER, 2011-2012)

The Palliative advanced homecarRE and heart FailurE caRE (PREFER) study is a prospective, randomized investigation of whether integrating palliative homecare and active heart failure treatment will reduce symptom burden, increase quality of life and activities of daily-living and reduce the number of hospitalizations in patients with severe chronic heart failure [59]. It should be noted that – to date – only the study protocol has been reported in the litterature and the results of the evaluation are not yet available[6]. None-the-less, a comprehensive integrated care framework has been reported and the model is thus included in this review.

The PREFER model has been deployed in an advanced homecare unit, based in a county hospital (Skellefteå hospital) located in northern Sweden. PREFER aims to combine active HF treatment and palliative care – as practiced for cancer patients – early on in the process of illness. It aims to provide *holistic care* by including the management of *comorbidities*, – common among HF patients – and continuously monitor symptoms, quality of life, pressure sores, falling, and malnutrition. The patient's general practitioner, other specialists and out-of-hours palliative advanced home care service are thus included into a cooperative care partnership. Care is person-centred and includes initiating, working, and documenting the partnership. PREFER also provides active HF treatment (i.e. pharmacological and other types of device treatment, such as chronic resynchronization therapy) to reduce symptom burden

---

[6] We have contacted the study authors in January 2014 and we understand that the study results are now currently under peer-review.

in parallel to palliative care, and also extends to acute heart resuscitation if required and in accordance to patients' wishes.

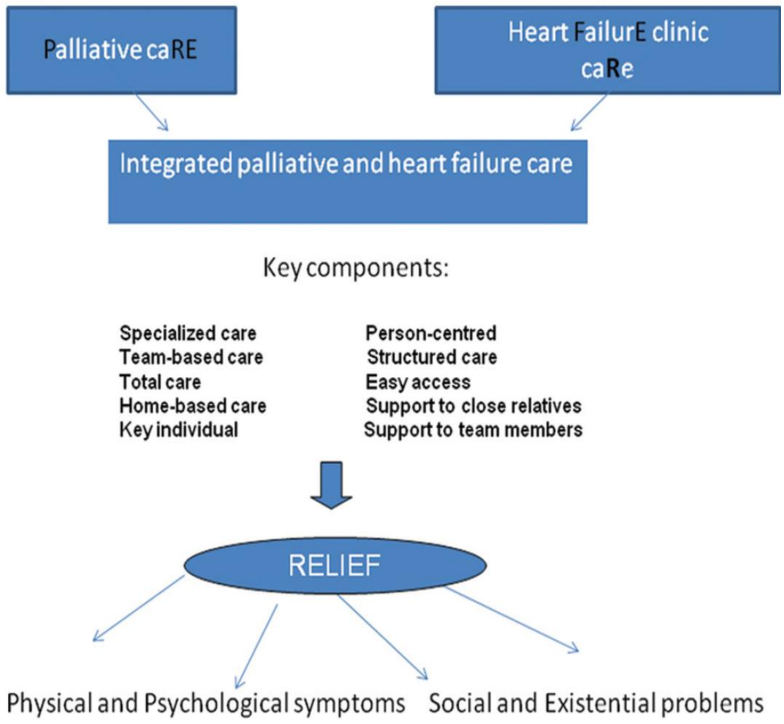

Figure 5. The Palliative advanced homecarRE and heart FailurE caRE (PREFER) model [59]

Key Components of the Palliative advanced homecarRE and heart FailurE caRE (PREFER) model [59]

- **Confirm diagnosis**
  - Essential to ensure optimal treatment
  - Verified chronic heart failure and with NYHA III-IV symptoms
- **Patient education**
  - Principles of self-care maintenance and management of heart failure
- **Establishment of an advanced care plan**
  - Designed with the patient and a family member. Reviewed regularly and including the patient's preferences for future treatment options
  - Person-centred and identity-promoting care. A concept applicable to palliative care planning. The six S keywords used are: self-image, self-determination, social relationships, symptom control, synthesis, and surrender. The person-centred care includes initiating, working, and documenting the partnership.
- **Symptom management**

  - Patients frequently have multiple comorbidities that need to be identified. The team is responsible for the total care, i.e. comorbidities, also.
  - Assessment of symptoms, quality of life, risks of decubitus, falling, and malnutrition are continually done.
  - Further are registrations in the national palliative registry and heart failure registry

planned

- **Identifying end-stage heart failure**
  - Confirmation of end-stage heart failure is advisable to
  - ensure that all appropriate treatment options have been
  - explored and a plan for the terminal stage of illness
  - should be agreed upon
- **Breaking bad news to the patient and family**
  - Explaining disease progression and a change in treatment emphasis is a sensitive issue and must be approached with care.
  - End-of-life issues are discussed
- **Establishing new goals for care**
  - End-of-life care should include avoidance of circumstances which may detract from a peaceful death.
  - All current pharmacological treatment and device programmes should be considered.
  - Consented resuscitation orders should be clear and written in the documentation.
  - The use of an end-of-life strategy, e.g. the Liverpool Care Pathway, for the dying patient should be initiated
- **Support for close relatives/bereavement**
  - Support to close relatives, both as a person and a caregiver.
  - Bereavement support. Visit and/or phone-call after the relatives’ death

Summary: Review of Integrated Care Models for Heart Failure

Many of the models identified in our review share several – or all – of the components of the CT model, and this is reviewed in more detail in section VII (Manualisation and Transferability of the Models Developed by Caring Together). S*trict criteria for referral into the programme* (i.e. AHF with deteriorating symptoms despite optimal treatment), *comprehensive or holistic, patient-centred assessment* using a range of bespoke and standardised tools to cover the various dimensions of the assessment (physical, emotional, social, spiritual, etc.), the allocation *of a care manager* – usually a nurse with specialised training in HF – tasked with coordinating the care management plan of the patient*, training and education for patients*, family and carers – including meetings and support groups – and *multidisciplinary work* have all been identified as essential elements of successful integrated palliative care models for HF. Although each model has defined each of their core components slightly differently, they all have most of these elements in common and none can be described as radically different from all the others. Little has been reported in terms of facilitators and barriers, but it is clear that several of the implementations have benefited from some form of extra financial resources at the time of implementation, typically through participating in a larger quality improvement programme *(Robert Wood Johnson Foundation for PhoenicCare, Veterans Administration for Pathways of Caring, British Heart Foundation / Marie Curie for the Bradford HF/PC partnership, Premier, 2008 for the Memorial Medical Center continuum of care, etc.)* However, in most cases, the models strived to be sustainable in the long term by either being cost-saving or at least cost-neutral. Several emphasised that new models of care delivery can be achieved with little or no extra cost at all, but simply by changing the culture and processes of care delivery. Little was reported in terms of barriers to implementations, although the few allusions to these aspects reported in the literature – perhaps unsurprisingly – referred to some professional resistance from groups of health providers (e.g. primary care or cardiology) or to a lack of wider organisational support as well as concerns about the potential financial implications of the programme implementation. All of the models did however require substantial implementation effort and / or dedication. Time was also reported as being crucially important for care managers (e.g. see Comprehensive Care Team). Most studies reported care-quality and processes improvement, either in terms of increased patient, family and / or professional satisfaction. One common feature was the substantial increase in advanced-care planning for those participating in the programme when compared to control groups (when reported in the studies e.g. PhoenixCare, Comprehensive Care Team, Supportive Care program) and the increase of people dying at their chosen place of death (e.g. Pathways of caring). Several studies also reported benefits on physical functioning (PhoenixCare) and / or emotional well-being. Impact on hospitalisation and acute-care admission was less clear however. Of particular relevance here should be the results of the Palliative advanced homecarRE and heart FailurE caRE (PREFER) study of Brannstrom & Boman (under peer-review). Overall, it is clear that the case for the routine deployment of integrated palliative care model for AHF would certainly benefit from a future, large, robust and multi-dimensional randomised control trial (i.e. quality of life and well-being patients and families, patients and health professionals / social care satisfaction, clinical outcomes and cost-effectiveness).

VI- Qualitative Data Analysis

Participants Characteristics

We interviewed 23 CT stakeholders from the 3 pilot sites between September 2013 and January 2014. Three of these performed a role across all 3 sites (CT project manager, lead HFNS, and NHS GGC cardiology service manager). In addition, we interviewed another n=8 stakeholders from the North-East implementation site, n=5 from the South-West and n=8 from Inverclyde. Their professional roles were: CT programme manager (n=1), NHS GGC cardiology service manager (n=1), HF liaison nurse (n=6), consultant cardiologist (n=3), Palliative care consultant (n=2), Palliative care nurse (n=3), Geriatric Medicine consultant (n=2), district nurse (n=2), General Practitioner (n=2), hospice manager (n=1). In the subsequent qualitative analysis here presented, we shall refer to these participants as P1 to P23.

Qualitative Data Analysis Using Normalisation Process Theory

We developed specifically a qualitative coding framework for the analysis of interview transcripts, which is enclosed as Appendix VI. The coding was performed by one researcher (K.S) and the codes and themes subsequently reviewed and refined collectively by the research team (K.S, M.M.B, F.M).

Based on this analysis and using the 4 NPT constructs *(coherence, cognitive participation, collective action and reflexive monitoring)* we now review and interpret the findings of our study in turn.

Caring Together Themes under the 4 NPT Constructs
Coherence
Rationale of CT
The Key Aims of CT
The Perception of CT as implementing innovative practice
Defining Roles and Responsibilities
Raising Awareness
Cognitive Participation
Barriers to Implementation
Facilitators to Implementation
Engagement of Stakeholders
Collective Action
Facilitation Groups
Patient Identification and Referral into the CT Programme
Holistic assessment
Care Management and Coordination (including information sharing)
Training and Education
Multidisciplinary working and Joint Working.
Advance Care Planning
Resources
Reflexive Monitoring
Integration of Programme
Areas of Success
Acceptability
Remaining Challenges and Area for Further Development

Table 2. Caring Together, NPT themes

Coherence of Caring Together Programme

Coherence refers to the “sense-making” work undertaken when a complex intervention or new service is implemented: to determine whether users see it as differing from existing practice, have a shared view of its purpose, understand how it will affect them personally and grasp its potential benefits [24, 25]. Several themes have emerged from our interviews with regards the CT stakeholders’ conceptualisation of the Coherence of the programme and we now review each of these themes in turn.

Rationale of CT:

CT stakeholders felt overall that there was a strong rationale for the CT programme in addressing an important gap in the provision of care for patients with AHF, aiming to redress inequity in access to care in comparison to other groups of patients (i.e. those with a cancer diagnosis) and therefore addressing important and unmet care needs. This was highlighted in the 2010 NHS GGC Palliative Care Needs Assessment report [60] and by most of the studies described in section V.2 (scoping review). The following excerpts from transcripts highlight how these inequities were well recognised.

> ***P2:*** *“Well, I think there was recognition amongst certainly heart failure nurses and palliative care teams… there was some acknowledgement that people with chronic, non-malignant conditions weren't having their needs met in the way that cancer patients do…*
>
> *I think I have always felt quite strongly about this group of patients and that their needs weren't being met”*
>
> ***P5:*** *“I think it has been identified over a number of years that the palliative care offered to patients always focussed around cancer patients but heart failure patients quite often have actually a more troublesome time, symptom-wise, towards the end and it was a big gap”*

Comments from participants provided some explanation for these inequities, which ranged from the inherent culture of cardiology which was seen as predominantly intervention focussed to lack of availability of appropriate services.

P6: *"…well, I guess there was kind of increasing evidence for COPD and HF patients that they had a poor prognosis but didn't get as much support in their last year or 2 of life."*

I think – as kind of palliative care services for cancer patients were getting better and better – I think there's more of a stark contrast and I think traditionally the culture of cardiology has been very aggressive management.

I mean… I guess the HF patients didn't fit neatly into the hospice model because of their trajectories and often if they did, few come and say they would want hospital treatment and things to… so I guess it was looking for a different model to support them. I guess it's just thinking about: is there unmet need? beyond that I'm not sure of the stats but you get a sense that there must be, there must be more out there […]"

P13: *"There was nowhere for – kind of… – heart failure patients to go I think… they ended up in the acute sector."*

P16: *"…there's a lack of palliative care provision for heart failure patients who do have a poor prognosis"*

P18: *"Well… my understanding was that it was because there really… there was a lot of these patients in the community that weren't probably getting the care that they should be receiving."*

P19: *"I think there was probably a lack of structure in the type of care that was being delivered and for some patients perhaps an unmet need for care."*

P23: *"the heart failure patients were so obviously a group of patients that you need to have palliative care and it's something that you know we have known for a long, long time but we hadn't physically sort of done anything about it. You know they have a poor prognosis. They tend to have ongoing symptoms despite their treaments and you know again if you either, their prognosis is similar to many common cancers. Their symptom burden is similar to patients with cancer, sometimes worse but they don't have access to palliative care."*

Key Aims of CT:

The above interviews excerpts clearly demonstrate that there was a wide awareness and understanding among the stakeholders of the unmet care needs for patients with AHF in NHS GGC. Hence, of particular interest is participant perceptions of how the CT programme was aiming to address gaps in service provision and unmet needs for patients with AHF in practice. As the programme was designed using a *`whole-system thinking'* to service redesign, the aims of the CT were both wide-ranging and ambitious. Articulated aims of the Programme included reducing hospital admissions or treatment in acute care settings.

> ***P1:*** *"…I think, the thing is about caring together and other palliative care initiatives, what we are trying to do is keep the patient out of hospital"*

Promotion of joint-working across professional groups was another key feature which was generally perceived as important.

> ***P4:*** *"For me: I thought it was mainly about joint-working together and obviously the HF specialist with palliative care specialist… bringing… together to provide a service for patients and – you know – to ensure the end of life stages were looked after appropriately*
>
> *[…] one of the things that I wanted was – you know, really… kind of… – joint-working within the HF team – really… kind of… – trying to promote… because I think a lot of it we can do together for patients.."*
>
> ***P8:*** *"Well… better care and better venues for the patient… improving patient care and outcomes and a more team-approach to it – I think as well – is definitely where we are at…"*
>
> ***P11:*** *"…its really – to my mind you know – looking at and enhancing the kind of relationship between professionals and ensuring ongoing care of patients in the community and in the hospitals was appropriate"*

Most participants realised the Programme had multiple aims which included providing a formal structure for the care management of patients with AHF, advance care planning and appropriate bereavement support as well as improving symptom control, general management and the quality of life of AHF patients at the end of life. Overall, improving the quality of care for AHF patients was a major aim.

> ***P5:** “…providing the same sort of palliative care that cancer patients have had for a long time… but the focus on the heart failure needs.”*
>
> ***P6:** “…reduce hospital admissions in the last 6 months of life and improve quality of life and support and bereavement thereafter”*
>
> ***P12:** “…think the idea behind it was partly to manage symptoms with more of a focus on symptom management than just prognostic therapies and partly also to have a strategy and a support network whereby these patients don't need to be repeatedly admitted to hospital […] how to manage the cardiology of specific parts of their condition along with the symptom management and try to meet the patients preferred place of care… place of death.”*
>
> ***P17**: “just to provide more service, more support for patients and their families especially sort of trying to facilitate end of life care plans you know and decisions”*
>
> ***P19:** “…I think the main aim was to try and improve the quality of care for patients with heart… palliative care for patients with heart failure.*

The importance of improving the documentation of AHF patients’ care and communication of relevant information across professional groups was emphasised.

> ***P9:** “…our main aim out of this was to improve our communication and our documentation with patients with end stage heart failure needing palliative management as well.”*

Ensuring that those with AHF experienced greater equity of access to appropriate palliative care, with a focus on AHF care needs, was also perceived as an important aspect of the programme.

> ***P16:** “…I think the motivation behind it was a desire for all patients with chronic illnesses to have access to palliative care […] heart failure has a poor medium term prognosis and that patients – if possible – should have access to the same services as cancer patients”*

Perception of CT as implementing innovative practice:

We asked stakeholders to describe their perceptions of how the CT programme contributed to implementing – or not – new practices and ways of working. As it is clear from the previous statements about the programme's wide-ranging and ambitious aims, innovative practice was principally centred around challenging professionals previous ways of thinking around HF care and the means of delivering care. Changing professionals' mindset about the management of AHF patients was therefore an important aspect of the Programme.

> ***P1:*** *"…the cardiologists, up until now, have been very interventionalist: they will try and do things specifically for the heart failure until the last moment, without actually thinking about the quality of life the patient has…"*
>
> *[…] they are getting access to support that they wouldn't got earlier and it's... the same goes for carers […] I think the referral onto other services is a big one because – you know – they are getting referred for benefits advice, for housing advice and things like that... And that's they just wouldn't have got access before, or... it wouldn't have been considered before and where maybe they should have access to it."*

> ***P5:*** *"Previously, I don't think there would have been as much input in terms of anticipatory care planning, discussions around resuscitation and pacemakers through the team and from ourselves […] the caring together programme maybe focussed us more on our patients that might not have terribly long to live."*
>
> ***P17****: "makes us think a wee bit more quickly about palliation you know and maybe referrals to hospice and getting other people involved so I guess it's thinking a wee bit quicker than you probably would have you know about end of life issues and end of life care for this type of patient"*

Developing and providing new services to patients which were not previously available to them, such as setting up regular outpatient HF and supportive care clinics was a key feature of the model implemented in the NE of the city.

> ***P6:*** *" Since the project has been up and running, they've developed a weekly HF and supportive care outpatient clinic which we can refer to and they've also linked patients in with day services at the hospice [...] it would be the holistic assessment – you know – those... and conversations about death and dying... I'm sure cardiologist are very used to talking about DNR, etc. but I would imagine they would be the things that would be different in this group of patients [...] linked in with us for bereavement support afterwards, which I think previously – had they not been linked-in – that would have been... wouldn't have been possible"*

The CT programme implemented standard holistic assessment and documentation processes ensuring that those with AHF had access to more holistic advice, including information on what additional support is available to AHF patients (e.g. social care and/or benefits) which they would not necessarily be aware of. This was achieved through transforming informal and ad-hoc practices into formalised, standard and systematic ways of working, contributing thereby to professionals reflecting on their conceptualisation of the care of AHF patients.

> ***P9:*** *"I think it's much more patient-centred, and much more holistic! It's a bit more prescriptive with documents and things that have maybe been put together"*
>
> ***P10:*** *" […] personal and very sensitive conversations […] we would never... we would have these conversations but they were never documented […] we were able to have them sort of thing but it was never documented, you know […] So from that perspective, it's changed our... – you know – sort of what we are actually documenting."*

> ***P13:*** *"I think because a lot of the hospices are really emphasised with their cancer diagnosis and things... I don't know where there is any specific unit other than – kind of – acute-side for heart failure patients... whereas they have a lot of the same psychological needs and symptom needs as well... and it's good for them to have input."*

The CT programme provided a framework in the patient journey so that the palliative care needs of AHF patient can be addressed and managed. It emphasised the need for patient-centred care, implemented a system for patient identification and referral into the programme, promoted joint-working between different health professional groups, increased the focus of care for patients at the end-of-life and implement anticipatory care planning as part of the AHF patient journey. In particular, it provided AHF patient with an expression of choice for their potential preferred place of death as well as providing and coordinating bereavement support

> ***P15:*** *"…educate and support people about – you know – the end stage heart failure… to recognise these patients a bit earlier, to try and manage their symptoms a bit earlier, to have a bit more joint-working – you know – with other health care professionals […] I think they are trying very hard to change the mindset of some health care professionals. "*
>
> ***P16:*** *"…patients are getting identified at an early stage and we are having more... we are more likely to identify patients for palliative care now."*
>
> ***P18:*** *"…initially, we didn't really know very much about it but it does seem to kind of co-ordinate their care better […] McMillan type nurse / hospice involvement with those patients that they probably wouldn't have had before... and in addition to that of course: they have been able to access Marie Curie for support, especially overnight […] I think these patients have been given the choice and the ability to die at home, which I don't think they would have had before.*
>
> ***P20:*** *"These patients are just looked at in a much more global way, we, again, as someone who looks after older patients we do have to practice in the same way because rarely do our patients have one single organ pathology."*
>
> ***P23***: *"Okay so in the North East as I say we have this specialist clinic, we have the MDT where we see and discuss the in-patients and also the community patients because a lot of what we do particularly in the North East is to try to manage patients at home"*

However, it also worth reporting here that several stakeholders felt that they had always taken a holistic approach to AHF patient care. For those, the CT programme mainly formalised what – until then – were informal or ad-hoc ways of working. Naturally for those professionals who already using a holistic approach to AHF patient care management, the CT programme may have appeared not as innovative as to those professionals who did not. Here the CT programme thus mainly contributed to having these groups of professionals reflect on and formalise their conceptualisation of the care of AHF patients:

> ***P3:*** *" […] we were doing... a lot of it, we were doing anyway. We were doing a lot of it. I think we maybe didn't realise that ourselves, we didn't recognise it because it wasn't maybe formalised in the same way. The main difference would be is that they would have the holistic assessment documentation used"*

P9: *" […] we are a wee bit different here because we already had the links with the palliative team – local palliative team – so we... it wasn't such a change in our work because of that."*

P11: *" […] I'm not sure, because we already had a relationship. I don't know that... that has changed in any dramatic way, but that's probably because... part of our – you know – our particular role in palliative care."*

Roles and Responsibilities within CT:

While promoting greater co-operation between the various professional groups and encouraging joint-working would appear in principle to bring about benefits to patients' care by improving the coordination of care, needless to say that this can only be operationalised effectively in practice with well defined and understood roles and responsibilities within the patient care management plan. This process seems to have been refined over time, with the HF nurses being designated at the care managers and principal point of contact for the programme. The care managers are responsible for conducting the holistic assessment, managing the patient documentation and care plan and communicating relevant information regarding patient treatment and management to the MDT.

P3: *"…I think in the beginning… because the role wasn't clear in terms of what was expected of us… and then it was decided that the heart failure nurses would be identified as the care manager for the patients…"*

P9: (asked about who acts as the care managers) "*We… again because we are solely managing for these patients… for heart failure patients… so we are saying that we are the ones that do the holistic assessment, and do all the correspondence to all the and link into all the multi-disciplinary team."*

[…] we could be approached for advice on palliative care input from a variety of perspectives as things I've mentioned: symptom management, (care?) in the community, end of life care […] it was just ensuring that – you know – we were liaising with people appropriately and – which we kind of tended to be doing really to begin with – but probably just consolidating that […] I have to say, I wouldn't be – you know – getting particularly involved with the cardiac side of things… that… I think that's where the interaction comes in… about – you know – having the skills and the different groups so… but yes I mean there's flexibility"

The cardiology service was therefore perceived as playing a key role in the programme implementation and coordination.

> ***P12:*** *"It's centres around the heart function and supported care clinic..."*

> ***P16:*** *"basically my major role is – you know – identifying the patients and – you know – ensuring that there is nothing else that we should be considering before going down the palliative care route […] I think you need a cardiologist who is going to – I mean I'm not massively involved in the project and it doesn't take up a massive amount of my time – but who is a point of contact."*

> ***P17****: "we are taking a more holistic view approach with them rather than specifically just you know the HF symptoms we are asking them about their mood…"*

Palliative care services provide advice in symptom management, care in the community and end-of-life care. Each professional group contributed their respective expertise to ensure the best possible care for patients.

> ***P4:*** *" […] looking at a lot of patients – non cancer patients – and finding there's quite a lot that we can do as long as we are working with the specialist in that field... and building relationships... so for us, that was quite a big pull in why we were doing what we were doing..."*
>
> *[…] For me I thought it was mainly about joint working together and obviously the HF specialist within, palliative care specialist bringing together to provide a service for patients and you know to ensure the end of life stages were looked after appropriately,*
>
> *one of the things that I wanted was you know really kind of joint working within the HF team... really – kind of – trying to promote... because I think a lot of it we can do together for patients.*

However, again and again the importance of shared responsibilities and increased interactions was emphasised.

> ***P11:*** *"Really… we've always had quite an informal relationship and it's really – to my mind you know – looking at and enhancing the kind of relationship between professionals and ensuring ongoing care of patients in the community and in the hospitals was appropriate… So I think it's more towards you know consolidating that to some degree […] So you are trying to, you are really looking at professional interactions but to achieve the best for patients.."*

Raising Awareness

A key aspect of the CT programme, especially in its' initial phases was the importance of raising awareness of the programme. This was not a one off activity but rather an ongoing effort throughout the life of the programme. Attention to this aspect of the programme was important in order to increase the visibility of the programme and to ensure the broadest range of stakeholders gained an understanding of the unmet needs and the way in which the CT programme aimed to address such gaps. Awareness raising was essential in order to optimise identification of individuals with AHF who would be eligible for the programme and increase buy in from the broadest range of stakeholders. If only a small cadre of individuals knew of the programme then this would limit accessibility of the programme.

> ***P11***: *"But it's certainly in the hospice you know patients for example with cardiac failure, end stage cardiac failure could be admitted there so there is more of an awareness of I think the role of palliative care in non-malignancies in general."*

> ***P15***: *"About actually kind of I suppose increasing the profile of non-malignant disease so I suppose that was the basis of the caring together wasn't it?"*

> ***P20:*** *"Yeah I think it is because its, hopefully it's been, it's helped me to be very supportive of the project because I understand the need for it."*

Cognitive Participation in the Caring Together Programme

Cognitive participation focuses upon the work undertaken to engage with professionals or potential recipients of an intervention or new service and get them to “buy into” the new intervention. Clinical pathways redesign, focused on patient assessment, improved communication within the MDT, improved planning and management, and patient participation have shown the potential to be effective quality improvement interventions [61]. However, it is also essential that clinical staff understand the rationale for changes, and are actively engaged in service redesign, as previous studies have suggested that frequent reorganisation of services can lead to ‘change fatigue’, and occasionally, staff disaffection and poor morale [62, 63].

Barriers to Implementation of the CT:

Of particular interest to any successful implementation of a new service or complex intervention are the range of existing barriers to implementation and how these were overcome in practice. There was considerable caution from NHS GGC as to whether the programme implementation would then entail additional cost to the health-board to sustain it in future if the charities involved in the CT programme (Marie Curie Cancer Care and British Heart Foundation) eventually withdrew their financial support for the programme. In addition, there were – and still are – concerns in terms of the additional time-burden on work-loads, particularly for the HF liaison nurses who act as the care managers and whether the service had the capacity to absorb all eligible patients for the programme, particularly if a systematic referral system were to be implemented and equity of access to service guaranteed.

> ***P1:*** *“ …Greater Glasgow and Clyde […] wanted something that didn't have a cost burden at the end of the programme so that, when the two charities walk away, they are not left with a bill and a service that they can't support…”*

> ***P19:*** *“Well… potential barriers… depends on what the recommendations and the outcomes and the resource required actually to role this out across the health board.*

Do we have the capacity to meet the demand?... If they have that information, we can then look at… – you know – existing resources and how we can best realign them or at least try and secure additional funding […] another thing to add onto that… it has been… actually trying to find nurse time, in actual fact, to actually support the clinics. There was an assumption that this would be… could be something that the heart failure nurses could actually pick up… but with a very busy work schedule and work load, there is very little slack or capacity in their existing work plan.

There was an assumption I think made at the outset that the patient group that they were focussing on would actually be within the heart failure service so therefore there should be an…– you know – an exchange… there should be no great increase in demand of the heart failure nurses time but… I don't think that has actually proved to be the point."

P23: *"also, you know you can't – if somebody has a job – you can't add to that job if you've already got a full job, you know... you are already working more than your job as most people are... you can't just add to that"*

Facilitators to implementation of the CT:

For a programme such as the CT, it is clear that organisational support from the NHS health-board is critical to successful implementation. In addition, a number of key stakeholders took on an important role as champions of the CT and played crucial roles in the programme implementation and sustainability. In addition, the programme has provided support to the teams implementing the new service on the ground:

P1: *"…we've got two individuals that are in the programme who are such passionate speakers and also passionate in how they actually manage this group of patients, although we suspected there were people out there to begin with. I think having them both join the programme, and work so well with the programme, has exceeded our expectations as well…*

[…] I think, I think it goes back to this idea we were saying earlier on about the clinical… the champions on each site… Because we had champions on each site – who were keen to take things forward in the majority of sites – that kind of… required the least effort to actually get everybody together to start thinking about this. "

P6: *" … …we are in the geographical area of the north east facilitation group for caring together and I think in some ways in our area we've had an advantage because we have (NAME): we had a designated consultant with sessional time to be involved in the `Caring Together' project and my understanding was: she had 6 sessions of consulting time when the pilot… well… when the project started which is*

> *great to dedicate to – I guess – creating dedicated palliative care services for HF patients and… since the project has been up and running, they've developed a weekly HF and supportive care outpatient clinic […] from a local point of view, for the first year the clinic was running, (NAME) – our lead palliative care nurse specialist in the hospital – attended the clinic every week…"*

> ***P3:*** *" …(NAME) has done a huge amount of work… But I think they have done a lot of work to raise awareness and help support us as well and (NAME) is ongoing support – you know – if you have any issues we can contact her and she will help us if she can…"*

> ***P5:*** *" …the local cardiology team, (NAME) and the specialist nursing team. They worked really hard at it…"*

> ***P6:*** *" … (NAME) who is the lead consultant in Glasgow… there's (NAME) – who is excellent – who is a nurse specialist in HF and palliative care background and education as well… (NAME) is involved in the kind of project management and writing documents and things… (NAME), who is on the facilitation group, she is one of the geriatricians with an interest in HF – and again, I think – clinically… she will see the elderly patients with HF as well…"*

Engagement of Stakeholders

Within the CT, a great deal of effort was put into ensuring the widest possible range of stakeholders was aware of the CT and its implications for their work. Major effort was put into trying to engage with the range of stakeholders responsible for care for those with AHF. This was frequently challenging because not all stakeholders "bought into" the ideas underpinning the programme as the following comments highlight.

> ***P5:*** *"…we have sent out information to all the local GPs and I've been round certainly just round local area to try and raise awareness, raising it at local meetings."*

> ***P6:*** *" The cardiologist... I think, is really trying to get them on board because for a lot of them this isn't a priority I wouldn't have thought and they are not that interested in the palliative care aspect of things they perceive it as touchy feely so I'd say probably trying to win them round if you like... some of them were very keen to take this on but a lot of them really weren't, didn't feel it was their job, it was extra work they were being given, they didn't have time for it, so I think there was some resistance to change from some of the existing HF nurses, obviously because they felt they were busy and stretched with you know"*

Collective Action in the Caring Together Programme

The emphasis of collective action involves the work performed by individuals, groups of professionals or organisations in operationalising a new intervention in practice and socio-technical issues, such as how new systems affect the everyday work of individuals, organizational structures and goals [24, 25]. Clinical care pathways are often local implementations of standardised regional and national guidelines in response to contextualised priorities. A successful clinical pathway implementation requires that all the individuals involved in the setting up of the new service have an opportunity to define their own roles in terms of responsibilities and relationship to others, fostering both a sense of participation and accountability.

Facilitation Groups:

Of particular interest to any successful implementation of a new service or complex intervention are the range of existing barriers to implementation and how these were overcome in practice. The core components were designed collectively by experts in both HF and palliative care, and the responsibility to implement these core components of the CT model in each of the three pilot sites facilitation was the responsibility of the facilitation groups. So these facilitation groups, although not core components of the CT programme, were crucial to driving forward the planning and initial implementation in their local areas.

> ***P1:*** *"…there have been a group of key stakeholders across the whole of Greater Glasgow and Clyde… got together – who are both knowledgeable in palliative care and heart failure – and together with them, we identified six core components which we felt made a model that was going to improve palliative care of heart failure patients.*
>
> *We then left that up to how we would implement in each area to local facilitation groups… and these are the people who will be actually dealing with these patients on the ground in each of the pilot sites and so… that's how we have actually implemented it in the `Caring Together' overall… but we have left it up to local facilitation to do that…."*

The core components of the CT programme were therefore implemented rather differently across GGC in order to suit local circumstances and the facilities that were available.

> ***P3:*** *"...we are all at different sites we do all work slightly differently within the broad umbrella of guidelines and you know professional practice but you know different cardiologists at different sites, different politics at each site so we will all do thing slightly differently so maybe our ways of assessing patients will be more streamlined and that will be benefit to us."*

> ***P9:*** *"We've had in each of the pilot sites there is like in each of our heart failure teams a lead within and everybody has got together with different views on what they've done but it's just that if you are working outside Glasgow Royal because you have a specific palliative consultant in clinic, cardiology. So they will work differently because of the facilities that they have."*

> *P23: "They are seeing one or two patients once a month kind of thing and that's, and that's absolutely fine as well because it's important to say that because one of the things that I've been very clear about from the outset is that you know it's very unlikely that we would have one model that would fit everybody and the whole point of caring together was to start it in Glasgow and then to roll it out.....palliative care team so that's obviously quite a different model but that works with Inverclyde. It wouldn't work for the numbers that we are seeing and we see a much greater number of patients in the North East."*

Core Components

The CT programme had a number of core components that were operationalised across GGC. These are now discussed in turn.

Patient Identification and Referral into the CT programme:

There are a variety of routes into the CT programme and while the stakeholders were generally satisfied with the referral protocols – which had been refined over time – there were also some suggestions that the mechanisms for referral could be more consistently applied across the programme. Key aims of the CT programme included providing earlier palliative care in parallel with ongoing active illness treatment and the identification of AHF patients who would benefit from the programme so this is a key issue.

> ***P3:** “ …We do work well with the cardiologists but they tend to adopt the approach that we will come to them if we've got problems with our patients. They refer patients from their clinics or from the ward… but most of the patients that are in the `Caring Together’ programme have actually been identified by ourselves (referring to Heart Failure specialist nurses)…”*

Although the CT programme has been successful in achieving several of its original aims, several substantial challenges remain. One of these challenges is setting a robust system in place that can systematically identify *all* the patients in the pilot site that are eligible to be referred into the programme. At the moment, it would appear that there are disparities in referral routes, based on the awareness or not of the programme among professional groups and whether professionals buy into the model. It is likely that the disparity in referral routes and patterns go some way to explaining the differences in the referral volumes at the three implementation sites, with some services more likely to refer eligible patients into the programme than others. The main concern here is that this would therefore only partly address the issue of unequal palliative care service provision through NHS GGC, highlighted in the 2010 palliative care needs assessment [60]. Having a health-board wide monitoring system will be an important step towards addressing the issue of the disparity of palliative care provision for HF. In NHS GGC, it would appear that the recent implementation of a health-board wide electronic clinical portal offers a unique opportunity to implement a system which replicates and even surpasses that implemented in the *Memorial Medical Center* [54]. So while many patients had benefited, not all had been reached.

> ***P8:** “ …" I think better access for some of our elderly patients would be better I think it focused on the sort of largely cardiology patients so I think there's a whole lot of HF out there that's not within the team who have been managed by GPs and I think that group are maybe slightly underrepresented in who's been there… Because it's not been picked up by health professionals to refer on more than it's not the programmes fault, I think there's an under-recognition of elderly patients with HF in the community and who have never been referred onto cardiology services – never mind ours…."*

It is important to be clear that there were a range of explanations for variations in referral and some of these relate to the complexities of assessing those with multimorbidity, which is the case with most individuals with AHF.

> ***P8:*** *" … I'd say so but I mean I do emphasise though that it's maybe not quite as straightforward: it's not one pathology, there's multiple pathologies so it's not always as easy… and it's not easy to include someone with comorbid disease into a set pathway or a set referral programme, I think there are people there that we don't recognise…"*

There was also the difficulty of reaching all those who should be eligible for the CT programme so for example, those with diastolic dysfunction were considered to be largely neglected:

> ***P23*** *"They are not part of the heart failure nursing service because it's not funded that way (referring to those with diastolic dysfunction). So they are a group of patients that in a way, – not only they don't have equity of access to heart failure services but they don't have equity of access to palliative care services – so in some way they are almost worse off than the LVSD patients."*

Pre-existing collaborative relationships had a positive influence on referrals to the programme:

> ***P11:*** *"…we always had a relationship to begin with that you know that if patients came to the hospital for example with cardiac issues or had palliative issues then there was already a relationship between the cardiac failure nurse and the consultant and they said they can call us or refer to us at any time for our input and I think as well there is also the rapport between the cardiac failure staff or the cardiac failure nurse and the hospice clinical nurse specialist so it was about I think probably joining things up."*

Holistic Assessment

A comprehensive assessment of those with AHF is a key feature of the programme, and a range of tools are used to ensure that a holistic picture is gained so as to be able to address the broad range of needs of both the patient and their carer:

> ***P6:*** *"Well, I've seen the holistic assessment document that they use so that's the various assessment tools that look at physical, psychological and spiritual needs and they are all pretty much validated assessment tools... I think they've got an assessment tool for that as well the carer stress index."*

This feature of the programme was clearly seen as beneficial as it ensured that previous gaps in care were addressed. A range of problems such as financial issues and carer needs were being identified through use of the tools, whereas these subjects or aspects of care might have been neglected previously.

> ***P15:*** *"Things that we identify that the patients never got, they very seldom got benefits assessment. They didn't get OT assessment; they had lots of symptoms that weren't identified because if their symptoms weren't heart failure nobody asked them about them."*

It is important to be clear that using such tools is time consuming and professionals sometimes choose to use the bits that are most useful to them. However, overall these tools were welcomed and viewed positively.

> ***P8:*** *"I don't always find the set bit of paperwork or a set proforma works for my patients…"*

Care Management and Coordination

Across the three models implemented in GGC the HF nurses have the responsibility of conducting the patient holistic assessment, managing the care plan and coordinating the overall care management plan. However, this also relies on all the members of the broader care `partnership' to develop and maintain both good communication channels and personal relationships. In addition, regular meetings of the MDT allows for discussing individual patient care management plans.

> ***P21:*** *"[talking about HF nurse] …who would be the care manager because she sees them more than we do however if that balance changed then I would take over the role perhaps of care managing, you know once they get to the terminal stage and they are at home but the heart failure nurse would never be excluded obviously…"*

So it is important to be clear that while the heart failure specialist nurses had a pivotal role to play in the CT programme across GGC, liaison with and role of the wider MDT was strongly emphasised. A key worker functioning in isolation would not have worked. In the North East area, in particular, the lead cardiologist, for example, similarly had a key role.

> ***P9:*** *"…we are the ones (referring to Heart Failure Nurses) that do the holistic assessment and do all the correspondence… and link into all the multi-disciplinary team. We've had one lady who was managed and is still being managed by the primary team with the understanding that they could contact here or the cardiologist if there was problems…"*

> ***P23:*** *"So things like the network of care actually allow you to spread that time within the different health care professionals but you are not wasting time because everybody knows what's going on so you are not sending out different health care professionals to the patient, everyone sort of speaking and in communication obviously within the network of care, having IT is critical to that. So either that's the heart failure nurse or NAME, the specialist nurse and even if they couldn't get the heart failure nurse they can still kind of phone NAME for example and then if necessary they can contact me etc. I think the fact that we have this joined up co-ordinated care so the patients will either have, all patients will have a heart failure management plan."*

Improving communication and information sharing across sectors and between professional groups was also a key feature of this core component of the CT programme. Care coordination can only follow on from effective communication and information sharing. As care managers, the HF nurse is the guardian of the patient care management plan, which is currently a paper-based record. There are a variety of media used for communication among the CT team: face-to-face meetings, telephone, letters, electronic communication. The recent introduction of the electronic clinical portal in NHS GGC – as a single health-board wide data repository - would appear to provide potentially an ideal solution for information sharing within the CT. However, it appears that not all stakeholders are able to access the portal, with community care practitioners and voluntary partners (e.g. hospice) not having access to information on the clinical portal. Equally, the electronic palliative care summary record (ePCS) created in primary care by GPs in only accessible in unscheduled care and not generally accessible to the MDT. Additionally secondary care stakeholders who formulate management plans as part of CT must share these in hard copy with the GP's and rely on GP's to upload the information.

If the CT were to scale up in volumes or if it were to be implemented in other settings, then it would be worth exploring options of using a central electronic repository (e.g. electronic portal) as a single system for communication and information sharing, with role-based control access to the patient’s care management plan, in accordance to each partner’s information governance framework [64].

> ***P3:*** *" …I mean: every time we see a patient, our own service generates a letter that goes onto clinical portal that everyone else can access, so we don't specifically – now – copy our letter to everybody that is involved in the patients care… And the financial team: that would be a telephone referral. We wouldn't... we don't do any paperwork for them […] for instance, if the patient was getting seen regularly at another clinic, we would maybe – you know – flag that up with that specialist and say – you know – keep an eye out for our letters on the portal..."*

> ***P5****: " …we spoke to them on the phone and we corresponded by letter as well. We get a letter with a summary of what has been discussed from cardiology. The consultants are really approachable; they will give you a call back if they are not available immediately. We've got a good relationship with them…"*

> ***P11:*** *" … we tend to interact most closely with the cardiac failure nurse or with – you know – the cardiac patients on the wards. I would tend to go and speak to her and say: I've been – you know – I've been asked to see you and – you know – what their perspective is... so it tends to be fairly – you know – a kind of informal relationship. […] Every Thursday afternoon... and at that meeting, we discuss the patients who are either patients belonging to the clinic or patients who are going to be referred to the clinic…"*

> ***P12:*** *" … in some cases, we get in touch with the palliative care consultant and the palliative care specialist nurse and that tends to be the situation in the outpatient clinic and a lot of discussion occurs thereafter... communication with also the GP and the DN (District Nurse) and sometimes PTs OTs (Occupational Therapists) working in the community […] often the prompts to change things come from the HF liaison nurse or from the GP or from the patient…"*

> ***P13:*** *" … When the patient has been up and been assessed and we've decided on where we are going with things, we always write a letter back to the GP. If it's something very specific: I would usually drop the heart failure nurse maybe a wee email or try and phone them.…"*

Training and Education

It is clear from our interviews that the CT programme success hinges on both formal training and education but also importantly through informal knowledge transfer and shared learning between the various professional groups. So learning and knowledge transfer takes place during both formal events (i.e. dedicated study days) as well as through informal discussions on an opportunistic or as needed basis. The flow of knowledge transfer operates in multiple directions, from cardiology to palliative care, community / hospice to acute care and vice-versa:

> ***P13:** “ … (talking about key cardiologist & HF nurse) they are very good to go to for advice and they can bounce ideas off of us so that's very important time, when they manage to come up (i.e. to MDTs) […] if there is anything outstanding about any medication or anything that we maybe need to go back to the GP about, or we need to go back to the heart failure specialist, then we would do that as well but it would be outlined.”*

> ***P9**: "...we've done education days for the district nursing and it's educated them on heart failure, ...*
>
> *We had study days to educate us on ways of communicating and the best tools to break bad news and to give patients time and their relative's time to answer your questions. So we had a lot of support within the project to do that and again also within that the education day is bringing some of the palliative team throughout the health board. ....*
>
> *I suppose it's a bit like you would have similar to what we did with the district nurses and like even the GPs did training days as well. We went along to forums and things and we had."*

Thus education, training and shared learning of the broader care team are crucial to the CT programme implementation and sustainability.

However, again continued effort is needed in this arena and investments in training and shared learning need to be ongoing and cannot be considered a “one off expense”. Additionally problems with staff being released to attend events and back fill to allow this training must also be in place to allow the ongoing training.

> ***P5:** "I believe there have been training days for the district nurses but I think they are all still quite nervous that they wouldn't have the knowledge and skills to look after quite a complex group of patients."*

> ***P17:** "I would have liked some sort of training on you know end of life making plans, anticipatory care plans, I think somebody, I can't remember, NAME and it was DNs or*

> *somebody was doing seminars about it but we couldn't go we weren't allowed to go just because of demands elsewhere but that would have been good…"*

Multidisciplinary working and Joint Working

There are a number of key activities undertaken as part of the CT programme including

- dedicated weekly clinics in the NE for AHF patients, attended jointly by a cardiology consultant and heart failure nurse specialist and dedicated clinic slots in the other sites for CT patients. Having a specialist HF nurse attending the weekly HF clinic was deemed essential to its fulfilling its purpose.
- multi-disciplinary team meetings to discuss the care management plans of individual patients.

Multidisciplinary working and improved team working is an obvious strength of the programme and again helped to ensure patients were receiving more joined up and consistent care. This partnership working extended beyond health professionals and included engagement with third sector organisations. All of this promoted better coordination of care and ensured communication between groups was seen as easier and more straightforward making it more likely for individuals to be willing to just pick up the phone and contact others as required. It is important to note that, as one might expect, the introduction of CT was particularly successful where it served to build on pre-existing good links or relationships.

> ***P2:*** *"….partnership working with other organisations you know like long term condition partnership, they have become increasingly aware of increased referrals of HF patients and carers for maximisation of their benefits."*

> ***P11:*** *"….every Thursday afternoon and at that meeting we discuss the patients who are either patients belonging to the clinic or patients who are going to be referred to the clinic…"*

> ***P14:*** *"…and I guess it's the nature of this area is that she has already been working very closely with the GPs, possibly the district nursing teams….. Because it's quite a compact hospital it's very easy to liaise with people…..it depends on the timing either brought to the MDT that we tend to discuss there or they will be brought to our*

> *attention if they are in hospital. You know they are currently in needing sort of our input."*

Additional Key Activities included Advance Care Planning and the importance of adequate Resources should not be underestimated.

Advance Care Planning

The value of advance care planning and the Medical Anticipatory Care Plan (MACP) used in the CT programme was generally agreed. This plan was shared with the multidisciplinary team to ensure there was a common understanding of the patient's clinical condition and preferences for care.

> ***P12:*** *"[talking about MACP] so the GP, the DN, the HF nurse, the palliative care nurse, the cardiology consultant, other consultants in other specialties dealing with the patient all get a copy of it and the patient if they are happy to have this get a copy in their house with the idea being that if they become unwell in the middle of the night it's out of hours you know the ambulance the paramedics come out they can just hand the envelope over…"*

Such plans are not static documents and will naturally evolve over time as an individual's condition changes over time. It is therefore necessary to have good systems in place to ensure that all involved in care are aware of changes in the plan and have appropriate access to it at any time of day. So due attention is needed to underpinning infrastructures to enable this.

> ***P23:*** *" When you have got your medical ACP its all fine and well myself and the GP talking about it but you have to make sure that's updated and on the electronic systems so that if for whatever reason something untoward does happen, other people are able to see that."*

Resources

Any new initiative requires adequate resources to succeed. Resources is a very broad term and definitely includes financial resources but also includes having appropriate management support and sufficient personnel available to deliver services as well as having adequate underpinning systems, for example, information technology systems to support the aims and objectives of any new service or programme.

The CT programme was initially designed to operate within existing resources and many of the stakeholders acknowledged this. One of the main resources identified that had been utilised in the programme and that many stakeholders identified a further need for was time. Many acknowledged that the CT patients required more time and that this was a major resource demand. However, providing adequate resources (i.e. dedicated consultation time at weekly clinics) to carry out the holistic assessment of patients' needs was seen as very important and something that transformed the way patients were managed.

> ***P2:*** *"Well I suppose the resources that are available is time from the HF nurses and the professionals that are attending the facilitation group meetings"*

> ***P5:*** *"I think... certainly in terms of time... the biggest effort is probably on the cardiology nursing service."*

> ***P12:*** *" […] having been seeing patients with HF in cardiology clinics since about 2003... you see patients with HF at the cardiology clinic... you've got 5 or 6 minutes per patient... there's no time and no facility within a regular general cardiology clinic setting to actually address those significant symptom problems that these patients have... so being able to see them in the clinic where you've got 45 minutes for an appointment – you know – ...time to really explore all the issues that they have […] so the benefit of the clinic is: it's much longer appointments, you've got plenty of time to discuss it... discuss it with the doctor, special nurse then discuss it again."*

The need for time to participate echoes the concerns over workload with some stakeholders identifying that there were difficulties in where HFSNs would fit these duties into their existing roles:

> ***P20:*** *"I think if they had the time and we had additional resource and by that I mean additional nurses because they cannot continue, they cannot take on this role and continue with their current case load so they are going to do this or some of them are going to do this they need to have an appropriate case load and so that's an issue"*

There was a suggestion that extra staff may alleviate the difficulties with workload but it was also acknowledged by many that in the current financial climate this would likely not be feasible.

Technology and IT systems were another resource identified by stakeholders as being important for the successful implementation of the CT programme. As noted in the care management and coordination section above the ‘clinical portal’ resource has been found useful for information sharing between stakeholders. However there are still problems with this resource in the disparity in access. Many stakeholders highlighted that ‘joining up’ of the IT systems would benefit patient care and make participation easier.

> ***P5:*** *"I think it would be really useful to have the computer systems joining up."*

> ***P17:*** *"If systems could talk to each other would be brilliant"*

As identified the IT and technology systems have been a good resource for the CT programme however there would be scope for further development of this resource which could potentially facilitate the programme.

Reflexive Monitoring in the Caring Together Programme

Reflexive monitoring deals with the evaluation and monitoring of health interventions and how these are used to influence utilisation in future [24, 25].

Programme Integration

The CT programme was much more about service redesign and adapting existing structures rather than parachuting in more staff. It was therefore good to hear that for some, integrating CT into their everyday work seemed a fairly easy transition.

> ***P3:*** *" …I think the hospice staff probably thought they would have been affected more by it and I think in reality in this pilot site they haven't been."*

> ***P10:*** *" ... I wouldn't say in this job that its really affected us because as I say the nature and we've always had a very sort of close relationship with our patients especially ones that we do tend to see on home visits and things like this."*

However, equally the integration of the CT within existing services was dependent on levels of engagement of key individuals.

> ***P6:*** *" I think it's been interesting to see the differences between 3 pilot sites and why things have worked well and why things haven't and I think some of that's been to do with personalities of the team involved…"*

Equally, it was clear that a "one size fits all" model of CT was unlikely to be successful and this is an important point to consider when thinking about rolling out the CT nationally across the UK NHS. The need for flexible models that could be configured to meet local needs, as happened in GGC, was clear.

> ***P2:*** *"I suppose the biggest difficulty down to what resources the other sites have because for instance if you had heart failure nurse up in the Highlands you would be it for a huge rural area..."*

> ***P11:*** *"how people work in the North of the city compared to the South of the city now you might think that that's fairly identical but they are not. So you know I think that's a factor as well, I think it's not one… one model fits all."*

> ***P15:*** *"So you can't directly transfer a cancer model to a non-malignant model I mean… I learnt that from working… you can't do that, their disease trajectory is very different."*

> ***P20:*** *"I guess one of the key messages; you know one size doesn't fit all. If you look at how all clinical services work on different sites, they are all slightly different and they have all grown up that way for a combination of reasons, the resources they have, the people they have, the geography of the place so I think…"*

The second last quotation highlights an important point, especially when considering the transferability of components of CT to other non malignant conditions. It would seem likely that careful thought would need to be given to differences in disease trajectory for example of AHF when compared with neurological disorders or chronic lung disease.

Areas of Success

Encouragingly, there was a general view that CT was well on the way to achieving its original aims and a great deal of positive feedback was given about its impact and professionals seemed confident that the programme was beneficial. Positive comments covered a range of issues but particular areas of success related to: awareness raising; effective tools and processes for documentation; strengthened relationships between different professional groups; improved communication both between professionals and also between professionals and patients; better support for caregivers; improved coordination of care; increased provision of holistic care; up-skilling of staff; and objective evidence of positive effects on duration of hospitalisation and achieving choice regarding preferred place of death.

> ***P1:*** *" … more patients are dying in their preferred place of care, which is home, and they are being cared for in their preferred place of care and also... patients who entered Caring Together are spending less time in hospital in the last year of life than those who are not in Caring Together, so I think we are beginning to address that…"*

P3: *“it's made us much more aware….. Much better at assessing patients and assessing their ongoing symptoms.... we certainly probably implement support a bit earlier in terms of you know social support, financial support. We probably address the carer's needs a bit better than we did before."*

P4: *… I think the fact that you know if you are building up you know your holistic assessment you are building up your picture of your patient including the family within that because to me that's a true holistic assessment then because it's not just focusing in on anything physical you are bringing in quite a lot to the patient, you are including the carer within that anticipatory care planning you know your focusing in assessments on the needs of the patient and what you can do…."*

P6: *“… one of the biggest kind of... I think the... raising the profile. I think that's the thing actually.... we' got increasing up people's awareness of it, I think... It's hard to get a lot of cardiologists on board and I think (NAME) well... I think the people involved done a good job in just making it more prominent... getting it on the agenda... getting study days, you know, giving talks to Scottish parliament, getting it recognised. I think that's been the biggest achievement I'd say……….. I think getting the anticipatory care plans in place has made a key difference because I think you know even though the numbers have been relatively small compared to general palliative you know our palliative care population I think we have had good results."*

P9: *“Yes in that it definitely has improved our documentation and our communication of the significant conversations that we are having with patients and their carers."*

P12: *“I think there certainly is evidence that medical anticipatory care planning as a function of the HF and supported care clinic through caring together I think implementing that has reduced hospital admissions in patients where the preferred place of care is home and we presented that to the European society of cardiology."*

P18: *“I think it has yes I think in my area it has. I think these patients have been given the choice and the ability to die at home which I don't think they would have had before."*

P19: *“…is a view that it might also reduce length of stay etc but equally it will allow patients to have some input into their care."*

P23: *"what we found with that is that obviously as you know the majority of patients will come into hospital and die in hospital but for the patients who have got a medical ACP and their preferred place of care is home, they have made it, there will be no further re-admissions to hospital"*

However, despite the abundant positive comments it was clear that there was no room for complacency and that there was still much to do to improve the care for those with AHF. For example, it was clear that while progress was being made not all patients with AHF who might benefit were being reached by the programme.

> ***P3:*** *"…I don't think it's (the aims) been fully achieved."*

> ***P15:*** *"…[**when asked if CT meeting its aims]** I think it probably is to a certain extent. I think there is still a long way to go though. I think because it's very slow."*

Overall, it was clear that most professionals had confidence in CT and viewed it as beneficial. The programme had resulted in many positive effects and a move to provision of more holistic care, better support for caregivers and improved coordination and communication were perceived as key areas of success. However, further work was needed.

Acceptance of the CT

While in general CT seems to have been positively received because of its awareness raising activities and the fact that it addressed problems of quality of care for those with AHF, participants did raise some concerns or express some reservations about who the programme should target and about some of the tools being used as the following comments highlight:

> ***P3:*** *"…There are some thoughts that maybe you should identify patients as having ongoing symptoms at an earlier stage than we would, some of the younger patients but there is also some patients who if you told them at an earlier stage they wouldn't do well, you know, psychologically that would impact on them…"*

> ***P9:*** *"…That hasn't worked out as well as we thought it would do. It's strange in that because we've, what has come back from the patients, you know everybody saying …. most of the patients didn't feel they needed the ACP document…"*

> ***P10: […when talking about ACP and patients' view of this]*** *"I don't know if its maybe I think this is my opinion. I don't know if it's like a step too far for some people….. But when it comes to writing down for whatever reason in the black and white so no I've never had any of them returned at all."*

There also remained concerns about the acceptability of hospice care by those with non malignant disease and also the readiness of some patients to discuss prognosis:

> ***P15:*** *“....if you have got to explain to somebody what caring together is you know, but the patient's might not necessarily pick that up but I suppose that might be a disadvantage being linked to a hospice because not everybody with non-malignant disease will be comfortable…”*

> ***P3:*** *“…some of our patients we referred for day services went and didn't like it or they didn't feel comfortable there so…”*

> ***P16:*** *“…for some patients they don't necessarily want to face up to these things. They don't necessarily want to be told that you know their prognosis isn't great."…”*

Expected negative impacts on workload did not necessarily materialise across all sectors contributing to the CT. So hospice staff who had initially expressed concerns that they might be overwhelmed by the number of individuals referred with AHF, discovered that this did not actually happen and some heart failure specialist nurses also felt that the introduction of CT had not been as burdensome an experience as they had anticipated.

> ***P3:*** *“…if you had asked me a few years ago what the effort would be I would have had a whole big list and name would probably be going aaah but now I would say I can't think of anything now that is difficult".*

> ***P6:*** *“…I think in terms of you know we did wonder how much will this impact on our workload in the hospice but there's been very few actually inpatients maybe 1 or 2 that I think of because really often they would be managed out of hospice…”*

> ***P17****: “I think initially it was the paperwork was quite onerous and there was a lot of duplication like certainly away at the start but you know it's definitely slimmed down, definitely slimmed down quite a bit”*

Also, staff could see that the models of care being promoted in CT could have broader applicability to other serious chronic conditions:

> ***P18:*** *"…I think that I can see probably that you know that other illnesses it would be beneficial to have more input from the specialist nurse maybe like motor neurone disease MS and things like that.…"*

However, it was clear that certain aspects of CT were not acceptable to all professionals:

> ***P1:*** *"…trying to find a cardiologist who is willing to have those kind of discussions with palliative care professionals is going to be difficult. There is other people out there that have that interest that they are not, there is not a huge number of them so I think having, finding cardiologists who are willing to have those palliative care discussions is going to be the limiting factor."*

Remaining Challenges and Areas for Further Development

One of the successes mentioned earlier was in relation to the beneficial awareness raising efforts undertaken as part of CT. However, while much had been achieved there was a sense that there was still much to do. This may be because awareness levels were starting from a very low base. This suggests that while the initial education and training and efforts to raise awareness had been successful there is a clear need for this to be an ongoing strand within CT with continuing emphasis on this aspect of the programme over time.

> ***P3:*** *"I don't think it's been fully achieved. I think it's gone a long way to raising awareness. I think that is, was a huge hurdle for the team… I still think some of the cardiologists and some of the sites are, just don't get it. Just don't get the palliative, the whole palliative thing, they just don't get it or they don't see a need for it or they don't think it's relevant."*

While there was much agreement that the CT had achieved many of its aims there was still concern that more objective evidence of the benefits of the programme needed to be gathered. When considering wider dissemination of CT models it will be important to integrate evaluation within the CT package.

> ***P1:*** *"I think we need to gather sufficient evidence of the benefits of caring together both in terms of the volume of patients that are going through and the changes that that had made and we are in the process of doing that and we are hoping that if there is an independent evaluation that that would gather some of the evidence as well.."*

> ***P3:*** *" …we don't formally audit our patient's satisfaction if you like with anything that we do as a team."…"*

> ***P16:*** *"…we are certainly aware that, of looking, are keen to look at, well what our cohort patients died that we hadn't referred….. You know what are we missing here? Are we missing something is there or have these been unexpected deaths so.."*

> ***P19:*** *" … So that's how I see an improvement but per say around clinical management I don't have any knowledge or awareness of any improvements until I have seen a report…. Such evaluation should include assessment and monitoring of patient and caregiver perspectives. It is clear that this has been done but participants were unclear about the extent of this work and it certainly was not routinized as part of the programme…"*
>
> *[…] "Well as part of the project I understand that there has been patient satisfaction and patient questions and surveys…. you know satisfaction or some sort of a audits have actually been carried out…"*

One of the major areas of success for CT was the effects on improving communication and collaboration across professional groups. However, one professional group seemed far less involved, particularly in two of the sites, and that was the general practitioners (GPs). The absence of evidence of GP involvement was quite glaring and evidenced itself in the difficulty we had in identifying any GPs willing to talk to the evaluation team about CT because of a feeling they had little to say as they did not know much or have very much to do with the CT. This certainly seems to be an aspect of the programme that merits further development. There was, for example, a view that CT got little input from the community, especially GPs, and that levels of awareness in the wider community remained suboptimal.

> ***P3:*** *"But all these other various people that need to be involved aren't very good at passing information back and there is still even after all this time I think some lack of awareness of some of the GPs and some of the district nurses about what is expected of them… I'm surprised that he's still here but he told me that his district nurse had told him he'd been told too soon… mean there is still some when you phone up and say you know the patient is going to be part of the caring together programme they don't know what you are talking about." …the local cardiology team, (NAME) and the specialist nursing team. They worked really hard at it…"*

> ***P9:*** *" … No just the only thing that's we've been a bit disappointed is that we hand out all this information from the acute sector and send it to primary and we don't always get that information back from primary…"*

Rather than being inundated, as some had feared, the relatively low volume of patients participating in the service was in itself a challenge with regards to maintaining skills. Again, reinforcing the need to improve reach of the programme and to provide ongoing education and support. Some of this was probably related to the problem of lack of GP engagement outlined above as it was felt that there were many people in the community who would benefit from CT but were not being referred into the service.

> ***P3:*** *" … "I think the other problem is that because there hasn't been the numbers of patients that we expected… so they are few and far between. So when you have a patient and you are talking about a `caring together' patient and everyone knows what you are talking about and then that patient maybe dies and then you don't have anybody else for a wee while and then you've got to say oh it's another, `what does that mean again?'…"*

Alongside this, is the challenge of maintaining engagement of stakeholders which is obviously essential to the long term success of CT.

> ***P4:*** *" …There's quite a few people within the caring together group the past 2 meetings have been cancelled because I think more people can't you know so I think it ended up there was only going to be 2 at the last meeting so it was kind of cancelled so that might be a benefit to you know if we do have one I mean I don't know what your timescale is for completing…"*

> ***P11:*** *" …the problem is that we are coming in from one perspective and so you know we are not involved at all you know with the actual documentation side of it or anything you know. We are obviously involved in the meetings and things but it's so long since I have actually, actually been to the meetings. I think the last two were cancelled I've kind of lost track of it so you know some of that side of it so."*

CT had improved communication sharing and IT systems had played a central role in this but there remained technology issues that served as a barrier to effective information sharing. This was particularly evident when sharing information across sectors, for example, hospice to NHS, and between different health boards, for example the Jubilee and GGC. This is a problem that is likely to occur even more when wider scale deployment is undertaken and will be a key issue that needs addressed.

> ***P5:*** *“* …And if there was that joining up of IT systems it would make such a difference…*”*

CT is essentially a disease specific problem aimed at improved care for those with AHF. However, most people with heart failure are multimorbid and this was an issue that complicated care and may have affected access to services.

> ***P6:*** *“* …I guess potentially if there's a disagreement between different specialists involved in someone's care because often HF patients will have lots of other co morbidity, can't think of any examples but if there was differences in opinion in terms of how people were with things. I've not known for that to happen…*”*

> ***P8:*** *“* …I'd say so but I mean I do emphasise though that it's maybe not quite as straightforward it's not one pathology, there's multiple pathologies so it's not always as easy and it's not easy to include someone with comorbid disease into a set pathway or a set referral programme, I think there are people there that we don't recognise…*”*

> ***P5:*** *“* …I suppose one of the barriers is that these patients often do still have hospital admissions and because we've got lots of the complex comorbidity they don't always come in automatically under cardiology…*”*

Summary: Qualitative Study of Caring Together

Our qualitative work with CT programme stakeholders has highlighted a number of programme drivers, for example, the role of champions but also a range of other factors that promoted the success of the Programme. These relate in particular to the work undertaken to engage with the broadest range of stakeholders, to achieve buy in of all those needed to ensure the success of the programme and the emphasis placed on raising awareness of the Programme and its potential to address unmet needs. In addition, the educational efforts and promotion of skill sharing and better communication across sectors and disciplines were also extremely important activities that were generally viewed as beneficial. The flexibility of the Programme and the ability to be able to operationalise the core components differently in different locations in order to meet local requirements was a clear strength. The underpinning support of the NHS healthboard was also a feature critical to the Programme success and has implications for sustainability. The core components of the Programme such as holistic assessment, care management and coordination, and multidisciplinary and joint working were generally perceived as being very positive and successful. However, while certain core components such as patient identification and referral into the programme had improved things, there remained challenges. Difficulties had been encountered reaching all those who should be eligible for the CT programme, so this is clearly an aspect of the Programme which is still very much a work in progress. Also, despite major efforts at engaging all stakeholders, there remained work to do, especially in relation to primary care.

While there was a great deal of positive feedback and a general view that the CT programme was achieving many of its original aims it is clear that there is still much to do to ensure the sustainability of the programme and to increase the reach of the programme. From the interviews it was clear that information sharing had improved a great deal through the implementation of the CT programme and this was a highly valued aspect of the programme. However, while IT and technology systems were being used as part of the CT programme to enhance information sharing there were still barriers to access that need addressed in order to ensure the full potential of its usefulness is achieved.

VII- Manualisation and Transferability of the Models Developed by Caring Together

Before we describe our suggested recommendations for the transferability of the CT models of care to other settings, it would be useful to clearly define the current core components of the CT programme.

Following on from this model description, we divide our recommendations for the CT implementation into 2 distinct phases:

(i) the implementation of the programme structure followed by

(ii) the implementation of the core components and model processes

VII-1. Core Components of the Caring Together Programme

In order to be able to draw meaningful comparisons with other related studies and models previously reviewed in section V of this report, we describe below the CT core components:

The Core Components of Caring Together	
I – Patient Identification and Referral	If a patient is registered with a GP within the 3 pilots area, • **has a diagnosis of AHF (NYHA III or IV)** • **has distressing or debilitating symptoms despite optimal medical therapy** • **has supportive or palliative care needs** that may include a combination of physical, social, emotional, spiritual or psychological needs
II – Holistic Assessment of CT patient	• cardiology review: (outpatient / in-patient as appropriate) • holistic assessment: review with patient of the physical, social, psychological and spiritual aspects of their needs in order to identify appropriate solutions
III – Care Management and Coordination	• patient is assigned a care manager (usually the HFNS), acting as the main point of contact for care management, information, advice and support
IV – Training & Education	• Training provided to stakeholders delivering services within the programme • Shared learning between specialties (palliative care / cardiology and service delivery settings, community / acute care)
V – Multi-disciplinary work and Joint Working	• Joint working and care coordination across teams (community, out-of-hours care and acute care) • care manager, coordinates care with the MDT and can action additional referrals if required • a care plan is devised with individual patients to fulfil personalised medical and palliative care needs and national guidelines.

VII-2 - Implemention of Caring Together Programme Structure

Developing a Local Facilitation Group

The facilitation groups have played a key strategic role in developing and facilitating the implementation of the CT models of care in the 3 pilot sites in NHS GGC. Importantly, they have developed models of care which considered local needs and priorities, and which could be operationalised within existing service capacity in terms of services, resources and expertise available locally. Hence, the structure of the facilitation group is a key element of the *transferability* of the model to other geographical settings by providing *flexibility* and *adaptability* to the local context and priorities of future CT implementations. The facilitation groups have included representatives from all the programme stakeholders and it is likely that this is the composition most likely to lead to future successful implementation of the programme.

Hence, the first step in implementing the programme will be to identify and recruit key stakeholders into a facilitation group.

Once the local facilitation group has been convened, it needs to:

- **define the mission and remit** of the local facilitation group
- **identify and invite any additional stakeholders** which may contribute to the fulfilment of the programme aims and objectives. In particular, it is important to identify potential local, regional and national synergies for the programme roll-out
- **develop an understanding of existing capacity** and services in the local area (e.g. through process-mapping
- **develop an understanding of AHF patients' experiences of care**
- based on the above, **develop an a integrated model of care for HF patients** based on the NHS GGC programme experiences, while adapting to the local needs and context (staffing, resources, systems and processes).
- ensure that the model developed is both person-centred and holistic, through consultation with local patients representative organisations or patients, families and carers themselves

- use the service-redesign / care development process as an opportunity for **Quality Improvement (**both in terms of clinical outcomes and patients' experiences) and care delivery standardisation
- ensure that the model is accessible and equitable, i.e. that it does not introduce new inequalities in care provision across new geographical areas (i.e. patients who have access to integrated palliative care services vs. those who do not) – or at least, have a strategy to minimise any new potential access to care inequalities introduced as the result of the programme implementation (through phased roll-out for example).
- **define the core components of the local model,** and in particular the preferred **care manager, role and responsibilities.** Specify the resources available to the care manager and how the multi-disciplinary team and different health professionals will support the CT care manager.
- **develop a strategy for the implementation of the core components**, paying particular attention to who are the best people to move this implementation forward, what are the potential facilitators and barriers, who are potential champions to take on these responsibilities, on how they can be best supported in these endeavours by the facilitation group
- **develop a strategy for encouraging joint-working** between the different health and social professionals involved in the patient journey, paying particularly attention to information-sharing and knowledge-transfer activities
- examine **information-sharing capacity** (e.g. paper-based vs. computer systems) among the key professional teams (outpatient/inpatient services, community care, nursing homes and hospices). Are there existing systems in place which would allow seamless information sharing between all the professionals (e.g. electronic portal). Are there information governance barriers in place and how can these be satisfactorily addressed and overcome (e.g. by implementing strong information governance and audit trails)
- raise **awareness** of the programme and the core components among professionals and the public.

VII.3 - Implemention of Caring Together Programme Processes

Identifying and Supporting Champions

Our scoping review of the literature and qualitative data analysis have both highlighted the crucial role of champions in the successful implementation of integrated models of care for AHF and of the CT programme in NHS GGC. Thus, the Local Facilitation groups need to carefully select and support a number of champions to promote the programme implementation. In the CT implementation in NHS GGC, the role of champion has been fulfilled by the programme manager, lead heart failure nurse and a consultant cardiologist. Bearing in mind that resistance to integrated models of care may potentially come from the cardiology specialty – which may have a particular focus on active illness treatment – having a consultant cardiologist and/or senior heart failure specialist nurse as advocates of the care model is likely to be beneficial to chances of successful implementation.

Operationalising Referral into the Programme

Critical to the programme success is to deploy a robust structure for referring eligible AHF patients into the programme. This requires both general awareness of the programme among health professional groups but also the systematic identification of all eligible patients, in order to provide equitable access to the service provided by the programme. Of particular interest here is the system implemented in the *Memorial Medical Center Heart Failure Continuum of Care,* where an IT system collated information from multiple sources in order to identify potential eligible patients in the hospital on a daily basis, results which were then reviewed by the Heart Failure Nurse Specialist / care manager for further consideration [54].

Operationalising the Holistic Assessment of Patients Needs

Once a patient has been admitted into the programme, the next step will be to carry out a holistic assessment of needs. This will need to be contextualised in relation to the services available in the local area. There is naturally a trade-off to be made between carrying out a holistic assessment and the process being overly burdensome for patients and professionals. In practice, this is a process which has been developed and refined through the CT programme over several iterations, after use with patients and carers. Tools need to be deployed and iteratively refined in order to reach a system which will suit the range of local partners while ensuring a coherent and standard process across sites.

Coordinating Care

In the CT programme, the role of care manager has been fulfilled by the heart failure nurses, which is justified by both their expertise in heart failure and their close relationships with patients. Of importance for care coordination is the process of information-sharing and communication among the stakeholders and ideally a robust framework will be put in place to facilitate this (e.g. an electronic portal if this option exists and is available). Facilitating access to information about the patient care management plan among all the stakeholders is desirable but often difficult to implement in practice due to information governance barriers between professional groups and agencies (e.g. ePCS not accessible during scheduled care in hospitals; primary care and hospices not being able to access certain information on the clinical portal). However, our experience is that these barriers to effective information sharing can be overcome if appropriate safe-guards and governance arrangements are put in place.

Training, Up-skilling and Knowledge Sharing

Both the literature and our qualitative analysis have highlighted the importance of training for a successful integrated care model implementation. The training needs are likely to be specific to the local context but will normally involve some element of palliative care management training for heart failure nurses and equally some training in symptom management of HF for palliative care nurses and community nurses. This was identified as important both in the course of our interviews and in the literature. Handling difficult conversations about end-of-life has also been suggested as a particularly useful skill by HF nurses and may be useful for doctors in training and physicians not regularly involved in these types of conversations.

VII.4 – Transferability of CT Core Components

The review of integrated palliative care models for those with AHF shows that most have many elements in common with the CT programme core components. This in itself suggests that the transferability and integration of the CT core components to other care settings is likely to be high, providing that the implementation of the components takes into consideration the local context and priorities.

Core component 1: Patient Identification and Referral

All of the models described in the review build upon the implementation of a robust mechanism for the identification of patients eligible to be included in the integrated care programme. Where specified, the referral criteria have been included in the review summary table (Appendix VII). Although there are some small variations across the referral criteria, most of them are very similar to the existing CT referral criteria: AHF patients being defined as NYHA Class III/IV with deteriorating symptoms or significant functional impairment due to CHF despite optimum treatment (PhoenixCare model [48], Bradford Heart failure and Palliative Care services Partnership [53], the Supportive Care Program [55], heart failure care framework [57], Scarborough joint-care model [65]) with 2 models in particular including the surprise question *("would you be surprised if this patient died in the next year?")*: Bradford Partnership [53] and the Supportive Care Program [55]. Of particular relevance here are those models which have adopted proactive, systematic and multimodal identification systems – including for some the early identification of patients in primary care – such as the Comprehensive Care Team [51], Pathways of Caring [52], the Memorial Medical Center continuum of care [54], the heart failure care framework [57] and Palliative advanced homecarRE and heart FailurE caRE (PREFER) [59]. This is therefore a key component in any future roll out of CT but one that needs particularly careful attention in view of some of the challenging experiences described in relation to this in the GGC CT programme to date. CT has been successful in recruiting many AHF patients that have had the opportunity to benefit from the Programme but it appears that many with AHF are still to be reached, for example, individuals with diastolic dysfunction.

Core component 2: Holistic Assessment of Patient

All of the models described in our review, again in common with CT, include a comprehensive assessment of health status of eligible patients included in the integrated care programmes. These in-depth assessments – often including family or carers – focused on elucidating current health status, existing symptoms and management needs, reviewing support needs – both physical and emotional –, support availability and preparing an advanced-care / emergency response plan (PhoenixCare model [48], Comprehensive Care Team [51], Pathways of Caring [52], Bradford HF/PC Partnership [53], the Automated home telephone self-monitoring for AHF [56], heart failure care framework [57], Disease Specific Advance Care Planning (DS-ACP) [58], and Palliative advanced homecarRE and heart FailurE caRE (PREFER) [59]). Here, the comprehensive assessment of patients is also taken as an opportunity for patient education about symptoms, self-management and disease trajectory. Holistic assessment is therefore an essential component of most models of care and we would suggest that, based on the review and our empirical data, from those involved in the CT programme would have high transferability potential.

Core component 3: Care Management and Coordination

As with CT, most of the models' central activity consists of proactively coordinating the care delivered by a variety of providers into a joined-up, coherent management plan with a particular emphasis on avoiding acute care admissions. In most cases, this task is allocated to a nurse – usually but not always – specialised in the management of HF. An interesting variant model was that of the Comprehensive Care Team (CCT) [51], where the case-management was carried out by a social worker while also providing individual psychological support. A suggested limitation of this was the suggestion that as the result of the care coordinator being a social worker rather than a clinician, primary care providers may have been less inclined to follow the CCT recommendations [51]. The Care Management and Coordination aspect of CT was particularly successful and in theory should have a high potential for transferability. However, the presence or not of underpinning systems to facilitate information sharing or willingness or ability to invest in such infrastructures will be an issue that will affect transferability and is an important issue for consideration when choosing future implementation sites.

Core component 4: Training & Education

Again, as with CT, several of the integrated models emphasised that shared-care and care coordination was best implemented within a programme of shared-learning and knowledge-transfer, both for patients (initially during assessment and subsequently through regular meetings either with health professionals or support groups) and care providers (Bradford HF/PC Partnership [53], heart failure care framework [57]). Feedback about this aspect of CT was very positive and again the transferability of this component is likely to be high, but there are always resource implications in relation to such initiatives which need to be borne in mind.

Core component 5: Multi-disciplinary work and Joint Working

Most integrated models emphasised that multidisciplinary work was critical to the programme success and this usually involved both regular meetings and efficient communication and information sharing. Perhaps as may have been the case with CT, some studies have reported difficulties at times in sustaining engagement and participation from primary care partners (St. George integrated care model [49], Comprehensive Care Team [51]). The transferability of this component will depend to some extent on the prevailing organisational cultures at any future implementation locations. It is a key aspect of the programme which should be advocated but clearly is most successful at sites where there are pre-existing links and relationships to build upon.

VIII- Discussion and Conclusion

It is clear from this study that the CT programme has achieved a great deal. We have outlined the key components of the CT programme and also the key components of a range of other interventions aimed at improving the care for those with AHF. Across interventions of this type the key common features relate to: raising awareness of the problem and providing educational support for professionals; earlier and more effective identification of those with palliative care needs; an emphasis on improving knowledge and understanding of the condition; improving patient and caregiver support, addressing the full spectrum of physical, emotional, social and spiritual needs; a greater use of specific tools to facilitate identification and discussion of important issues likely to be of importance to patients and caregivers; improved individual case management with better continuity and coordination of care, so an emphasis on more holistic care; promoting better information and skills sharing across teams with greater collaboration across professional groups; improved out of hours care planning; greater collaboration between health and social care; a greater emphasis on advanced care planning; and in some, bereavement support.

We have outlined key facilitators and barriers to the implementation of the CT programme in GGC and highlighted key successes and outstanding challenges. When considering transferability issues in relation to the CT programme a key learning point from the work in GGC has been the need to individualise and contextualise the specific care models rolled out across the city to meet local needs and circumstances. It is very clear that a "one size fits all approach" to the further extension of the programme across the UK NHS or elsewhere in the world would be very unlikely to be successful. Flexibility will be a key attribute of any further CT roll out. While the NHS, at first glance, would seem to be a homogenous service, in fact, as has been evident in GGC it is quite heterogeneous with each area often being quite unique in the way services are delivered. That is why the tailoring of the CT programme in GGC provides an excellent example of how this can be achieved. This is a crucial point to note when considering the transferability of different components of CT.

Key features likely to enhance transferability of the programme relate to:

a) **Facilitation groups**. These have played a crucial strategic role in developing and facilitating the implementation of the CT models of care across NHS GGC. Importantly, as outlined above they have developed models of care which considered local needs and priorities, and which could be operationalised within existing service capacity in terms of services, resources and expertise available locally.

b) **The structure of the facilitation group**. This is a key element of the transferability of the model to other geographical settings by providing flexibility and adaptability to the local context and priorities of future CT implementations. The facilitation groups have included representatives from all the programme stakeholders and it is likely that this is the composition most likely to lead to future successful implementation of the programme.

c) **Identifying champions**. This is an important feature of the most successful models of care identified in our scoping review and has clearly been central to the success of the CT. Champions are essential to drive the successful implementation of the CT in other areas. Such champions need to be: individuals who would be deemed credible in their localities, so influential; but also to have enthusiasm and be willing to sustain their commitment to the programme. The CT programme had a number of champions from different backgrounds but was driven particularly by a very dedicated cardiologist and heart failure nurse specialist. We would expect that it would be essential that individuals from such backgrounds were available in any given locale to ensure “buy in” of key players in future implementations. There are also inherent risks from over reliance on a single champion, in terms of sustainability, so we would suggest it is important to try to get as broad a range of champions as possible.

d) **Operationalising robust and equitable referral mechanisms**. This is an outstanding challenge for the CT programme in GGC. It is likely that the scale of this challenge will vary considerably across the UK, depending on how local services are presently configured and the electronic and/or paper systems already available for identifying suitable patients and sharing information in any given area.

e) **Use of holistic assessment tools**. A range of tools are available and have been used in the CT programme. There is always a trade-off between utility and the degree of burden posed by such tools. Again it is clear that tools need to be deployed and iteratively refined in order to reach a system which will suit any locality.

f) **Identification of a key individual to coordinate care**. This is a feature of CT and of most models identified. In the CT programme across GGC, the role of care manager has been fulfilled by the heart failure nurses, which is justified by both their expertise illness and their close relationships with patients BUT other professional groups have taken on this role elsewhere. Once again, we would see this as an issue that would need to be determined on a case by case basis by local facilitation groups in collaboration with partners.

g) **Training and Education**. This is another of the core components of the CT programme, and has been very positively received. Such activities are central to most models of care described in the literature, and while tailoring to specific contexts and needs will be necessary, it seems likely to have great transferability based on the feedback received on the CT. It will be important to ensure such training takes account of multimorbidity and complex care needs in AHF, as well as the challenges of advanced care planning. We base this recommendation on feedback from participants regarding the particular difficulties posed by these issues. The need for investment in training does have resource implications.

h) **Information and skill sharing and multidisciplinary working**. This has been another particularly successful aspect of the CT programme which was highly valued. The presence of underpinning electronic infrastructures in GGC has been helpful to facilitate information sharing, although even here, there remains room for improvement. It is clear that skill sharing and multidisciplinary working are facilitated when there are already existing links or relationships, serving to strengthen these. The input of local facilitation groups regarding how best to promote this in any given area would be essential.

i) **Advance Care Planning** - operationalizing this effectively clearly still remains a challenge within the CT programme in GGC. It is an element of CT that is common to most models of care but is clearly an area which needs revisiting throughout the course of an implementation and that needs to be addressed in training and education and for which ongoing support will be essential. Experiences from CT suggest that some individuals with AHF and perhaps some professionals resist such conversations but also that it has been very positive with others.

j) **Cardiological review** of AHF patients has been another successful aspect in GGC, particularly in the NE model. Therefore, “buy in” from cardiology and cardiological involvement is likely to promote transferability.

The CT programme across GGC has been extremely successful in a range of ways, contributory factors to this success include: the flexible approach to implementation (permitting three different models to be deployed); the presence of local management support; some additional resources; an enabling local and national policy environment; dedicated and enthusiastic champions; the presence of IT systems to help facilitate information sharing; a very active awareness raising and engagement programme. There is much to be learned from the positive experiences of implementation of the different models in this area but also from the challenging aspects, for example, in terms of "reach of the programme". The core components of the CT programme in GGC are likely to be transferable to other areas. However, one of the most important lessons from the GGC experience is the importance of tailoring future implementations elsewhere, to meet the needs and fit the circumstances of any local environment. The core components described above will be essential elements at any location and generic structures or features such as facilitation groups, champions, key individuals to coordinate care, multidisciplinary working, education and training, holistic assessment tools and advance care planning will be likely to be broadly applicable and transferable but precise details of who does what will need shaped and adapted iteratively to meet the needs of any specific area. Importantly, the policy context both nationally and locally supported the implementation and integration of the CT programme in GGC and this, along with management support and resources (both financial and manpower), are other important factors underpinning success. Such issues also need to be considered at any future implementation site.

REFERENCES

1. Stewart, S., et al., *More 'malignant' than cancer? Five-year survival following a first admission for heart failure.* European Journal of Heart Failure, 2001. **3**(3): p. 315-322.
2. Jhund, P.S., et al., *Long-Term Trends in First Hospitalization for Heart Failure and Subsequent Survival Between 1986 and 2003: A Population Study of 5.1 Million People.* Circulation, 2009. **119**(4): p. 515-523.
3. Rogers, A.E., et al., *Knowledge and communication difficulties for patients with chronic heart failure: qualitative study.* BMJ, 2000. **321**(7261): p. 605-607.
4. Murray, S.A., et al., *Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community.* BMJ, 2002. **325**(7370): p. 929.
5. Murray, S., et al., *Illness trajectories and palliative care.* BMJ 2005. **330**.
6. Barclay, S., et al., *End-of-life care conversations with heart failure patients: a systematic literature review and narrative synthesis.* Br J Gen Pract. , 2011. **61**(582): p. e49-62.
7. Low, J., et al., *Palliative Care in Advanced Heart Failure: An International Review of the Perspectives of Recipients and Health Professionals on Care Provision.* Journal of Cardiac Failure, 2011. **17**(3): p. 231-252.
8. Solano, J.P., B. Gomes, and I.J. Higginson, *A Comparison of Symptom Prevalence in Far Advanced Cancer, AIDS, Heart Disease, Chronic Obstructive Pulmonary Disease and Renal Disease.* Journal of Pain and Symptom Management, 2006. **31**(1): p. 58-69.
9. Nordgren, L. and S. Sörensen, *Symptoms Experienced in the Last Six Months of Life in Patients with End-Stage Heart Failure.* European Journal of Cardiovascular Nursing, 2003. **2**(3): p. 213-217.
10. Barnes, S., et al., *Prevalence of Symptoms in a Community-Based Sample of Heart Failure Patients.* Journal of Pain and Symptom Management, 2006. **32**(3): p. 208-216.
11. Walke, L.M., et al., *Symptom Assessment in Community-Dwelling Older Adults with Advanced Chronic Disease.* Journal of Pain and Symptom Management, 2006. **31**(1): p. 31-37.
12. Browne, S., et al., *Patient, carer and professional perspectives on barriers and facilitators to quality care in advanced heart failure.* Plos ONE, 2014. **in press**.
13. Hogg, K.J. and S.M.M. Jenkins, *Prognostication or identification of palliative needs in advanced heart failure: where should the focus lie?* Heart, 2012. **98**(7): p. 523-524.
14. Haga, K., et al., *Identifying community based chronic heart failure patients in the last year of life: a comparison of the Gold Standards Framework Prognostic Indicator Guide and the Seattle Heart Failure Model.* Heart, 2012. **98**(7): p. 579-583.
15. Joan M. Teno, et al., *Dying Trajectory in the Last Year of Life: Does Cancer Trajectory Fit Other Diseases?* Journal of Palliative Medicine, 2004. **4**(4): p. 457-464.
16. Davis, M.P., N.M. Albert, and J.B. Young, *Palliation of heart failure.* American Journal of Hospice and Palliative Medicine, 2005. **22**(3): p. 211-222.
17. Scott A Murray and A. Sheikh, *Palliative Care Beyond Cancer: Care for all at the end of life.* BMJ, 2008 **336**(7650): p. 958-9.
18. Hunt, S.A., et al., *ACC/AHA 2005 Guideline Update for the Diagnosis and Management of Chronic Heart Failure in the Adult: A Report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines (Writing Committee to Update the 2001 Guidelines for the Evaluation and Management of Heart Failure): Developed in Collaboration With the American College of Chest Physicians and the International Society for Heart and Lung Transplantation: Endorsed by the Heart Rhythm Society.* Circulation, 2005. **112**(12): p. e154-e235.
19. *SIGN Guideline 95: Management of Chronic heart failure*. 2007.
20. Jaarsma, T., et al., *Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology.* European Journal of Heart Failure, 2009. **11**(5): p. 433-443.

21. Beattie, J., *Implantable cardioverter defibrillators in patients who are reaching the end of life. London: British Heart Foundation,*. 2007.
22. Frances Mair, et al., *Patient, Carer and Clinician Experience of the Palliative Care for Patients in the Advanced Stages of Heart Failure - Final Report*. 2013. p. 51p.
23. Pettit, S.J., et al., *ICDs in end-stage heart failure.* BMJ Supportive & Palliative Care, 2012. **2**(2): p. 94-97.
24. May, C. and T. Finch, *Implementing, Embedding, and Integrating Practices: An Outline of Normalization Process Theory.* Sociology, 2009. **43**(3): p. 535-554.
25. May, C., et al., *Development of a theory of implementation and integration: Normalization Process Theory.* Implementation Science, 2009. **4**(1): p. 29.
26. Scottish Partnership for Palliative Care, *Living and dying with advanced heart failure: a palliative care approach*. 2008. p. 52p.
27. The Scottish Government Edinburgh, *Better Heart Disease and Stroke Care Action Plan*. 2009. p. 93p.
28. Department of Health, *End of Life Care Strategy: Promoting High Quality Care for All Adults at End of Life*. 2008. p. 171p.
29. Michael Connolly, et al., *End of Life Care in Heart Failure: A Framework for Implementation, NHS Improvement*. 2010.
30. Healthcare Improvement Scotland, *Heart Disease Improvement Programme: National Overview – Take Heart* 2011.
31. NHS Quality Improvement Scotland, *Clinical Standards: Heart Disease.* 2010: p. 55p.
32. *Living and Dying Well: a national plan for palliative and end of life care in Scotland. The Scottish Government, Edinburgh* 2008: p. 38 p.
33. *Heart Disease Improvement Programme: Summary Local Reports | NHSScotland. Healthcare Improvement Scotland.* 2011: p. 70 p.
34. *The British Heart Foundation heart failure palliative care project report: The Glasgow and Clyde experience; British Heart Foundation; London.* 2010: p. 73p.
35. *Role of the British Heart Foundation heart failure palliative care specialist nurse: a retrospective evaluation; British Hear Foundation; London.* 2010: p. 60p.
36. *Caring Together Programme: North East Glasgow Pilot Site Model Descriptor. 2011.*
37. *Caring Together Programme: South West Glasgow Pilot Site Model Descriptor. 2011.*
38. *Caring Together Programme: Inverclyde Pilot Site Model Descriptor. 2011.*
39. *Lacey, A. and D. Luff, Qualitative Data Analysis, The NIHR RDS for the East Midlands / Yorkshire & the Humber. 2009.*
40. *Chronic heart failure: the management of chronic heart failure in adults in primary and secondary care. National Clinical Guideline Centre. London.* 2010.
41. Lindenfeld J, et al., *Executive Summary: HFSA 2010 Comprehensive Heart Failure Practice Guideline.* Journal of cardiac failure, 2010. **16**(6): p. 475-539.
42. McMurray, J.J.V., et al., *ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure 2012: The Task Force for the Diagnosis and Treatment of Acute and Chronic Heart Failure 2012 of the European Society of Cardiology. Developed in collaboration with the Heart Failure Association (HFA) of the ESC.* European Heart Journal, 2012.
43. Yancy, C.W., et al., *2013 ACCF/AHA Guideline for the Management of Heart Failure: Executive Summary: A Report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines.* Circulation, 2013. **128**(16): p. 1810-1852.
44. Arnold, J.M.O. and e. al., *Canadian Cardiovascular Society consensus conference recommendations on heart failure 2006: Diagnosis and management. Canadian Journal of Cardiology, 2006. 22 (1): p. 23-45.*

45. McKelvie, R.S. and e. al., *The 2011 Canadian Cardiovascular Society Heart Failure Management Guidelines Update: Focus on Sleep Apnea, Renal Dysfunction, Mechanical Circulatory Support, and Palliative Care. Canadian Journal of Cardiology 27 p. 319-338.*
46. Allen, L.A. and e. al., *Decision Making in Advanced Heart Failure A Scientific Statement From the American Heart Association.* Circulation, 2012. **125**(15): p. 1928-1952.
47. Wagner, E.H., B.T. Austin, and K. Michael Von, *Organizing Care for Patients with Chronic Illness.* The Milbank Quarterly, 1996. **74**(4): p. 511-544.
48. Aiken, L.S., et al., *Outcome evaluation of a randomized trial of the PhoenixCare intervention: program of case management and coordinated care for the seriously chronically ill.* Journal of Palliative Medicine, 2006. **9**(1): p. 111-26.
49. Davidson, P.M., et al., *Integrated, collaborative palliative care in heart failure: the St. George Heart Failure Service experience 1999-2002.* Journal of Cardiovascular Nursing, 2004. **19**(1): p. 68-75.
50. Davidson, P.M., et al., *End stage heart failure patients - palliative care in general practice.* Australian Family Physician, 2010. **39**(12): p. 916-20.
51. Rabow, M.W., et al., *The comprehensive care team: a description of a controlled trial of care at the beginning of the end of life.* Journal of Palliative Medicine, 2003. **6**(3): p. 489-99.
52. Rosenfeld, K. and J. Rasmussen, *Palliative care management: a Veterans Administration demonstration project.* Journal of Palliative Medicine, 2003. **6**(5): p. 831-9.
53. Daley, A., C. Matthews, and A. Williams, *Heart failure and palliative care services working in partnership: report of a new model of care.* Palliative Medicine, 2006. **20**(6): p. 593-601.
54. Manning, S., M.C. Wendler, and K. Baur, *An innovative approach to standardizing heart failure care: the heart failure support team.* Journal of the American Academy of Nurse Practitioners, 2010. **22**(8): p. 417-23.
55. Bekelman, D.B., et al., *Outpatient palliative care for chronic heart failure: a case series.* Journal of Palliative Medicine, 2011. **14**(7): p. 815-21.
56. Kurtz, B., et al., *Automated home telephone self-monitoring reduces hospitalization in patients with advanced heart failure.* Journal of Telemedicine & Telecare, 2011. **17**(6): p. 298-302.
57. Boyd, K.J., et al., *Making sure services deliver for people with advanced heart failure: a longitudinal qualitative study of patients, family carers, and health professionals.* Palliative Medicine, 2009. **23**(8): p. 767-76.
58. Schellinger, S., A. Sidebottom, and L. Briggs, *Disease specific advance care planning for heart failure patients: implementation in a large health system.* Journal of Palliative Medicine, 2011. **14**(11): p. 1224-30.
59. Brannstrom, M. and K. Boman, *A new model for integrated heart failure and palliative advanced homecare--rationale and design of a prospective randomized study.* European Journal of Cardiovascular Nursing, 2013. **12**(3): p. 269-75.
60. Chaplin, J. and K. Lennon, *Palliative Care Health Needs Assessment, NHS Greater Glasgow and Clyde. .* 2010: p. p. 108.
61. Evans-Lacko, S., et al., *Facilitators and barriers to implementing clinical care pathways.* BMC Health Services Research, 2010. **10**(1): p. 182.
62. Nordang, K., M.-L. Hall-Lord, and P. Farup, *Burnout in health-care professionals during reorganizations and downsizing. A cohort study in nurses.* BMC Nursing, 2010. **9**(1): p. 8.
63. Verhaeghe, R., et al., *Impact of recurrent changes in the work environment on nurses' psychological well-being and sickness absence.* Journal of Advanced Nursing, 2006. **56**(6): p. 646-656.
64. Bouamrane, M.-M. and F. Mair. *An overview of electronic health systems development & integration in Scotland. Proceedings of Managing Interoperability and Complexity in Health*

Systems, MIXHS'11, 20th ACM Conference on Information and Knowledge Management, CIKM 2011, Glasgow, United Kingdom, 2011: p. 59-62.

65. Johnson, M.J. and T. Houghton, *Palliative care for patients with heart failure: description of a service.* Palliative Medicine, 2006. **20**(3): p. 211-4.