IMPERIAL COLLEGE LONDON

TREATMENT DECISION-MAKING IN HEART FAILURE MANAGEMENT

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ABSTRACT

Background

Demands for increased patient and public involvement in healthcare has led to changes in policy on decision-making. The shared decision-making (SDM) model is advocated in current health policy and encourages partnership between patients and professionals. Yet limited evidence exists of its effects on clinical outcomes and cost. As a result, a policy-practice divide has emerged. Heart failure management has adopted a more personalised approach to treatment. Yet knowing the treatment that is likely to have the best therapeutic effect does not mean it is right for that individual patient. Patients' health decisions are influenced by a variety of factors, including their experience of illness and disease beliefs. Professionals need increased understanding of how patients make decisions to support the integration of SDM in to practice.

Purpose

This thesis aims to explore different stakeholder perspectives of decision-making in heart failure management and to identify the barriers and facilitators to SDM.

Method

A mixed-methods study design involving: Pan-London analyses of multidisciplinary team (MDT) meetings; a qualitative interview study analysed by thematic analysis (Glaser and Strauss, 1967); a Delphi consensus survey. Together these data inform key recommendations to improve communication about treatments and the design of future research.

Results

The structures, functions and processes of MDT meetings varied within and across NHS Trusts. Professionals' assumptions about patient preferences, information needs and approach to decision-making were key barriers to a SDM approach. There was agreement that patients should be involved in treatment decisions, yet there was limited consensus on the priority areas for improvements to practice.

Conclusion

Considerable variation exists in the process of treatment decision-making and there is limited concordance between the views of patients, their families and health professionals. Professionals need to tailor their approach

to treatment discussions and assess patients health information-sourcing behaviour to better support patient involvement in decision-making.

STATEMENT OF ORGINALITY

I hereby declare that this thesis contains my own work except where otherwise acknowledged. The design of the studies presented in this thesis were assisted by my primary supervisor Dr. Jillian Riley. As an experienced qualitative researcher, Dr. Riley assisted with the validation process of my qualitative interview data. The work of others that is discussed in this thesis is referenced accordingly and its origins provided in the bibliography. No part of this thesis has been previously submitted for application of a higher degree.

COPYRIGHT DECLARATION

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ABBREVIATIONS

ACEi	Angiotensin Converting Enzyme inhibitors
AHA	American Heart Failure Association
API	Autonomy Preference Index
ARB	Angiotensin II Receptor Blocker
BB	Beta-blocker
BHF	British Heart Foundation
BNP	Brain Natriuretic Peptide
CABG	Coronary Artery Bypass Graft
CI	Confidence Interval
CMA	Cardiomyopathy Association
CNS	Clinical Nurse Specialist
CQC	Care Quality Commission
CQUIN	Commission for Quality and Innovation
CRT	Cardiac Resynchronisation Therapy
CRT-D	Cardiac Resynchronisation Therapy with Defibrillator
DA	Decision Aids
DoH	Department of Health
EOL	End of Life
ESC	European Society of Cardiology
GMC	General Medical Council
HDAS	Health Depression and Anxiety Score
HF	Heart Failure
HFmrEF	Heart Failure with mid-range Ejection Fraction
HFpEF	Heart Failure with preserved Ejection Fraction
HFrEF	Heart Failure with reduced Ejection Fraction
HRQoL	Health-related Quality of Life
ICD	Implantable Cardioverter-defibrillator
KCCQ	Kansas City Cardiomyopathy Questionnaire
LAE	Left Atrial Enlargement
LVAD	Left Ventricular Assist Device
LVEF	Left Ventricular Ejection Fraction
LVEF	Left Ventricular Ejection Fraction
LVH	Left Ventricular Hypertrophy
MDT	Multi-disciplinary Team
MLHFQ	Minnesota Living with Heart Failure Questionnaire

NHS	National Health Service
NICE	National institute of Health and Clinical Excellence
NMC	Nursing and Midwifery Council
NYHA	New York Heart Association
PAM	Patient Activation Measure
PCC	Patient-centred Care
PCI	Percutaneous Coronary Intervention
PCT	Primary Care Trust
PPM	Permanent Pacemaker
PROMS	Patient Reported Outcome Measures
PSQ	Patient Satisfaction Questionnaire
RCT	Randomised Controlled Trial
SDM	Shared decision-making
SERCA2a	Sarcoplasmic (endoplasmic) reticulum calcium ATPase 2a
SpR	Specialist Registrar
ToR	Terms of Reference
UK	United Kingdom
US	United States
WHO	World Health Organisation

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CHAPTER 1: INTRODUCTION TO THESIS

Shared Decision-making (SDM) is a patient-focussed model of care that encourages partnership between patients and professionals to reach a mutually agreed treatment decision. It aims to support decisions that are based on clinical evidence, professional expertise and the patients individual goals and preferences. The premise of SDM is that it facilitates the sharing of information between patients and professionals, giving patients joint ownership over decisions about their treatment and disease management. The intended outcome of this approach is to improve the quality of decisions, increase patient satisfaction, improve adherence to treatment and reduce inappropriate interventions and unwarranted variations in treatment. In the United Kingdom (UK), SDM is on the national policy agenda and has been prioritised as part of the health reform bill. The National Health Service (NHS) Constitution emphasises patients' rights to be involved in decisions and this is reinforced in standards set by professional regulators. Today financial implications face health services who fail to demonstrate adoption of SDM in practice.

One of the key challenges to implementing a SDM approach is the increasing complexity of decision-making. Advances in heart failure management mean that treatments are now targeting smaller, more specific patient populations. Newer treatments and advanced management strategies have led to patients living longer, often with multiple comorbidities and increased frailty. However, the limited clinical guidance to support professionals on how to adopt a shared approach to decision-making has resulted in a slow integration of SDM in to routine practice.

This thesis aims to challenge current health policy on decision-making and determine its applicability to heart failure management. A series of studies are reported that explore and compare the decision-making processes and views of patients, their family members and health professionals towards the treatment and management of heart failure.

The following Chapter presents a critical review of the literature that provides the rational for this thesis, the research questions posed, its aims, study design and research methodologies. The review starts by providing a background to the treatment of heart failure, including comparisons of national and international clinical guidance. How treatment decisions are made in current practice is reviewed. The patient pathway and the multidisciplinary approach to heart failure management highlights the challenges faced by professionals in making complex treatment decisions. The emergence of health policy on decision-making and the concept of a 'Shared Decision Making' (SDM) approach is then presented. The quality of the evidence-base for a SDM model of care is appraised by reviewing the evidence underpinning health policy, clinical guideline recommendations and the wider literature-base. Together these findings highlight a policy-practice divide.

To date no research has explored the preferences and decision-making processes of patients with heart failure. Therefore, to better understand the application of SDM in practice, a review of patient preferences for involvement in decision-making was conducted. Chapter 2 concludes by reviewing Behavioural Theory constructs. These theoretical frameworks guide the in-depth exploration of patients' decision-making processes and support better understanding of the influences on patient health decisions and behaviours. A conceptual model is presented which was used to support the mixed-methods design of this thesis and guide the study enquiry.

To explore the process of decision-making it was firstly important to understand how treatment decisions are being made in current practice. Chapter 3 extends the findings of the literature review, by introducing the role of the multidisciplinary team (MDT) meetings and their core process in decision-making in chronic disease management. The Chapter reports a Pan-London analyses of the structures, functions and processes of cardiology and cardiothoracic MDT meetings within and across NHS Trusts. The findings of these analyses further evidence the disparity between decision-making policy and practice.

Chapter 4 details the methods and processes used in the collection and analysis of data for the qualitative interview study and the Delphi consensus survey. The Chapter is divided in to two study strands. Strand I, the qualitative interview study designed to explore how patients make decisions about their heart failure management. Strand II, a Delphi consensus survey used to extend the findings of the qualitative interview study and identify priorities for practice recommendations.

Chapter 5 reports on the qualitative findings of the interview data that were analysed by the process of constant comparison and thematic analysis (Glaser and Strauss, 1967). The three key themes that emerged from these data are presented: Preferences for involvement in decision-making; Health information-sourcing behaviour; Delivering an SDM approach. Each theme is divided in to sub-themes which illustrate the key findings and similarities and differences between the views and experiences of each cohort: patients, family members, health professionals. Chapter 6 presents the quantitative results of the mixed panel Delphi survey using descriptive statistics. A priori level of consensus threshold, response feedback to the panel and variation in agreement are reported.

Chapter 7 presents an in-depth discussion of the combined findings of this thesis, drawing on the literature-base and wider societal perspectives. Together these data inform recommendations aimed at supporting health professionals to tailor their communication about treatments to individual patients disease needs and personal preferences. Recommendations for the next steps in this field of research are outlined. Chapter 8 concludes this work through reflection on the key findings and the importance of interdisciplinary collaboration and organisational change.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction to chapter

This chapter presents a review of the literature on health policy on decision-making and heart failure management. The Chapter starts by providing a background to the treatment and management of heart failure. This is followed by review of current health policy on decision-making. The introduction of the Shared Decision-making (SDM) model is discussed and its integration in to practice is reviewed. Together these findings highlight important gaps in the literature which inform the aims of this thesis. The review then explores the theoretical underpinnings of human behaviour and behavioural change. This provides the theoretical framework and rationale for the study design and research methodologies chosen. The chapter concludes by presenting a conceptual model, designed to guide this study enquiry.

2.2 Background

2.2.1 Treatment and management of heart failure

Heart failure is a complex disease associated with high levels of mortality, morbidity and cost. European population-based studies have reported high mortality rates in heart failure, with estimates of mortality at 59% within 5 years (McMurray et al, 2012). In the United Kingdom (UK), over half a million people are living with heart failure and the burden is increasing (Townsend et al, 2016). Recent estimates report a 12% increase in the number of people newly diagnosed with heart failure in the UK and a 23% increase in the number of prevalent cases (Conrad et al, 2018). Today there is considerable financial burden on healthcare services with the annual cost of managing heart failure estimated at over £600 million (NHS, 2008).

Patients with heart failure require chronic care management from periods of decompensation and hospitalisation through to end-of-life care (Jaarsma et al, 2009). Patients are burdened by symptoms which affect their social interactions as well as their psychological health (Lesman-Leegte et al, 2009). Poor quality of life and depression are common in heart failure and shown to increase patient risk of hospitalisations and mortality (Iqbal et al, 2010). Importantly, the burden of living with heart failure affects both patients and their families (Luttik et al, 2007).

Developments in biomedical science and newer treatments have helped to improve patient survival. Advanced management strategies such as Left Ventricular Assist Devices (LVADs) have demonstrated two-year survival rates of 70% in complex patients (Kirklin et al, 2013). In the United States (US), these devices are being used as destination therapy. Increased survival means that patients are living longer often with multiple comorbidities that worsen their prognosis (Mentz and Felker, 2013). This aging population has led to high levels of frailty which means that many patients are at increased risk of conventional treatment. These complex patients require input from multiple professional disciplines, specialties and services. Consequently, health professionals today are facing increasingly complex treatment and management decisions, with many patients falling in to the '*grey zone'* of clinical guideline recommendations.

To diagnose patients with heart failure there needs to be evidence of signs and symptoms, objective evidence of cardiac dysfunction (Gold standard echocardiography) and response to heart failure treatment (ESC, 2016). The New York Heart Association (NYHA) classification is traditionally used to class the severity of heart failure and indicate prognosis. The specific signs of heart failure include: Elevated jugular venous pressure, hepatojugular reflux, third heart sound and laterally displaced apical impulse (ESC, 2016). The typical symptoms that patients present with include: breathlessness, orthopnoea, paroxysmal nocturnal dyspnoea, reduced exercise tolerance, fatigue, tiredness and peripheral oedema (ESC, 2016). Atypical signs and symptoms may also be present therefore it is imperative that each patient receives a comprehensive clinical history and physical examination.

The treatment of heart failure is based on each patient underlying heart failure aetiology, their Left Ventricular Ejection Fraction (LVEF) and their presentation of symptoms (whether they be acute or chronic). Heart failure aetiology is diverse with patients often presenting with both cardiovascular and non-cardiovascular pathologies. *Table 2.1* summarises the heart failure aetiologies listed in the ESC (2016) Guidelines for the diagnosis and treatment of acute and chronic heart failure. Identification of patient aetiology is the priority, so professionals can offer treatment based on evidence-based recommendations.

Patients are sent for a series of diagnostic tests based on their clinical presentation to establish aetiology. Typically, these include: echocardiography, electrocardiogram, blood tests (natriuretic peptides and genetic testing if indicated). Cardiac imaging may be required such as: chest x-ray, transoesophageal echocardiography, cardiac magnetic resonance, cardiac computed tomography. Exercise testing and more invasive investigations may include coronary angiography and right heart catheterisation (ESC, 2016). Dependent on these findings patients are offered evidence-based treatments based on their underlying pathology. The goal of patient management is to treat potentially reversible causes first and reduce the risk of mortality and hospitalisations. Improving patients health status and their quality of life are the primary outcomes of heart failure management. First line treatment includes pharmacotherapy and device implantation such as implantable cardioverter-defibrillator (ICD) and/or cardiac resynchronisation therapy (CRT) if indicated (Class 1, Level A evidence; ESC, 2016).

Table 2. 1 Heart failure aetiologies

Disease of the Myocardium	Abnormal Loading Conditions	Arrhythmias
• Ischaemic heart disease • Toxic damage e.g. Chemotherapy treatment • Immune-mediated and inflammatory damage • Infiltration • Metabolic derangements • Genetic abnormalities	• Hypertension • Valve and myocardium structural defects • Pericardial and endomyocardial pathologies • High output states • Volume overload	• Tachyarrhythmia • Bradyarrhythmia

Source: Adapted from the ESC (2016) Guidelines for the diagnosis and treatment of acute and chronic heart failure.

Until recently, evidence-based treatment recommendations focussed on patients with heart failure with reduced ejection fraction (HFrEF) which reflected the evidence-base at the time. Pharmaceutical and device trials demonstrated reductions in mortality and hospitalisations in HFrEF, but there were mainly neutral findings for patients with heart failure with preserved ejection fraction (HFpEF) (McMurray et al, 2012). Recent epidemiology studies and registries have reported more than 50% of the heart failure population having HFpEF (Dunlay et al, 2017). Since then large-scale clinical trials have been conducted to identify effective HFpEF treatments, but current guidelines remain limited (ESC, 2016; NICE 2018; Senni et al, 2014).

There is variation in the classification of heart failure in the UK, Europe and the US. Clinical guidelines from the UK and the US classify patients in to two categories based on LVEF for treatment selection: patients with heart failure with reduced ejection fraction (HFrEF) and patients with heart failure with preserved ejection fraction (HFpEF) (NICE, 2018; Yancy et al, 2017). In contrast, the European guidelines classify patients into 3 groups: HFrEF, HFpEF and heart failure with mid-range ejection fraction (HFmrEF) *(Table 2.2)*. The addition of the category, HFmrEF, aimed to encourage further research in to the treatment of this population (ESC, 2016). Despite these differences, guideline recommendations focus on the treatment and management of patients with HFrEF as this is the patient population where the evidence of benefit is the strongest.

Table 2. 2 Classification of heart failure

Type of HF	**HFrEF**	**HFmrEF**	**HFpEF**
Criteria	**Symptoms +/- signs**	**Symptoms +/- signs**	**Symptoms +/- signs**
	LVEF < 40%	LVEF 40-49%	LVEF ≥ 50%
		1 Elevated levels of natriuretic peptides BNP>35 pg/ml and/or NT-proBNP>125 pg/mL 2. A least one additional criterion: a. Relevant structure heart disease (LVH and/or LAE) b. Diastolic dysfunction	1. Elevated levels of natriuretic peptides BNP>35 pg/ml and/or NT-proBNP>125 pg/mL 2. A least one additional criterion: a. Relevant structure heart disease (LVH and/or LAE) b. Diastolic dysfunction

Source: ESC (2016) Guidelines for the diagnosis and treatment of acute and chronic heart failure.

The highest quality of evidence comes from Randomised Controlled Trials (RCTs) with primary outcomes of mortality and hospitalisations. Treatments that have demonstrated significant positive clinical outcomes are awarded Class 1 Level A Evidence. For patients with HFrEF, pharmacotherapy recommendations include Beta Blockers (BB), Angiotensin Converting Enzyme inhibitors (ACEi), Angiotensin II Receptor Blocker (ARBs) and device therapy (CRT-P, CRTD) if indicated (ESC, 2016). Studies of these treatments have demonstrated improved mortality and morbidity with the UK National Institute for Health and Clinical Excellence (NICE) recommending their use as cost-effective (NICE, 2018).

Since then, an increased understanding of the molecular changes in heart failure has shifted the focus of treatments towards genetic applications. A more personalised approach is reflected in the clinical guidelines with the recent additions of molecular diagnostics and genetic counselling (ESC, 2016). Building on conventional treatment, there has also been advances in the development of novel therapies in heart failure. Gene therapy offers potential to target pathways currently untreated by pharmacotherapy. In recent years, several clinical trials have been conducted in patients with advanced heart failure. The CUPID trials (Phase I and II) investigated the effect of increasing SERCA2a expression. These multi-centre, international RCTs involved the percutaneous administration of gene therapy (SERCA2a gene) using a viral vector (AVV1) by intracoronary infusion. The researchers reported promising potential of this gene therapy, but no significant difference was found between the intervention and control group (Greenberg et al, 2016). The choice of vector and the mode of gene therapy delivery requires further testing to improve delivery.

Targeting treatments to different phenotypes is important so patients can benefit from the best predicted therapeutic effect. Advances in DNA sequencing methods have seen an increase in the number of genes associated with different types of heart failure. The Exome Aggregation Consortium (ExAC) conducted large-scale DNA sequencing in large patient cohorts (Lek et al, 2016). Variation in responses to heart failure medications such as BB and ACEi were demonstrated in patients with HFrEF (Liggett et al, 2006; Wang et al, 2016). Yet the findings in the literature are mixed. Further study into the use of pharmacogenetics in heart failure is ongoing.

The emergence of new sub-specialisms (such as cardio-oncology) supports this shift towards a more personalised approach to treatment. Yet the identification of new taxonomies and increased levels of frailty in heart failure, means that decision-making is becoming more complex (Charron et al, 2018). Such a narrow focus may encourage professionals to treat disease silos rather than treating the 'whole patient.'

To encourage holistic care a multidisciplinary team (MDT) approach is recommended as the gold standard in heart failure management (NICE, 2018; ESC, 2016). MDT collaborative decision-making promotes the treatment of patients' psychological health as well as their physiological disease needs. This is important in heart failure as high levels of anxiety and depression have been reported and shown to lead to poorer patient outcomes. Rutledge et al (2006) conducted a meta-analysis of the literature reporting association between heart failure and depression. Over 21% of patients were found to have clinically significant depression. Pooling of the results reported rates of mortality being twice as high in patients with symptoms of depression (RR: 2.1; 95% CI: 1.7 to 2.6). Prevalence of depression varied widely between studies (9-60%) and follow-up ranged from 6 months to 4 years. The use of multiple tools and methods to measure depression (validated scales e.g. HDAS through to clinical review of medical notes) made it difficult to compare the results. Importantly, the findings illustrate the existence of multiple psychological factors that often co-exist in patients with heart failure (anxiety, depression, poor quality of life and social isolation).

Chronic heart failure care is a major driver of health service utilisation (NICE, 2018) and national policy directives advocate chronic disease management programmes (NHS Confederation, 2011). The promotion of healthy lifestyles is a core component of heart failure management. In the US, Del Gobbo et al (2015) assessed lifestyle habits (diet, exercise, alcohol consumption, smoking and obesity) with incidence of heart failure in the Cardiovascular Health Study. The patient mean age was 72 years and maximum patient follow-up was 21.5 years. One thousand three hundred and eighty cases of heart failure were identified in total. The authors reported varying associations between healthy lifestyle choices [activity level, modest alcohol intake (1-3 drinks/week), avoiding obesity and not smoking] with a lower risk of heart failure. Patients who demonstrated ≥4 of these healthy lifestyle habits had 45% lower risk of heart failure (HR 0.55; 95% CI: 0.42 to 0.74) (Del Gobbo et al, 2015). It is important to note that most outcomes were based on measures of self-report. Differences between self-report measures and objective measurements of nutritional intake and smoking have been reported elsewhere (Lennie et al, 2008; Stelmach et al, 2015).

In addition to modifying risk factors, supporting patients to manage their heart failure at home is a key focus of current research and disease management programmes. The value of patient education on self-care behaviour in a chronic heart failure patient population has been demonstrated. Jarsmaa et al (2008) performed a randomised, multi-centre study in the Netherlands (the COACH study) investigating the effects of advising and counselling in heart failure (n=1023). This representative study sample included patients with HFrEF and HFpEF (mean age = 71 years; NYHA II= 50%, NYHA III-IV=50%) with at least 439 (43%) having 1 or more comorbidities. Patients who had recently been discharged following heart failure hospitalisation were allocated to follow-up by the cardiologist; follow-up by the cardiologist and basic support; and follow-up by the cardiologist and intensive support. The intervention groups received a variation of in-person visits with the heart failure nurse specialist (trained in education support) and telephone contact. Patients were followed up over an 18-month period. The researchers reported no statistically significant reduction in the combined endpoints of death and heart failure hospitalisation for patients who received the interventions, basic or intensive support (Jarsmaa et al, 2008). However, on further analyses of this group (n=830), Van der Wal et al (2010) reported that patients who were non-compliant with self-management recommendations (such as daily weights, fluid restriction, low sodium diet, exercise) had an increased risk of mortality and hospitalisation (HR 1.4; 95% CI: 1.08 to 1.82, *p*= 0.01).

These findings highlight the importance of patient uptake of recommended health behaviours and add to the debate as to what is the best method to provide self-management education. Due to the lack of research demonstrating independent effect on rates of mortality, morbidity and on patient quality of life, UK clinical guidelines do not award a level of evidence to non-pharmacological and non-device treatments in heart failure (NICE, 2018; ESC, 2016). The updated clinical guidelines (ESC, 2016) emphasise the importance of psychological and social support to be provided to patients and their relatives. But the focus of guideline recommendations is on increasing patients' understanding of their heart failure and patient involvement in management and monitoring of their heart failure at home.

New disease management programmes have been developed in the US. In an underpowered study, Clark et al (2015) conducted an RCT (n=50) investigating the use of a programme using health promotion education to enhance the self-efficacy of patients with chronic heart failure. The authors added a memory component to the intervention. Health status was measured by quality of life questionnaires validated in the heart failure population (KCCQ); Depression (Geriatric Depression Scale); Metamemory (Metamemory in Adulthood questionnaire); knowledge (HF Knowledge Test); and self-care ability (Revised Self-care of Heart Failure Index). The mean age of patients was young (62.6 years) and most patients had multiple comorbidities. The authors reported a significant improvement in self-efficacy, quality of life and knowledge in the intervention group (*p*=0.028, *p*=0.018 and *p*=0.005 respectively.) There was no significant difference found between groups for levels of depression. This was a small single-centre study and therefore the findings need to be approached with caution. Finding new ways to improve patients' memory is important to facilitate patient education in an aging population. Lainscak et al (2007) reported association between patient adherence to non-pharmacological advice and their memory recall. These findings highlight how the evidence-base is evolving to meet the needs of today's heart failure population, but further research is needed in this area.

Strategies to support patients to self-manage their heart failure offer potential to reduce pressures on services, but better measures of self-management are needed. Jaarsma and colleagues (2003) European Heart Failure Self-care Behaviour Scale (EHFScBS) has been validated in European and UK heart failure patient populations (Gonzalez et al, 2006; Shuldham et al, 2007). The tool has recently been evaluated and concluded to be reliable and valid (Sedlar et al, 2017). This tool supports quality assessment of self-care however, further research is required to evaluate its effect on clinical outcomes. This research reflects the changing face of heart failure management where emphasis is on preventative cardiology and patients taking responsibility for their own health.

However, not all patients chose to follow the recommendations of their health professionals. Medication compliance is a longstanding problem in heart failure and has shown to lead to poorer patient outcomes. Van der Wal et al (2006) reported heart failure patients rate of compliance with their heart failure medications ranged from 10% to 70% and uptake of recommendations for exercise and daily weights (41% to 58% and 12% to 75% respectively). Fitzgerald et al (2011) conducted a retrospective longitudinal cohort study of patients with HFrEF (n=557) to assess the effect of medication adherence on all-cause mortality and hospitalisations (mean 1 year follow-up). The authors reported a statistically significantly association between medication adherence (less than 80% adherence) with all-cause mortality and hospitalisations (HR 2.19; 95% CI: 1.72 to 2.79; $p < .0001$) (Fitzgerald et al, 2011). It is important to note that studies of adherence to medication and non-pharmacological advice frequently use measures of self-report. The accuracy of these data is important to consider when assessing the quality of the research. Nevertheless, patient education has shown to be important in supporting patients with chronic diseases to improve adherence to treatment (Vanhaecke et al, 2017; Zhao et al, 2015). The factors that influence patient decisions to follow the advice of health professionals needs further exploration.

Changes in decision-making practice have attempted to tackle some of the challenges faced by professionals in treating and managing patients with heart failure. For example, MDT meetings provide an established framework for decision-making in current practice. They were introduced to facilitate high quality decisions by increasing interdisciplinary collaboration by joining the knowledge and expertise of multiple professionals (DoH, 2010). MDT meetings are endorsed by the Department of Health as the core model for managing chronic disease and regular discussion is advocated by best practice service models (Coulter et al, 2013). As a core process of the treatment decision-making pathway, little evidence exists examining their effects on the quality of decisions made and patient outcomes. Further analysis of MDT meetings is needed to better understand decision-making in practice.

2.3 Health policy on decision-making

2.3.1 Patient-centred care

Health policy on decision-making emerged from demands for increased patient choice and involvement in health care. In the UK, the principles of Patient-centred Care (PCC) and transparency were championed by the Labour government through the Department of Health's NHS Plan (DoH, 2000). PCC was a model introduced to help refocus the delivery of healthcare back to the patient and their family. The principles of PCC are that the patient is at the centre of planning, implementation and evaluation of care. Its emphasis is on the importance of understanding how patients experience their disease and promoting patient involvement and engagement in their care (NHS England, 2018). It is important to clarify the difference between patient-centred care and person-centred care. Often there is confusion as the terms are frequently used synonymously in the literature. The concept of person-centred care originates mainly from Europe and builds upon the principals of patient-centred care. It is defined as a holistic approach placing emphasis on the individual *'person.'* Individuals psychological well-being and social needs are the focus of the model. In contrast, UK health policy refers to patient-centred care. Patient-centred care focuses on the practical involvement of patients in the planning of care, its delivery and evaluation.

A key driver for the adoption of PCC in to UK health policy was the need to increase health service sustainability and reduce unwarranted variation in practice (NICE, 2018). The potential financial savings were reported in the Wanless Report (2002). The report outlined plans for the improved management of long-term conditions and policymakers considered PCC a desirable model. Today PCC is well established in UK health policy and practice (NHS England, 2018; The King's Fund, 2017). It is supported by the promotion and integration of patient-focussed models of care which form a core part of health policy (Mold, 2010; DoH, 2010; NHS England, 2014 NHS England, 2013).

The evidence of effectiveness of PCC referenced in UK health policy, largely originates from international literature. The focus is on the effects of PCC on depression, symptom burden and patient activation, predominantly around end-of-life care and advanced care planning. One of the largest studies was conducted in the US by researchers Schellinger et al (2011). In their prospective cohort study (n=1894) their intervention involved focussed education and training for health professionals who were part of advanced care planning. The authors reported an association between health professional referral and increased participation in advanced care planning ($p<0.001$). These findings demonstrate the potential benefit of PCC to increase levels of patient participation in decisions about their care.

Similarly, Evanelista and colleagues (2012) reported potential benefits of PCC. The researchers found significant improvement in patients' depression scores (measured by the MLHFQ), increased patient activation (measured by the Patient Activation Measure, PAM) and a reduction in mean symptom burden ($p=0.03$). The focus of their

PCC intervention was on palliative care consultations lead by specialist or advanced practice palliative care nurses. The sample size was small (n=36) so the findings cannot be generalised. Most outcome measures included HRQoL, Depression scores (HADS), symptom burden (NYHA), measures of participation (PAM) and end-of-life care (advanced care plans). The use of validated tools supported methodological quality yet a significant reduction in hospitalisations or mortality was not reported. The effect of PCC on patient clinical outcomes was not demonstrated.

A Swedish RCT (n=74) performed by Brannstrom et al (2014) investigated the effect of an integrated PCC intervention in patients with chronic heart failure. The authors did report a statistically significant increase in patient quality of life in the PCC intervention group (HRQoL measured by the EQ-5D, increased by 28%, *p*=0.013). Yet no significant difference in mean symptom burden or mortality between groups was identified. It is important to note that this PCC intervention required an increase in nurse visits (1075 in the intervention group compared to 230 in the control, *p*=0.0001). The cost-effectiveness of the intervention and effect on clinical outcomes were not demonstrated.

The effects of PCC interventions in the chronic heart failure population was reviewed by Kane et al (2015). The researchers conducted a systematic review examining the evidence for PCC interventions and identified 10 studies (n=2540 patients). The sample included 3 RCTs, 1 feasibility (no significant levels) and two controlled before and after studies, 1 mixed-methods study, 1 case-control study and 2 cohort studies. Following appraisal of the individual studies, the sample sizes were predominantly small (most <80) ranging from 20 to 1894. Most reported short-term follow-up periods (6 months) and all but one was single centre studies. The interventions reported involved nurse-led interventions either in-person education models or remote contact (telephone coaching). The interventions lasted between 3 weeks and 6 months (with one study reporting a single 3-hour education programme) (Ekman et al, 2012).

These studies are referenced in support of a PCC approach in UK health policy. This review highlights the mixed quality of the research and importantly, the need to challenge policy and its applicability to different patient populations and services.

2.3.2 Shared Decision-making

The Shared Decision-making (SDM) model of care builds upon the principals of patient-centeredness. It encourages partnership between patients and professionals whereby a mutually agreed treatment decision is made (NICE, 2010). SDM is described in policy as a partnership between health provider and patient, encouraging the sharing of information to support informed treatment decisions based on therapeutic effect, patient preferences, goals and personal circumstance (Coulter and Collins, 2011; NHS, 2013).

Shared decision-making is aimed at patients facing preference-sensitive treatment decisions. The focus is when multiple, realistic treatment options are available such as: diagnostic screening tests, medications, a medical/surgical procedure, participation in self-management programmes and uptake of lifestyle advice (Coulter and Collins, 2011). The model can be applied to decisions where there is uncertainty in clinical guidance or where the outcome of treatments is different (quality of life versus longevity). This sharing of expertise between the patient and professional is illustrated in *Table 2.3.*

Table 2. 3 Sharing of information

Clinician's expertise	**Patient's expertise**
Diagnosis	Experience of illness
Disease aetiology	Social circumstances
Prognosis	Attitude to risk
Treatment options	Values
Outcome probabilities	Preferences

Source: Coulter and Collins (2011) Making Shared Decision Making a Reality. No decision about me, without me. London: The Kings Fund.

One of the key drivers of SDM in health policy was the need to reduce inappropriate interventions and variation in practice. In the US, the Dartmouth Atlas Project was set up to allow better review of variation in healthcare practice (Wennberg et al 2008). The group reviewed specific categories of decisions which included preference-sensitive treatments. The group collected data on rates of surgery such as CABG and PCI for the treatment of coronary heart disease. The researchers reported a five-fold difference in the rates of CABGs and ten-fold difference in the rates of PCIs across different regions. Driven by these findings, Public Health England (2013) published a report on unwanted variation in practice in the NHS, 'The NHS Atlas of variation in diagnostic services.' Data was collected on heart failure diagnostics and included rates of echocardiography activity per one thousand population by Primary Care Trust (PCT). A decrease in variation was found between 2011 to 2012 and 2012 to 2013 but variation rates of 3.7-fold were reported across PCTs in England (Public Health England, 2013).

The shift in policy focus towards increasing patient involvement in decision-making led to widespread support of a SDM approach. Building upon the outcomes of Lord Darzi's report (2008) and the development of the NHS Constitution (2010), the Department of Health's White Paper, 'Equity and Excellence: Liberating the NHS' (2010) was the cornerstone document that led to a shared approach to decision-making becoming embedded in national health policy. The purpose of the policy was to present the government's vision for transforming the NHS and putting patients at the heart of healthcare services. It set out the government's mandate for the NHS which included: the need for greater patient choice of provider; joint agreement between patient and professionals on care planning; patients being supported to self-care; and involving patients and carers in decisions about their treatment. The vision was an NHS where SDM would become the norm, *'nothing about me without me.'*

Stakeholder consultation of the White paper highlighted the need to better define the concept of SDM. This resulted in the publication of guidance, 'Making shared decision-making a reality. No Decision about me, without me (Coulter and Collins, 2011). Shortly afterwards, the Health Foundation hosted a summit (December 2011) to consider how to make the proposal a reality. This led to a report by the Health Foundation (2012) outlining the benefits of SDM and proposed methods for its adoption in to practice, 'Helping People share decision making. A review of evidence considering whether shared decision making is worthwhile.' On this background, the NICE Quality Standard on Shared decision-making (Quality Statement 6) was developed as part of the NICE clinical guidance 138 'Patient experience in adult NHS services' (NICE, 2012). The statement outlined the need to actively involve patients through shared decision-making and the need to measure its implementation.

Around the same time there was a move to hold healthcare governing bodies accountable for the integration of SDM in to practice. This saw the initiation of the Department of Health's Right Care programme building on the Quality, Innovation, Productivity and Prevention (QIPP) programme (DoH, 2015). Similarly, the updated Health and Social Care Act (DoH, 2012) stated that NHS England and Clinical Commissioning Groups need to encourage patient and carer involvement in decisions about treatment and their care. One of the key initiatives endorsed by the NHS was the Five Year Forward View (FYFV) plan (NHS England, 2014). This policy provided a framework to support the delivery of key policy directives, including the adoption of SDM in to routine practice.

These UK policies led to increased funding of practical initiatives to facilitate the implementation of a shared approach to decision-making. One of the key programmes was led by The Health Foundation, whose primary aim was to achieve wider implementation of SDM (The Health Foundation, 2010). The initiative supported efforts by the East of England Strategic Health Authority including: the development of the Right Care Shared Decision Making Programme, as part of the QIPP programme; the MAGIC (Making Good Decisions in Collaboration) programme in partnership with The King's Fund; and the development of SDM implementation kits to support clinicians to adopt SDM in practice. In November, the Health Foundation and National Voices published their review of current practice, 'People in control of their own health and care. The state of involvement' (Foot et al, 2014).

Shared decision-making had policymaker support and became a UK priority indicator for the 2017 to 2019 health service performance review. Today health services are assessed on their ability to implement SDM in practice. The Commissioning for Quality and Innovation (CQUIN) national goals framework was introduced as a pay for performance scheme to improve sustainability and facilitate transformation plans. It outlined the need to engage patients in the decision-making process by informing them of the full range of treatment options, including those outside of the professionals' area of expertise (The Health Foundation, 2012). The need to measure SDM was a key focus in the cardiac treatments CQUIN (NHS England, 2017).

The main body of research demonstrating benefits of SDM originates from RCTs evaluating the use of Decision Aids (DAs). The aim of DAs is to support the communication of treatment risk and optimise the personalisation of difficult health decisions. Today decision aids are advocated in the UK, Europe, North America and Australia and their goal is to support patients and professionals to reach high quality decisions. Following their development, early studies investigated how DAs could be used in a SDM approach.

Loh et al (2007) conducted a cluster-randomised controlled study measuring the effects of physician training in SDM and use of DA support compared to standard of care, on patient satisfaction and perceived involvement. The study involved patients with depression (n=405) being treated by primary care physicians (n=23). Patients in the intervention group reported increased levels of satisfaction and patient involvement (*p*=0.014 and *p*=0.01 respectively). O'Connor et al (2007) found that use of these DA tools effectively facilitated SDM, without substantially increasing consultation time.

Since then, large-scale systematic reviews have evaluated the use of DAs in treatment discussions and their effective on patient outcomes (Stacey et al, 2011; O'Connor et al, 2009). In an update to their Cochrane review, Stacey and colleagues (2017) included 105 RCTs and reported positive outcomes for the use of DAs including: increased patient knowledge; improved perception of risk (RR 2.10, 95% CI 1.66 to 2.66); a reduction in major elective surgery (RR 0.84; 95% CI 0.73 to 0.97). Of the 105 studies only 24 (22.9%) measured patients perceived participation in decision making. The researchers did report a reduction in clinician-led decision-making in 16 of the studies (RR 0.68, 95% CI 0.55 to 0.83). Yet of the 15 studies that reported SDM, no difference was found between the level of patient participation in the DA group compared to standard of care (RR 0.95; 95% CI 0.83 to 1.10) (Stacey et al, 2017). Evidence of cost benefit was reported with fewer patients choosing invasive surgery compared to conservative treatment (RR 0.84; 95% CI 0.73 to 0.97). However, few studies evaluated the relationship between SDM and the direct cost of care or resources used. It is important to note that no study included in the review investigated the use of DAs in a heart failure patient population. Cost-effectiveness was associated with patient choice of conservative treatment rather than economic evaluations of the intervention and long-term clinical outcomes.

The evidence-base offers no RCTs investigating the effectiveness of SDM interventions in heart failure. The quality of studies assessing SDM interventions is mixed and challenging to compare. Few RCTs demonstrate positive patient outcomes and those that do, focus on the effects of SDM on patient activation levels. For example, Hibbard et al (2007) conducted a RCT of chronic disease patients (n=479) randomised to either a self-management programme or standard care. The aim was to assess the effects of patient activation levels on self-management behaviour [measured by the Patient Activation Measure (PAM) Score] at 6 weeks and 6 months. The intervention group had significantly increased activation scores compared to the control group at week 6 (*p*<0.001). This increased activation level was associated with a positive change in patients self-management behaviour.

However, there is limited evidence demonstrating a positive effect of SDM on clinical outcomes. For example, Deinzer et al (2009) conducted an RCT of hypertensive patients (n=86) comparing the effect of an SDM education programme on blood pressure control. The results concluded that patients whose physicians were trained in SDM did not have significantly better clinical outcomes compared to those receiving standard care. It is important to note that the sample was small, underpowered, with short follow-up. There was also only a single outcome measurement following one intervention, therefore it was difficult to assess any long-term benefits.

Comparison of physician and patient level of satisfaction and self-reported level of involvement, are frequently used in the literature as measures of the effect of SDM. Hirsch et al (2010) conducted a cluster-randomised controlled trial comparing the satisfaction ratings of physicians and patients undertaking a SDM supported cardiovascular prevention programme. A group of primary care physicians (n=44) and patients (n=550) were matched to a control group. No significant differences were found in the satisfaction ratings of both groups in either the intervention group or the control group. Satisfaction ratings may not be clinically meaningful and alternative measures such as the impact on patient behaviour, clinical outcomes and decisional conflict, may better assess the effects of SDM in practice.

One study referenced in support of SDM by Coulter and Collins (2011), was a US multi-centre, two-group quasi-experimental study by Frosch et al (2010). The study sample consisted of 116 older patients. The mean age of study patients was 70.6 years and 73.6 years in each centre. The intervention involved group screenings of five video programs that encouraged self-motivation over a 12-week period. The videos were of chronic diseases affecting older adults, one being congestive heart failure. Measures of patient activation (Patient Activation Measure, PAM), physical activity and health-related quality of life, were collected at 6 and 12 months following the intervention. The researchers reported the benefit of the intervention in increasing patients ability to self-manage. At 6 months, patients who attended ≥3 screenings were more actively involved in self-management ($p<0.001$), more physically active ($p<0.001$) and reported better health-related quality of life ($p<0.001$) (Frosh et al, 2010). Use of the Patient Activation Measure (PAM) and the SF-12 questionnaire had demonstrated validity. However, physician activity was measured using the WHI brief physical activity questionnaire, which has not been validated in each disease group. The sample size was small and not representative of each patient population and there was also evidence of selection bias with non-randomised intervention allocation.

Similar outcome measures (patient preferences for involvement and satisfaction) are reported in observational studies which comprise most of the evidence-base for SDM interventions. In a US cross-sectional, observational study by Golin et al (2002), patients with Type II Diabetes Mellitus (n=198) were interviewed before and after their consultation with their physician (n=57). Participation in medical decisions was measured pre-consultation through a previously validated questionnaire (Desire to Participate in Medical Decision-making Scale). Post-consultation patient's level of satisfaction with their involvement was rated using the Patient Satisfaction Questionnaire (PSQ 18). The researchers reported male patients desire for involvement in decision-making strongly correlated with their level of satisfaction with the consultation (*p*< 0.0001). Physicians who supported patients to participate in decision-making correlated with increased satisfaction in female patients (*p*<0.0001). It is important to note that this was a single-centre, small observational study and therefore the study findings cannot be generalised. These findings reiterate the differences in preferences and satisfaction rates based on patient socio-demographics.

This observational study is an early example of the growing interest in the patient-physician relationship. Today, measures of behaviour are commonly used to demonstrate the effect of SDM interventions in the literature. For example, Menear et al (2018) conducted a multi-centre cross-sectional survey in Canada of patient-physician interactions (n=117) at 17 primary care services. SDM was measured by how physicians involved patients in decision-making through observational recordings and the Observing Patient Involvement in Decision Making instrument (OPTION scale). The content validity and reliability of this scale has been tested and shown to assess the core components of SDM. Four trained coders rated the observed physician behaviour using the scale with 'adequate' inter-rater agreement (variability in intra-class correlations: 0.64 to 0.88). Interestingly, physicians who participated in multiple academic committees demonstrated higher scores of SDM (*p*=0.01). The authors attribute these findings to physicians who are active academically, are more likely to be exposed to new ideas and ways of working. Further research is needed to test these findings. This study highlights the multi-factorial nature of SDM from both the perspective of the patient and the professional. These are key factors that current measures of behaviour cannot adequately explore.

Shay and Lafta (2015) conducted a systematic review of observational studies reporting association between SDM and patient outcomes (n=39 studies). Studies were assessed using the Systematic Appraisal of Quality in Observational Research (SAQOR) tool. Only 3 (8%) of studies received a high-quality rating, with most 30 (77%) receiving a 'moderate' appraisal of quality. Only 42 (43%) of assessments made across the studies reported a statistically significant association between SDM and positive patient outcome (symptom reduction, increased quality of life, improved physiological measures). The authors reported the Control Preference Scale and the Patient Involvement in Care Scale as the most commonly used measures of SDM in 39 studies. Both scales have been validated across different patient populations and shown to have good reliability. Yet their validation processes and use varied widely between studies. The quality of the evidence reporting patient preferences for involvement in decision-making is confounded by the variety of tools used to measure preference. Of the 39 studies reviewed, 95 patient outcome measures for SDM were identified. A large proportion, 75% (n=479) of articles, were excluded from the review because there was no detail of SDM measurement (Shay and Lafta, 2015).

These findings are supported by Moumjid et al (2007) review of the literature on the variation of SDM definitions used in studies. The authors found that only a third of articles reviewed (n=25) used the term SDM consistently with the definition they stated. There was also evidence of selective reporting, small sample sizes unable to determine estimates of effect and most studies measured patient-reported health status with limited evidence of effect on clinical outcomes or cost effectiveness.

This is likely the reason why research referenced in health policy tends to report effects of SDM on quality of life and psychological well-being. For example, Coulter and Collins (2011) referenced a study by Hack et al (2006). The researchers found that patients with breast cancer who reported being involved in their treatment decisions (measured by the Decisional Role Preference Scale) had significantly higher quality of life compared to patients who reported passive involvement (*p*<0.01). Loh et al (2007) conducted a survey study in Germany of patients treated with depression in primary care (n=207). The researchers assessed the effect of patient participation on depression severity and adherence to treatment. The study findings suggested that increased levels of participation in decision-making reduced patient's depression severity score [modest improvement (24.2%) and no symptoms (11.4%)]. Patients depressive symptoms (measured by the Patient Health Questionnaire Data) were collected 6-8 weeks' post consultation therefore, long-term effects of participation were not explored. The study sample was also young with 42.5% aged 31-50 years and only 12.6% >70 years. Therefore, the findings cannot be generalised.

The studies referenced in UK health policy lack evidence of the cost-effectiveness of SDM. Those that report a cost benefit largely originate from the US and Europe. Hibbard et al (2013) referenced by Coulter and Collins (2011) conducted a cross-sectional analysis of patients enrolled in health services (n=33163) which included 41 hospitals, primary care and speciality clinics. The authors reported that patient activation level (measured by the Patient Activation Measure) was negatively associated with healthcare costs. Patients with the lowest activation score had predicted costs 8% higher than patients with the highest activation score (*p*<0.01). A further study referenced in support of SDM was by Veroff et al (2013). The researchers performed a subset analysis of a larger RCT by Wennberg et al (2010). The intervention was a large population health management program which provided health education to patients (self-care, lifestyle changes, informed decision-making). The sub-analysis (60,185 patients) reported those with a 'heart condition' who received enhanced support for SDM had 8.7% lower medical costs compared to those receiving usual care (*p*=0.01). These findings highlight the potential cost-saving of SDM, but evidence of cost-effectiveness is unclear. These findings cannot be generalised to a heart failure population managed in UK healthcare systems. Further research is required to test these interventions and their financial impact on service delivery.

There is no standardised definition of shared decision-making used across studies. This creates confusion over what constitutes a 'shared approach.' Some studies refer to SDM as increased involvement or active participation using terms such as 'shared or partnership' synonymously. In one systematic review (n=418), the researchers identified 161 different definitions of SDM (Makoul and Clayman, 2006). There is also considerable variation in the measures used to assess SDM outcomes. Many studies assess patient satisfaction as a primary measure as well as, decisional conflict, decision quality or patient-professional communication. This heterogeneity makes it difficult to compare results, particularly as how SDM is measured influences its association with patient outcomes. Studies of SDM interventions also report considerable variation in their aims, methods, duration of follow-up and patient populations. However, despite these findings, SDM is firmly established in UK health policy and is widely supported by professional regulatory bodies who advocate it as an ethical requirement (GMC, 2008; NMC, 2015).

2.4 Delivering a SDM approach

2.4.1 Patient preferences for involvement

In the past, decision-making in healthcare predominantly followed a professional-led approach. Physicians were the experts and their professional judgement was rarely challenged. Health professionals were expected to act in the patients best interest and a 'good patient' was viewed as an individual who accepted their passive role (Kaba and Sooriakuman, 2007). Since then beliefs have changed. The view that 'doctor knows best' and that patients are simply passive recipients of their care, is no longer the norm.

The introduction of the internet gave patients increased access to information and the ability to search independently for complex health information. This may in part explain the shift in power dynamic between patients and physicians whereby patients began to challenge the advice of professionals, ask more questions and search for additional information to validate the advice of professionals (Latimer et al, 2017). The influence of the media on public beliefs and social change has also been widely reported (Happer and Philo, 2013). The recent public concerns of underfunding and negative media publicity have led to increased support for greater patient involvement in decisions about their healthcare.

Survey data is the main source of evidence reflecting this change. Early surveys report patient preference to delegate treatment decisions to their physicians. Arora and McHorney (2000) conducted an analysis of 2197 patients with chronic disease (congestive heart failure, hypertension, diabetes, myocardial infarction and depression). Sixty-nine percent (n=1515) preferred physicians to make the final decision about their treatment. However, more recent survey data has reported a change in patient and public preferences.

In the UK, national surveys conducted by the Care Quality Commission (CQC) are referenced in support of SDM in health policy guidance (DoH, 2010). These surveys include data from over 50,000 adult inpatients (CQC, 2016) and approximately 72,000 adult outpatients (CQC, 2011) in acute and specialist NHS Trusts (n=154 and 163 respectively). The surveys reported that forty-eight percent of inpatients and 30% of outpatients wanted more involvement in decisions about their care (CQC, 2011). It is important to note that the quality of these surveys is limited by low respondent rates (47% and 53% respectively) and short periods of data collection (<3 months). Despite this, these are the largest national surveys reporting patients experiences and preferences for involvement in decisions about their care. An important limitation to these surveys is that they do not address the factors that may influence patients' preferences.

Large-scale survey data reporting patient and public preferred roles in decision-making including a 'shared approach,' largely originate from the US. This is likely due to SDM being widely established in US healthcare systems where it was introduced through the Patient Protection and Affordable Care Act in 2010. SDM has also been integrated in to research institutions in the US with a SDM Centre for Medicare and Medicaid Innovation and private organisations funding large-scale studies (Frosch et al, 2010).

In 2005, the US National Opinion Research Center (NORC) conducted a population-based survey of a representative sample of adults (n=2750) to assess public preferences for participation in decision-making (Levinson et al, 2005). The survey's response rate was 70.1% and of the respondents 96% (n=2640) wanted to discuss the different treatments options with health professionals and wanted to be asked their opinions. Preference for an active role in making the final decision (patients and professionals working collaboratively to reach a decision) was associated with being female and from higher education backgrounds (adjusted OR 1.53 and 1.4 respectively $p<0.001$). The mean age of participants was 46.3 years (*SD* 17.4), nearly a third (31.7%) had a higher education background (> high school) and over half (54.3%) reported 'very good to excellent' health status (Levinson et al, 2005). These findings cannot be generalised to a UK heart failure population but importantly they illustrate that preference for participation in decision-making is based on multiple factors. The authors also reported variance in preferences for physicians to offer choices; ask patients their opinions; provide additional information; and to make the final treatment decision.

Similar findings were reflected in more recent surveys of patients in the US. In 2007, Murray et al. reported 62% (n=1989) of participants wanted involvement through a shared approach to making decisions about their healthcare. The survey response rate was 72%. Preference for involvement was categorised in to three styles: paternalism, shared decision-making, consumerism. Paternalism was defined as physicians making decisions independently. SDM was defined according to health policy, reaching a mutually agreed decision. Consumerism was defined as patients making the final decision. Only 9% (n=197) of participants preferred a paternalistic approach. Participants with low incomes (defined as <$25,000/annum) and those whom had not completed high school education were more likely to experience a paternalistic approach compared to a shared approach ($p<0.002$ and $p=0.001$ respectively). The survey results illustrated three core components of the decision-making model: the transfer of information between patient and the physician; deliberation of the options; and deciding whether to implement the treatment. These results reflect the views of a US patient population and cannot be generalised to a UK heart failure population. Yet this survey highlights significant associations between patient socio-demographics and preferences for involvement as well as how patients experience decision-making.

Evidence from RCTs confirm these survey findings with reports that patients do want to be involved in decisions about their care. Chewning et al (2011) identified 115 RCTs in their systematic review of patient's decision preferences for treatment and screening decisions. The review focussed on physician-patient relationships and preferences for participation in decision-making. The researchers identified 63% (n=75 RCTs) that reported patient preference for participation in decisions. It is important to note that patient preferences (defined by patient group: chronic condition, cancer, general population, invasive procedure) varied dependent on the type of measure used [Autonomy Preference Index (API), the Control Preferences Scale (CPS)].

There is evidence that not everyone wants to be involved decision-making. One study referenced by Coulter and Collins (2011) was Flynn et al (2006). Flynn and colleagues categorised the preferences for participation of older adults using data from the Wisconsin Longitudinal Study. The study sample included over 10 thousand male and female graduates from Wisconsin High schools in 1957. Data was collected over 47 years. Participants completed telephone and mail surveys. The researchers reported 23% of participants preferred their physician to take control and make decisions. Specific data was collected about participant views (n=5199) towards the decision-making process. This included preferences for information about treatments, the different options available, and the final decision about which treatment to have. Having a higher education background was a significant predictor of patient preference for active participation in the discussion of treatment and involvement in the final decision. This was a large study but with a non-representative sample of adult graduates. Ethnic minority populations were underrepresented.

More recently, researchers have reported associations between preferences for involvement in decision-making and key demographics, patient characteristics and the type of decision being made. Yet there are limited research reporting heart failure patient preferences for involvement in decisions. A small survey study in the US (n=90), used the Control Preferences Scale (CPS) to assess heart failure patients preferred role in treatment decisions. The researchers also assessed patients level of perceived involvement (using the Perceived Involvement in Care Scale). Interestingly, 43 (48%) of patients preferred a passive role with only 21% preferring an active or shared role (Rodriguez et al, 2008). With a small sample size this study was insufficiently powered to demonstrate significant associations and cannot be generalised. However, the findings do offer insight in to how patients with different chronic diseases may prefer different levels of involvement.

In a mixed-methods study, Zizzo et al (2017) explored the preferences of patients with Parkinson's disease. The researchers used the Autonomy Preference Index (n=65) and qualitative interviews (n=20) to assess patient preferences for involvement and communication. When patients were asked about their preference for control of making decisions when their disease progressed, 20 (30.8%) preferred physicians to take control. The study sample was small, and participants had a mean age of 68 years (39-85). These findings cannot be generalised to a heart failure population. In a further study, Mansell et al (2000) conducted a cross-sectional survey (n=255) of patients at an outpatient veteran clinic in the US. Of particularly interest was the finding that patients who experience recent acute changes in their health (myocardial infarction, bypass surgery, angioplasty) wanted more involvement in decisions compared to patients with stable chronic conditions (angina). Changes to patients views towards decision-making along the disease trajectory requires further exploration.

Other patient populations have demonstrated preference for a SDM approach. A German cross-sectional study by Marahrens et al (2017) assessed preferences for involvement in decision-making in patients with diabetic retinopathy (n=810). The authors used a validated questionnaire to assess patient preference for physician-dominant decision-making, SDM or patient-dominant decision-making. Seventy-four percent (n=599) preferred a SDM approach with only 8.3% preferring a patient-dominant approach. Preference for a physician-dominant approach was associated with older age (OR=1.2 per decade, *p*=0.013).

Age and education are the two variables found most consistently to predict patient preference for involvement in decision-making. Younger patients and those from higher education backgrounds are more likely to prefer an active or shared role (Marahrens et al, 2017; Hack et al, 2006; Wallberg et al, 2000). For example, Hamann et al (2007) investigated patient preferences for participation according to whether the disease was acute or chronic. The authors reported a statistically significant association between younger age ($p<0.001$) and higher education ($p<0.001$) and preference for increased participation. However, these findings only account for 14% of the variance reported.

Significant associations between age and decision-making role preference have been reported elsewhere. Chung et al (2015) reported patient preferences for physician-led decision-making was associated with older age (OR per year: 1.02, 95% CI: 1.003 to 1.036) and higher education compared to low education (University versus high school) (OR: 0.6, 95% CI: 0.4 to 0.9). Similar findings were presented by Mah et al (2016) who found that younger patients with hypertension (<60 years, n=210) and those with higher education backgrounds preferred a SDM approach over passive decision-making ($p<0.01$). In a questionnaire study of in-patients with cancer (n=533) Ernst et al (2011) reported education background as a key predictor of preference for involvement ($p<0.05$).

An association between gender and preference for involvement in decision-making was also identified in the literature. Goggins et al (2014) assessed the preferences of patients hospitalised with cardiovascular disease (n=1249) using the Problem-solving Decision-Making Scale. Being female was found to be a statistically significant predictor of wanting greater involvement in the decision-making process. Conversely, a longitudinal study by Hack et al (2006), reported that widowed women with breast cancer preferred a more passive role in decision-making compared to patients who were single, married, divorced or separated. These findings highlight the possibility of additional variables independent of gender.

Large observational studies have also reported associations between patient preferences for involvement in decision-making and ethnicity and culture. In the UK, results of the national cancer patient experience survey (n=41411) reported that patients from ethnic minorities had fewer positive experiences of involvement compared to white patients ($p<0.001$) (El Turabi et al, 2013). Mead et al (2013) identified 23 studies in cancer care (19 from the US) where differences in preferences were reported between ethnic minority groups: African Americans, Latinas and Asian patient groups. In contrast, Peek et al (2011) conducted a cross-sectional survey in US patients (n=974) and used regression analysis to assess any association between ethnicity and preferences for SDM. The authors reported no significant differences in preferences between groups. Further research is needed in to the role of culture and ethnicity and patient preferences.

These findings emphasise the multi-factorial nature of patient preferences for involvement in the decision-making process. Their findings illustrate the association between key socio-demographics and the variation in preferences between different chronic disease populations. There is limited research referenced in policies that explore the variables associated with differences in preference styles. This is likely due to the nature of these data, many originating from small observational studies with a great deal of heterogeneity in outcome measures, definitions of involvement and patient populations. Policymakers need to acknowledge the multi-factorial nature of decision-making and the differences between information needs and preferences for involvement of individual patients.

2.4.2 Health information provision

One of the key drivers of patients wanting greater involvement in decisions is that patients want more information (Coulter and Collins, 2011). Policymakers and governing bodies have recognised the need to adapt service provision and improve communication between health professionals and patients. Health information provision has shown to be important factor in supporting patients with chronic diseases to adhere to clinical follow-up (Kamat et al, 2018) and to improve adherence to treatment (Vanhaecke Collard et al, 2017; Zhao et al, 2015). Yet despite efforts to train professionals to engage patients in health decisions, little has changed in the provision of health information.

This may in part be explained by limited clinical guidance available to professionals to support the delivery of SDM in practice. The NICE (2018) guidelines recommend a multidisciplinary approach to heart failure management through tailored programmes that include patient education, pharmacotherapy optimisation and psychosocial support to patients, their families and carers. The guidelines describe a ‘patient-centred’ approach where professionals focus patient education on self-care techniques and provide information to patients about their condition, treatment and prognosis. Patient involvement is advocated through its recommendations to educate and support patients to ‘monitor their condition.’ Yet evidence of the benefit of increased information provision on health-related outcomes is lacking. Similarly, the evidence referenced in the guidelines for cost benefit of increased information provision are outdated (Serxner et al, 1998). These specific studies measure cost effectiveness in terms of treatment adherence and include small sample sizes, so the findings cannot be generalised.

The sharing of information between patients and professionals is a key component of a SDM approach. Traditionally professionals have been the main providers of health information both verbal information and the use of professionally verified written information leaflets. But with increased access to health information online, more patients are turning to the internet. This information may be evidence-based and useful but can also be inaccurate and misleading. Today patients can undertake virtual consultations with doctors online, order DNA sequencing and use ‘symptom checker’ websites to establish provisional diagnoses. In a recent report published by the Academy of Medical Science in 2017 surveying public views towards medication information, 65% (n=1326) of

British adults reported greater trust in the experiences of their friends and family compared to 35% (n=714) who trusted evidence from clinical trials (Hawkes, 2017). Communicating complex information about treatments in a way that is meaningful to patients is important and is needed to translate clinical evidence in to better patient outcomes. In practice, it can take a lot of time for professionals to demystify information and explain its relevance to an individual patient. The major challenge is knowing the best way to tailor this communication, particularly when studies report disparity between patients and professionals' perceptions of information need (Ekman et al, 2007).

Few studies exist investigating the information preferences of patients with heart failure. One example is a German study by Lesch et al (2014). The researchers conducted a cross-sectional survey of patients with congenital heart disease (n=596). The participants were asked to complete a survey assessing their knowledge about their disease, their information preferences and the sources of information they used. Patients wanted more information to be provided by professionals on eight of seventeen topics including anxiety, pregnancy, sex and insurance. Thirty-seven percent of patients reported valuing the internet as a source of health information. These patients were more likely to be female ($p<0.001$). It is important to note that the sample population included children (aged 10-13 years), adolescents (aged 14-17 years) and young adults (18-30 years), with most (n=371) having mild congenital heart disease. Due to a lack of validated questionnaires in the congenital heart disease population, the researchers designed their own disease-specific, semi-structured questionnaire. However, measures of validity and test-retest reliability was not reported. These findings are an example of the unmet information needs of specific patient subpopulations.

The literature on health information provision tends to focus on patient preferences for end-of-life (EOL) care and information about prognosis. The evidence largely originates from observational studies and qualitative research. For example, Caldwell et al (2007) explored the preferences of heart failure patients towards receiving information about their prognosis using qualitative interviews (n=20). The researchers reported patients wanting more information about their prognosis in a timely manner, to be kept up-to-date on their disease trajectory and for the sharing of information between patient and the professional. This was a small qualitative study and therefore the results cannot be generalised. It is important to consider that some patients may want more information about their health status but may not necessarily want to be involved in treatment decisions. Further research is needed to examine the effects of information provision in SDM models and to assess the information needs and preferences of patients with heart failure.

Concerns have been raised about the feasibility of providing information to patients about the possible risks and benefits of all the treatment options, as this may cause confusion and act as a barrier to SDM (Shay and Lafta, 2015). An acceptable risk to one patient may not be to another. Treatment decisions are often influenced by patient experience of their illness, their stage of disease trajectory and social circumstance. Clinical trials also tend to have primary endpoints that focus on mortality, hospitalisation and cost, with mainly secondary outcomes measuring quality of life (Akacha et al, 2018). This lack of information makes it a challenge for health professionals to share all the information about treatment outcomes with patients. With a patient population growing in complexity, there is often no overall best treatment (Chizinga and Fares, 2018). Some argue that patients are in the best position to weigh up the risks and benefits of different treatments (Say et al, 2006). But the use of guidelines may conflict with SDM if patient preferences are different from the recommendations.

There is concern among professionals over the impact of adopting a SDM approach on clinic consultation times however the evidence-base reports mixed findings. There have been studies reporting no change in the time required to integrate SDM into clinical consultations (Stacey et al, 2011), yet others have demonstrated the need for more time (Kaner et al, 2007). Burton et al (2010) investigated SDM in patients having arteriography (n=85). The authors reported patient confidence in decisions correlated with consultation duration (p=0.001) and level of perceived involvement (p=0.05). Longer clinics times may increase patient confidence in clinical decisions, but further research is needed to investigate the impact of SDM on consultation time.

Patients may not want to actively participate in decision-making, but SDM encourages an environment whereby patient involvement is supported and patients can share in decisions if they so choose. Integrating SDM in to routine care requires buy-in from health professionals. This is challenging and requires evidence of benefit, particularly when asking clinicians to change practices already embedded in their care. With no standardised definition of what constitutes a shared decision-making approach, it is hard to train professionals in the skills needed.

2.5 Need for further research

Since the integration of SDM in to health policy, little appears to have changed in clinical practice. In 2016, the CQC reported disparity between patient perceptions of level of involvement in their care and their preferences (CQC, 2016). According to the report, there has been little change in the proportion of patients feeling they were involved as much as they wanted to be in decisions about their care between 2005 to 2014 (53% compared to 57%, respectively) (CQC, 2016). These findings illustrate little change in concordance between preference for involvement and experience of decision-making.

The literature suggests that patients may have different preferences for information provision, participation in decision-making and responsibility for making treatment decisions. The benefits of SDM are yet to be demonstrated and there is uncertainty as to whether heart failure patients want a shared decision-making approach. However, there is growing interest in the development of SDM interventions in heart failure management. Yet these are limited to small sub-specialty populations with interventions that are not necessarily applicable to general decision-making (Gauthier et al, 2016; Vucicevic et al, 2018).

Current research tends to focus on the development of tools to increase patient activation and improve patient satisfaction. Little research has explored the contextual influences on patients approach to making decisions about their treatment and disease management. Similarly, the role of family members in a shared decision-making approach has received little attention. Relatives of patients with heart failure often adopt primary carer roles, therefore their influence on patient health beliefs and behaviours are likely to influence patients' decision-making process.

Researchers have aimed to explore this gap in the evidence by adopting qualitative methods to better understand how patients experience involvement in decision-making. Studies in the qualitative paradigm have explored the meaning of involvement and patient perceptions of the process of decision-making. For example, Australian researchers Smith et al (2009) suggested that patient's level of education and level of health literacy influenced their beliefs about involvement in healthcare decisions. The researchers conducted a qualitative inquiry using interviews of patients from different education backgrounds and levels of health literacy (n=73). Patients with higher education backgrounds (defined as University degree or above) perceived involvement as a shared responsibility with health professionals. Those with lower education backgrounds (no formal qualifications, intermediate or high school), perceived involvement as agreeing with the advice of clinicians but retaining responsibility for the final treatment decision. It is important to note that the interview sample consisted of young patients (55-64 years), undergoing bowel cancer screening. These findings cannot be generalised but highlight variation in patient understanding of the concept of involvement.

Qualitative studies often have small sample sizes, but they are not designed to power significant associations. Alternatively, the qualitative paradigm aims to increase understanding of a phenomenon to inform future research so interventions can be tailored more effectively to patient needs. It could be argued that policymakers, academics and health professionals need to shift their focus. Rather than focussing on the development and testing of interventions to facilitate a SDM approach, what is needed is increased understanding of how patients make decisions. What is missing from the evidence-base is the exploration of the factors that influence patients decision-making processes. Addressing this gap in the evidence is the primary motivation of this thesis.

2.6 Behavioural Theory

This review of the literature highlighted the focus of current research on associations between socio-demographics and patient behaviour with little exploration of the contextual influences on decision-making. A holistic exploration of the factors that influence patients' decisions about treatments and their health behaviours has yet to be made. The evidence-base lacks clarity on the combined effects of internal factors (such as understanding of disease) and external factors (such as views of family and friends) on patients' decisions and health behaviour.

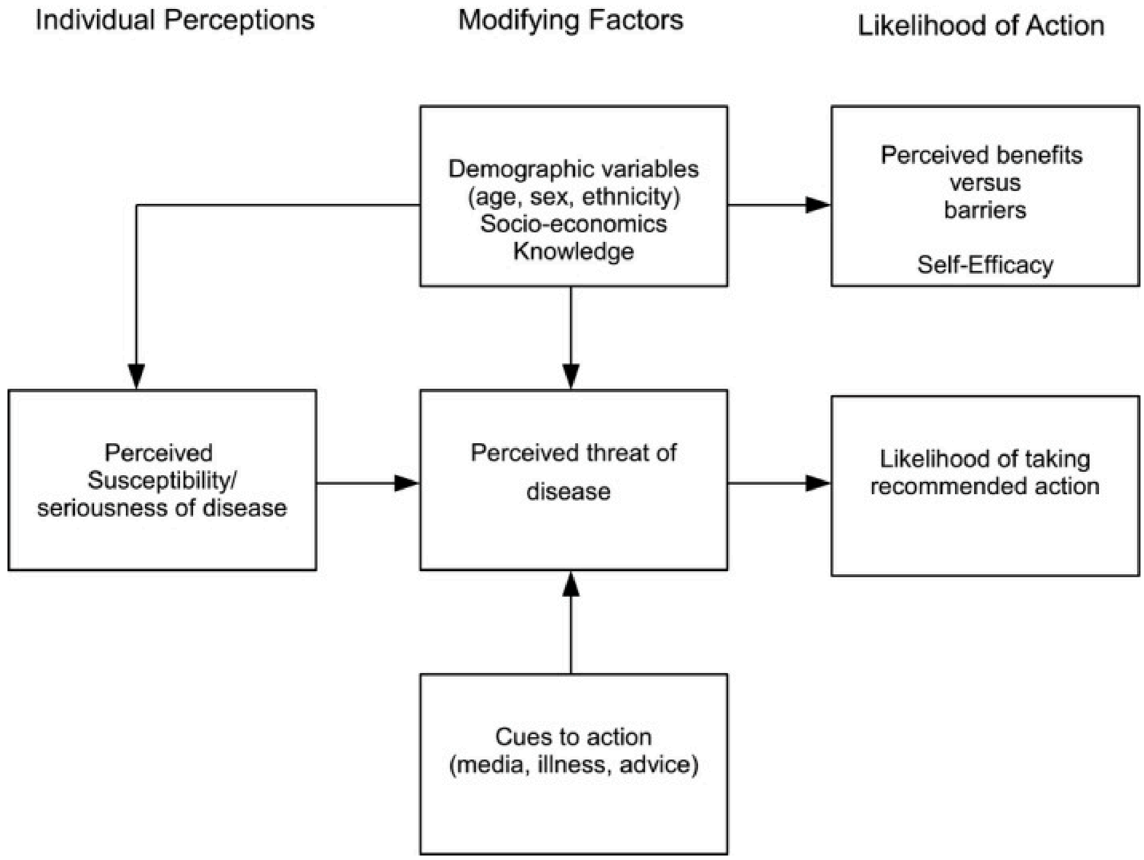
To explore how patients make decisions about their treatments and management of their heart failure, it is important to understand the theoretical underpinnings of human behaviour and behavioural change. A shared decision-making approach impacts on patients and health professionals' beliefs, feelings and behaviours and little evidence exists reporting how patients perceive and conceptualise decision-making in healthcare. The context for understanding patients' decision-making process is in their belief system of healthcare and their experience of service delivery. Therefore, it was important to integrate these systems in to the exploratory design of this study.

Patients health beliefs have long been explored by researchers and led to the development of social behaviour theories to better understand health behaviours. To explore patient health beliefs and behaviours, theoretical frameworks need to underpin study design. According to the literature there are four key behavioural theories commonly used in healthcare research: the Transtheoretical model of change; Information-motivation-behavioural-skills model; the Theory of planned behaviour; and the Social cognitive theory (Davis et al, 2015). These theories focus on the cognitive perspective of behavioural change, where an individual's attitudes and beliefs are important determinants of their health behaviour. One of the key limitations of these theories is that they do not consider external factors (such as relationships with professionals) that may influence patient behaviour. The Behavioural Learning Theory includes both internal and external influences on behaviour but is challenging to tailor to individual patients. The purpose of a SDM approach is to support collaborative decision-making therefore professionals need to be flexible in their approach to communication.

In contrast, the Health Beliefs Model provides a framework that can be used to explore individual patient beliefs and identify the mediators and moderates that influence their health behaviour. The model provides a conceptual framework for understanding health behaviour (Munro et al, 2007). It is based on the understanding that an individual will change their behaviour if they have a set of core beliefs. For example, if patients believe that taking a recommended action (take medication) they will avoid a negative outcome (increased symptom burden), they are more likely to change their behaviour. The model is based on the theory that patient attitudes and beliefs can explain their health behaviour and has been used to better understand how patients perceive the risks and benefits of decisions (Munro et al, 2007).

The model provides opportunity to explore how the behaviour of health professionals can influence patient perceptions of decision-making. It offers a framework to better understand patients ability to engage in behaviours and adhere to treatment recommendations. The model includes six constructs including perceived benefits and barriers to behavioural change (*see Figure 2.1*). Perceived benefits are the patient belief of the effectiveness of actions to reduce negative outcomes (expected benefit of medication) and barriers represent the consequences of taking the action (potential side-effects). Self-efficacy emphasises the importance of patient confidence in the action and how this is likely to influence whether they change their behaviour or not.

Figure 2. 1 The Health Beliefs Model



Source: Munro et al (2007) Review of Health Behaviour Theories.

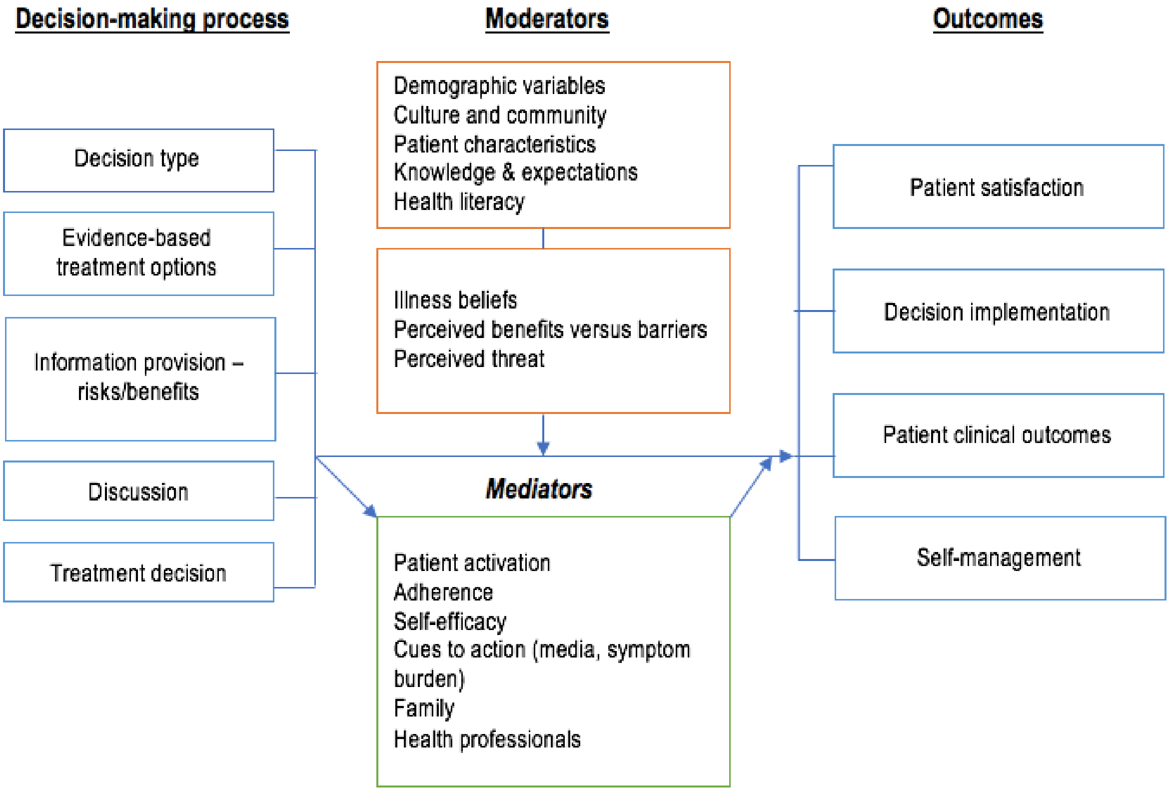
Associations between contextual factors and behaviours have been reported in patients with heart failure (Jaarsma et al (2009). These include their experiences of healthcare, cultural beliefs and values, functional and cognitive abilities, family support and relationships with health professionals. Rather than adopting a single theory to explore patient approach to decision-making, this thesis draws upon the principles of a combination of theories to enable in-depth exploration of the multiple constructs involved in behavioural change.

2.7 Conceptual framework

The adoption of a more personalised approach to heart failure management means the ideology of health decision-making needs to change. A patient may decide on a treatment that does not offer their best predicted therapeutic outcome. As an informed patient making the decision based on their personal circumstance and illness experience whilst considering professional advice, their final decision must be supported. It is clear from the literature that there is still a long way to go to define the best methods to support a successful and mutual partnership in decision-making in heart failure.

The conceptual framework used to guide this thesis *(Figure 2.2)* is built on the premise of challenging traditional biomedical ideology where patients are defined as either passive recipient of their care or active patients. This framework extends beyond the single focus on patient demographics as the primary indicator of health beliefs and behaviours. Alternatively, it incorporates both internal and external factors influencing the individual, their interactions in healthcare and wider society. The model provides a framework for this study to test whether current health policy on decision-making reflects the preferences and needs of patients today. It supports exploration of the applicability of SDM and the readiness of health services to adopt it into routine heart failure management.

Figure 2. 2 Conceptual model for treatment decision-making



This framework encapsulates the three key domains of a SDM approach: the sharing of information; discussion of options and the final decision. The model builds upon the traditional dyad relationship of the health professional-patient, to include family members as important stakeholders in the treatment decision-making process.

On this background, this thesis poses the primary research question: How do patients make decisions about their heart failure management?

This thesis aims to address the gap in the evidence-base illustrated in this review of the literature. Firstly, an in-depth exploration of patient decision-making processes; and secondly, the influences on the views of key stakeholders in decision-making, toward contemporary heart failure management.

2.8 Thesis aims:

1. To explore how patients make decisions about their heart failure management.
2. To explore the contextual influences on the views of patients, their families and healthcare professionals on the use of novel medical therapies and personalised medicine in heart failure.

To answer the research question posed, this thesis has been designed using a mixed-methods approach that involves two phases. The first is a qualitative exploration using sequential semi-structured interviews of patients, family members and health professionals. Phase II is the validation arm of this thesis and uses a Delphi consensus survey to test and extend the qualitative findings. Together these methods are used to explore the influences on patient beliefs, preferences, behaviour and approach to treatment decision-making.

2.9 Conclusion of chapter

Shared decision-making evolved to meet the demands of patients and the public for increased involvement in decisions about their care. With patients wanting greater transparency and choice, the model gained support from policymakers and is now widely advocated in health policy.

Appraisal of the literature illustrated a mixed evidence-base and the emergence of a policy-practice divide. The lack of evidence demonstrating positive patient outcomes and cost benefit has resulted in professionals having little guidance on how to integrate SDM in to their practice. Further research is required to explore the process of decision-making in greater depth. Consideration of behavioural factors and the contextual influences on treatment and management decisions are needed to meet the needs and preferences of patients with heart failure.

To better understand the process of treatment decision-making it is first necessary to review current practice. This is important to provide context for the views and experiences of health professionals and service users and to identify the barriers and facilitators to an SDM approach. The following chapter reports on a Pan-London analyses of the processes, functions and structures of cardiology and cardiothoracic multidisciplinary team meetings across NHS Trusts.

CHAPTER 3: MULTI-DISCIPLINARY TEAM DECISION-MAKING

3.1 Introduction to chapter

Treatment decisions about chronic disease management are made following regular discussion in dedicated multidisciplinary team (MDT) meetings. This process involves bringing together professionals from a variety of disciplines to share their expert opinion and collectively agree on a treatment and management plan. These meetings form a key part of the treatment pathway and offer an established framework to enhance collaborative decision-making. There is growing interest in the effectiveness of MDT meetings and their ability to reach quality decisions. To successfully integrate a shared approach to decision-making (SDM) in to practice, it is important to review how treatment decisions are being made. This chapter reports on analyses of the structures, functions and processes of cardiovascular MDT meetings across London NHS Trusts.

3.2 Background

3.2.1 The Multidisciplinary team approach

In the past treatment decision-making tended to focus on disease silos where decisions were made independently by a single consultant physician. Today newer treatments that prolong life and technology that has improved diagnostic capabilities has led to an aging population with increased frailty and multiple comorbidities. As a result, there has been a shift in healthcare focus from acute care to chronic disease management. Multidisciplinary team working has evolved to meet the demands for complex clinical decisions by promoting combined expert opinion and group consensus. A multidisciplinary approach is described in health policy as professional collaboration in the planning and evaluation of patient care, so treatment is delivered quickly and efficiently from experts in their field (NHS England, 2014).

There have been considerable developments in MDT working practice in heart failure over the last decade and this has made treatment decision-making increasingly challenging. The development of new sub-specialisms such as cardio-oncology, inherited cardiac conditions and cardiac sarcoidosis have led to an increase in professional expertise. This has led to the broadening of professional scope of many disciplines and the emergence of a complex, multi-faceted heart failure service. However, a greater number of specialists focused on narrow areas and more complex patient populations has made it a challenge for professionals, to reach evidence-based, collaborative treatment decisions.

The concept of MDT working is well established and considered to be best practice for the successful management of chronic disease (DoH, 2010; NICE, 2018, ESC, 2016). An MDT approach to heart failure management is accepted as the gold standard of care (ESC, 2016; NICE, 2018). This is based on evidence of significant benefits of MDT interventions and programmes of care demonstrating improved clinical outcomes.

McAlister and colleagues (2004) conducted a systematic review of randomised trials of MDT delivered programmes in heart failure (n=29). The authors reported that programmes which included patient follow-up by the heart failure MDT, were associated with reduced levels of mortality (RR 0.75; 95% CI 0.59 to 0.96) and heart failure hospitalisations (RR 0.74; 95% CI 0.63 to 0.87). Positive outcomes have also been reported by Whellan et al (2005), who performed a meta-analysis (19 studies, 5752 heart failure patients) and found a significant reduction in all-cause hospitalisations for patients being treatment by a MDT. Similar associations between programmes led by MDTs and a reduction in hospitalisations have been reported in systematic reviews and meta-analysis in heart failure (Sochalski et al, 2009; Gohler et al, 2006). However, these studies highlight considerable heterogeneity in the evidence-base which makes it a challenge to assess their quality. It is important to note that these studies report on the effects of different professionals being involved in the delivery of heart failure programmes, rather than the direct effect of interdisciplinary team working.

The benefits of collaborative working (particularly the involvement of different disciplines) has been reported in the literature. For example, the addition of clinical pharmacists to the heart failure team has shown to improve patient outcomes. Koshman et al (2008) conducted a systematic review (12 RCTs, 2060 patients) and reported a significant association between pharmacist collaboration with the team and a reduction in heart failure hospitalisations (OR 0.42; 95% CI 0.24 to 0.74). This may in part be explained by the core role of medication management and effective titration in the treatment of heart failure patients. It is important to note that these findings are based on studies with small sample sizes with variation in patient population, settings and primary outcomes. Moreover, only 6 (50%) of these studies described allocation concealment. Of these, 3 studies scored<2 using the 'Jadad score' reflecting overall 'inadequate' quality.

The involvement of clinical nurse specialists in medication management has also shown to improve patient outcomes. A recent systematic review by Driscoll et al (2015) (n=7 RCTs) assessed the effects of nurse-led medication titration (BB, ACEIs, ARBs) on clinical outcomes. The authors reported patients undergoing nurse-led titration had reduced rates of all-cause hospital admissions (RR 0.80; 95% CI 0.72 to 0.88). Yet their finding that patients with nurse-led titration of BB were more likely to reach targeted doses compared to titration by a family physician, were of low quality (RR 1.99, 95% CI 1.61 to 2.47). For many of these studies follow-up periods were short (<6 months) and no standardised programme was used. This makes it difficult to establish which parts of the intervention influenced the outcomes. In the UK, nurses who titrate heart failure medications complete a nurse prescribing course. This is an intensive training programme giving nurses the responsibility and accountability of prescribing and titrating certain medications (Cope et al, 2016). As an extension of their professional expertise nurses may be more risk adverse to up-titrating medications to target doses. However, this has not been demonstrated in the literature.

There is no national standard for MDT decision-making in heart failure. This is likely due to the high levels of heterogeneity in programmes of care, varying discipline representation in MDTs, diverse patient populations and outcome measures. The quality of the evidence-base is limited by small sample sizes, study design (predominantly single measure comparative and observational studies) and limited evidence of cost-effectiveness (Lam et al, 2011; Pillay et al, 2016). This is reflected in both national and international guidance with limited practical recommendations for the process of decision-making (NICE, 2018; ESC, 2016; Yancy et al, 2013). National guidelines recommend the delivery of heart failure care by a specialist MDT with regular MDT discussion of patient care and treatment (NICE, 2018). International guidelines recommend the delivery of care through multidisciplinary disease management programmes (ESC, 2016; Yancy et al, 2013). Despite these differences, the involvement of patients is widely advocated with emphasis on the consideration of patient preferences when managing their care.

3.2.2 Multidisciplinary team meetings

The process of decision-making within MDTs involves a series of team meetings aimed at producing high quality decisions that lead to improved patient outcomes. MDT meetings provide a structured forum for professionals to share information and ideas and promote evidence-based practice. In 2014, NHS England published a report launching a national collaborative programme to integrate care and support (NHS England, 2014). Multidisciplinary team meetings were one of the key strategies to help professionals work together to support patients with complex needs.

The evidence-base for the effectiveness of MDT meetings on patient outcomes is mixed. Hartgerink et al (2014) conducted a cross-sectional survey of 192 health professionals involved in the care of older hospitalised patients in the Netherlands. The authors measured the quality of communication among professionals in MDTs and the quality of their relationships (relational coordination). Using two validated instruments, ‘Relational coordination survey’ and ‘Team climate inventory’ (Cronbach’s alpha 0.96 and 0.94 respectively), the authors reported a positive correlation between the number of disciplines represented in the MDT meeting and relational coordination (r=0·36; $p \leq$ 0·001).

The effect of MDT meetings on clinical outcomes mainly originate from studies in cancer care. This is likely due to cancer care being one of the first specialties to adopt the principals of MDT meetings (DoH, 2007). National cancer organisations have developed a national policy framework for MDT meetings. The National Cancer Action Team (NCAT) through expert consensus (>2000 oncology experts) outlined key components of an effective MDT. For example, presence of an MDT coordinator; specialist knowledge and expertise required for the MDT; dedicated time for meetings; register of staff attendance and formal minutes; opportunity for staff education and training and discussion of clinical trial recruitment (NCAT, 2010). Importantly the team emphasise that patients should be made aware of the MDT and when their case will be discussed.

There is limited evidence of the effect of MDT meetings on the quality of decisions made (Lamb et al, 2011). Multiple observational methods and different measures to determine effectiveness make study findings difficult to compare. 'Decision implementation' is commonly used to measure the quality of decision-making, whilst others use 'team climate.' There have been several observational tools developed and tested to evaluate the quality of MDT meetings and decision-making (MDT-MOT tool: Harris et al, 2016; MDT-OARS: Taylor et al, 2012). However, these are yet to be validated in heart failure MDT meetings.

Current health policy is driven by research reporting patients wanting more information, more choice and more involvement in their care (CQC, 2016; Murray et al, 2007; Chewning et al, 2011; Levinson et al, 2005). Yet , there is evidence of variation in MDT practice across the UK and limited evidence of cost-effectiveness (DoH, 2004; Ke et al, 2013). Professionals need increased understanding of what is happening in current practice to support the integration of SDM in to routine practice.

3.3 Methods

A prospective cohort study was conducted of MDT meetings within adult cardiology and cardiothoracic departments across London NHS Trusts. The purpose of the study was to increase professionals understanding of treatment decision-making in current practice.

3.3.1 Ethical considerations

This study was agreed by the Sponsor (Imperial College London) and the local NHS Research & Development team to be a service evaluation process. It therefore did not require ethical approval. Confidentiality was maintained through anonymity of the respondent details and informed consent to participate was implied through study completion.

3.3.2 Recruitment

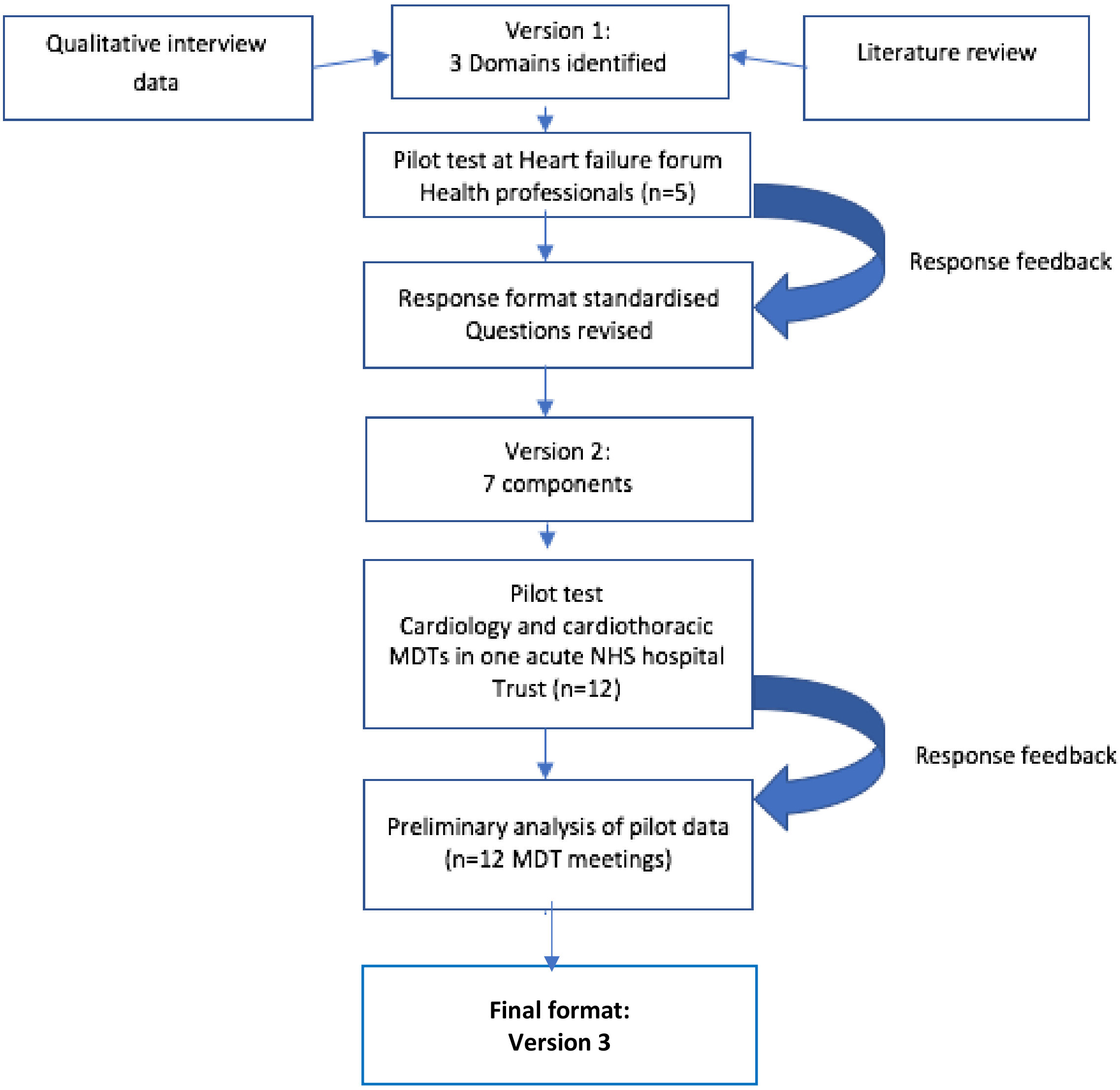
The study proforma was developed and distributed to members of the London Cardiac Clinical Network (LCCN), NHS England. The network was the primary route for recruitment based on its key focus on improving cardiac services and interest in the variation of cardiac care across London. This provided important buy-in for the respondents and encouraged increased response rates and minimal missing data. The network's mailing list consisted of professionals from seven London NHS Trust hospitals. These Trusts were chosen as they provided broad representation of the range of cardiac services provided by the NHS across London: specialist teaching hospital Trusts, tertiary care centres and smaller district hospitals.

The coordinators or lead clinicians of MDTs from Trusts not represented in the mailing list, were telephoned or emailed and invited to take part. Email invitations and the survey attachment were sent with an appended cover letter stating the purpose and background of the study. Following initial low response rates, a chain referral (snowball) sampling approach was adopted. Health professionals who responded were asked to contact colleagues, who then facilitated contact with another and so on. A follow-up discussion took place if the MDT coordinator or clinical lead requested clarification. Email reminders were sent at two weekly intervals to non-responders.

3.3.3 Data collection

The study proforma was distributed electronically to 26 recipients between July 2017 and December 2017.

Figure 3. 1 MDT meeting proforma design and development



Development of the study proforma was informed by review of the literature. The decision to collect data on MDT meetings in-house and across London Trusts was necessary to provide an overview of the current use of MDT meetings, modes of team functioning and decision-making in clinical practice. The proforma was designed to collect data on the structure, processes and functions of MDT meetings to provide meaningful insight in to clinical decision-making. Answer format for each component was reviewed and refined following pilot testing and staff feedback.

Version 1 of the proforma was pilot tested and distributed to staff at the Heart Failure Forum in August 2017 *(Appendix 3.1).* The proforma was completed by 5 staff members representing 5 London NHS Trusts and 5 MDT meetings. Meetings included: 3 heart failure MDTs (60%) and 2 general cardiology (40%). Feedback from respondents included: Response format was not standardised; specific information was unknown (e.g. whether the chairperson received formal training). Version 2 of the proforma *(Appendix 3.2)* included 7 components: Presence of a 'terms of reference' (ToR); chairperson; attendance; frequency; documentation; information provided to patients and recommendation feedback.

Version 2 was piloted through distribution at a central London tertiary NHS Trust across 2 hospital sties and 12 sub-specialities (*see Table 3.1*). Data was collected by sending out the proforma to each adult cardiology and cardiothoracic MDT meeting coordinator in the Trust. Reminder emails were sent after two weeks and phone call reminders following three weeks. This increased response rates and allowed refining of the proforma through real time feedback to ensure quality data was collected.

3.3.4 Revision and final version of the proforma

The findings of the pilot proforma illustrated marked variance in the structure, processes and staff invitations of the different MDT meetings. It was interesting to find such variance in one tertiary centre, where most teams originated from a single site. The verbal feedback received about the completion of the proforma highlighted some key issues that needed to be addressed. Six of the meeting coordinators raised the issue of their MDT meeting email invitation mailing list. Their lists were not updated regularly and therefore not all staff would receive the meeting invitation and information. Another issue was that some professionals would receive an email invitation to each meeting, but their attendance was not necessarily required. For example, the ACHD MDT meeting would invite the obstetrician for discussion of patients who were pregnant. Similarly, psychologists and pharmacists would only attend if they were specifically asked to do so about a particularly patient. It was clear from the feedback and differences in data collected that each MDT would tailor specific staff invitations to the needs of the patients discussed.

The pilot proforma was revised to collect data on the professional discipline of those staff that attended the MDT meeting rather than those who were invited. When this alternative option was fed back to staff who completed the initial pilot proforma, a further 4 staff raised the issue that there was not a formal attendance list recorded for every

MDT meeting. It was requested that staff complete the proforma for a ‘typical’ MDT meeting to allow for comparison between teams. In the final version, the questions were converted in to a multiple-choice format to improve clarity and ease of completion. The decision to remove the ‘don’t know’ response entry minimised missing data and the change of scale data to categorical data provided more clinically meaningful responses. Open-ended questions were removed or converted to closed questions due to limited data to compare. Instructions for completion of the proforma were added to clarify data entry for one MDT meeting per proforma.

The final version of the proforma V3 *(Appendix 3.3)* included 24 items grouped into 3 domains: structure of MDT meeting; attendance; and processes of MDT meeting. Domain 1, ‘Structure of MDT meeting’ comprised 7 items collecting data on the frequency, duration, patient populations, format and purpose of the meeting. Domain 2, ‘Attendance’ comprised 10 items and Domain 3, ‘Processes of MDT meeting’ contained 6 items on documentation and recommendation feedback. To test the pilot data the proforma was distributed to NHS Trusts across London.

3.4 Results

3.4.1 Pilot data

Data analysis was performed on the pilot data collected using Version 2 of the proforma. A total of 12 proforma were completed and returned for 12 MDT meetings conducted over two sites, at one NHS Trust. The teams that fed back data on their MDT meetings are summarised below in *Table 3.1.*

Table 3. 1 Cardiology and cardiothoracic MDTs

Multidisciplinary teams	**MDT meeting patient populations**	
	Site 1	Site 2
Heart failure	Heart failure	Heart failure and Transplant
Heart failure sub-specialties	ACHD Cardiac sarcoid Cardio-Oncology Pulmonary Hypertension	
Electrophysiology	Electrophysiology	
Joint surgical/medical	Revascularisation Angina	
Cardiothoracic	Structural heart Aortic	Heart and Lung Transplant

Response rate for the pilot proforma was 80%. Most feedback came from cardiology MDTs 10 (83%). Of these meetings, 2 (20%) invited both medical and surgical professionals. Invitation to attend these meetings for surgical staff were limited to cardiothoracic surgeons. Of the 3 cardiothoracic MDTs, one (Aortic MDT meeting) invited non-medical professionals to attend. Detail of the characteristics of each MDT meeting are displayed in *Table 3.2.*

Table 3. 2 Pilot data MDT meeting characteristics

Proforma components	**MDT meetings (n=12)** **N**	**(%)**
ToR* present	3	(25)
Dedicated chairperson	11	(92)
Frequency: weekly	12	(100)
Meeting documentation:		
Minutes taken	7	(58)
Outcomes recorded on EPR**	9	(75)
Clinic letters	2	(17)
Team spread sheet	1	(8)
Team database	1	(8)
Patients informed of MDT meeting	10	(83)
Inpatient feedback:		
In-person by consultant	7	(58)
Outpatient feedback:		
In-person by consultant	3	(25)
Telephone by clinical nurse specialist	5	(42)
Clinic letter	4	(33)

*ToR = Meeting Terms of Reference; **EPR – Electronic Patient Records

Only 3 (25%) of meetings had a formally documented Terms of Reference (ToR). All meetings were conducted weekly and 11 (92%) had an appointed chair. Ten (83%) of MDTs stated that inpatients were informed of the MDT discussion prior to the meeting. Two of the surgical MDTs (Structural heart; Aortic) stated that patients were not directly informed of the upcoming meeting. Feedback of the meeting outcomes also varied across sub-speciality. This included the method of feedback (in-person, phone, mail) and the professional responsible for this communication (consultant, medical team or clinical nurse specialist). Documentation varied across specialities. Formal minutes were taken in only 7 (58%) of meetings. Ten (83%) recorded meeting outcomes on the electronic patient record, those that did not were both surgical sub-specialities. No difference between surgical or medical sub-speciality for the remaining six components were observed. Staff invitations were sent electronically via a mailing list. Staff invitations to attend the MDT meetings are summarised in *Table 3.3*.

Table 3. 3 Professional disciplines invited to attend MDT meeting

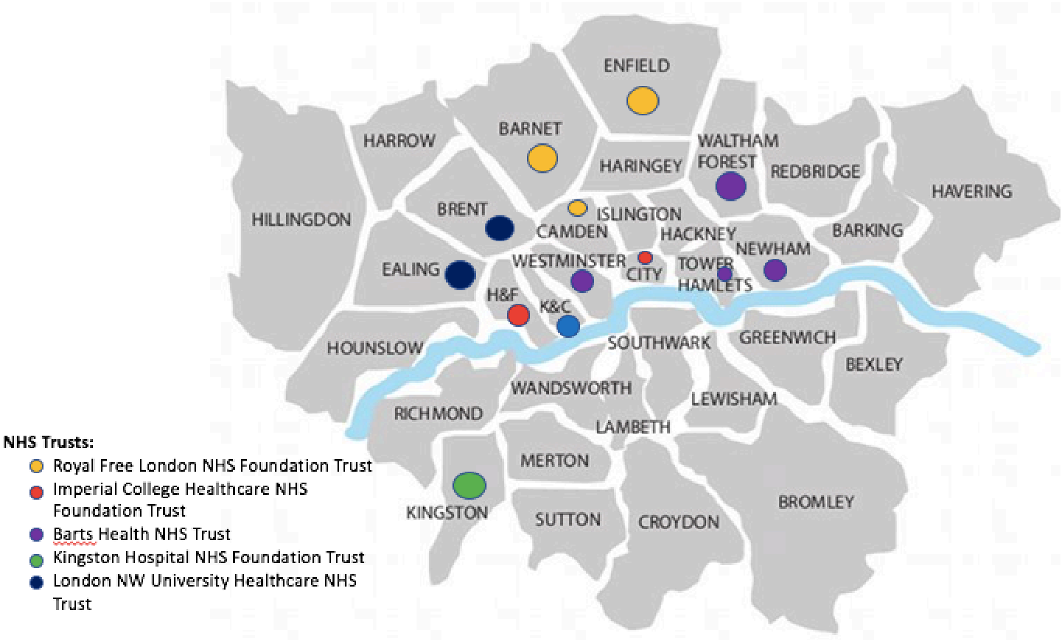
Professional discipline	**Cardiology MDT meeting (n=9) n (%)**	**Cardiothoracic MDT meeting (n=3) n (%)**
Physicians:		
Cardiology consultants*	9 (100)	3 (100)
Intensivists	1 (11)	1 (33)
Cardiac surgeons	3 (33)	3 (100)
Respiratory consultants	1 (11)	1 (33)
Obstetrician	1 (11)	0 (0)
Palliative care	2 (22)	0 (0)
Specialist Registrars	9 (100)	3 (100)
Senior House Officers	3 (33)	2 (67)
Non-medical professionals:		
Clinical Nurse Specialist	7 (78)	2 (67)
Research nurses	1 (11)	0 (0)
Cardiac physiologist	2 (22)	0 (0)
Pharmacist	2 (22)	0 (0)
Psychologist	1 (11)	1 (33)
Physiotherapist	1 (11)	0 (0)

*Cardiology consultants (includes specialists in Heart Failure, Transplantation, Electrophysiology, Devices, Imaging)

Eleven of the MDT meetings (92%) had a core group of consultant cardiologists/surgeons, imaging specialists and junior doctors. Nine (75%) of meetings invited clinical nurse specialists to attend but only 5 (42%) invited allied professionals. Two meetings invited a pharmacist (the Heart failure MDT and the Heart failure and transplant MDT). The two transplant MDTs both invited a psychologist (the Heart failure and transplant meeting and Transplantation heart and lung meeting). The two heart failure teams (17%) invited members of the palliative care team to attend their meetings (Heart failure MDT; Heart failure and Transplant MDT). The only team to invite research nurses to attend was the Heart failure MDT. No patients or relatives were invited to attend any of the meetings.

3.4.2 Results of London-wide analyses

Figure 3. 2 MDT meeting feedback across London



Sample

A total of nine proformas were completed providing data on nine MDT meetings across five London NHS Trusts. These included five different specialities: 5 cardiology (3 of which were heart failure); 3 joint cardiology and cardiothoracic; and one surgical meeting. Data were collected on four of the seven NHS Trusts represented in the London Cardiac Network (LCN). The response rate from the email invitation to the LCN was 25%. Following additional snow ball recruitment, nine completed proformas were collected. A total response rate of 35%.

Each participating Trust and their hospital sites are indicated in *Figure 3.2*. Data on at least one cardiology/cardiothoracic MDT meeting was collected from each Trust: one Trust completed 4 proformas; another completed 2 proformas, the remaining 3 Trusts returned a single proforma. Of the 9 MDT meetings 3 (33%) were joint cardiology and cardiothoracic and 3 (33%) were heart failure. Each specialism was represented by a different Trust. One was a Coronary MDT meeting and one was an Infective endocarditis MDT meeting. Most of the respondents who completed the proformas were consultants 5 (42%); 2 (22%) Specialist Registrars (SpR); 2 (22%) nurse specialists. *Tables 3.4 to 3.6* illustrate the results of each of the three domains: Structure of MDT meetings; Attendance; Processes.

Table 3. 4 Structure of MDT meetings

Structure of MDT meeting	Response options selected	MDT meeting (n=9) n	%
Patients discussed	Inpatients	9	100
	Outpatients	9	100
	Community	4	44
	New referrals	5	55
Meeting frequency	Weekly	7	78
	Fortnightly	1	11
	Other	1	11
Average duration (hours)	<1	2	22
	1	5	55
	2	2	22
Number of patients discussed	2 to 5	3	33
	6 to 9	3	33
	>10	3	33
Terms of Reference	Yes, formally documented	2	22
	Yes, not formally documented	2	22
	No	5	55
Chairperson	Yes	8	89
	No	1	11
Meeting used for teaching	Yes	6	67
	No	3	33

All MDT meetings discussed inpatients and outpatients; 5 (55%) discussed new referrals and 3 (33%) discussed patients being managed by community services. Seven (58%) of meetings were conducted weekly and lasted approximately 1 hour, 5 (42%). Eight (89%) had an allocated chairperson. The number of patients discussed per meeting varied with 6 (66%) discussing >6 patients on average per meeting. Of the five MDT meetings that reported an average duration of 1 hour, 2 (22%) reported discussing 6 to 9 patients in that time; and 2 (22%) reported discussing more than 10 patients.

Teaching was included in 6 (67%) of MDT meeting's frameworks. Only 2 meetings (22%) had formally documented Terms of Reference (ToR). Three (75%) of the surgical/joint MDT meetings did not have a ToR. No further differences between cardiology, cardiothoracic and joint MDT meetings were observed.

Table 3. 5 Attendance at MDT meetings

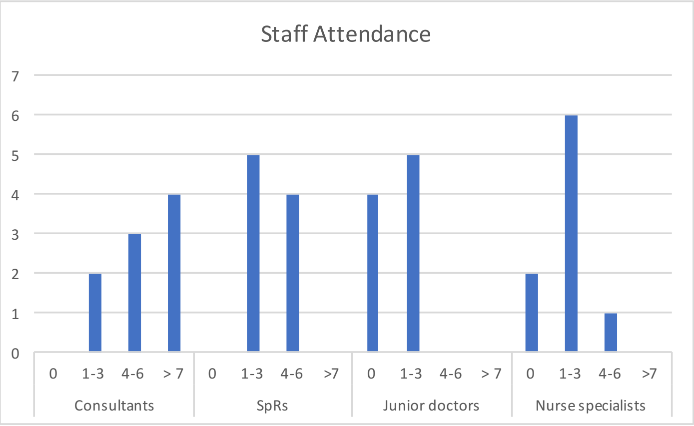
Attendance	**Response options selected**	**MDT meeting (n=9)**	
		N	**%**
Register of attendance	Yes	5	55
	No	4	44
Number of Staff attending	<5	0	0
	6 to 10	3	33
	11 to 15	4	44
	16 to 20	2	22
Patients invited to attend	No	9	100
Family members and/or carers invited to attend	Yes	0	0
	No	9	100
Number of consultants	0	0	0
	1 to 3	2	22
	4 to 6	3	33
	> 7	4	44
Number of specialist registrars	0	0	0
	1 to 3	5	55
	4 to 6	4	44
	>7	0	0
Number of junior doctors	0	4	44
	1 to 3	5	55
	4 to 6	0	0
	> 7	0	0
Number of nurse specialists	0	2	22
	1 to 3	5	67
	4 to 6	2	11
	>7	0	0
Attendance of other allied health professionals	Always	1	11
	Sometimes	2	22
	Rarely	1	11
	Never	5	55
Attendance of researchers	Always	1	11
	Sometimes	2	22
	Rarely	6	67

Seven (78%) of the MDTs had between 6 and 15 staff attending each meeting. Only 5 (55%) reported taking a staff register at each meeting. Two meetings (22%) reported a total staff attendance of 16 to 20 members. These meetings included one surgical and one joint cardiology/cardiothoracic meeting. Both MDTs reported an average of >10 patients discussed per meeting and involvement of >7 consultants, 4 to 6 specialist registrars and at least one specialist nurse. No patients, relatives or carers were invited to attend any meeting.

In terms of professional discipline, 7 (78%) reported the attendance of 4 to >7 consultants at each meeting. Two meetings (22%) reported 1 to 3 consultants attending. Both were Heart failure MDTs with at least 3 specialist nurses in attendance. The number of specialist registrars (SpRs) was near evenly split: 1 to 3 (42%), 4 to 6 (33%). Interestingly, 4 (44%) of MDT meetings did not have junior doctors attending (senior house officers, house officers or medical students). Of these, 2 (22%) reported teaching as part of their meeting framework. Of interest was that 3 (75%) of these were heart failure MDT meetings. Two MDT meetings did not have a nursing presence. One joint Cardiology and cardiothoracic meeting and one Coronary care meeting. Both discussed 6 to 9 patients per meeting. The joint meeting reported >6 doctors in attendance and the cardiology meeting reported >12 doctors. Attendance of physicians and nurses is summarised in *Figure 3.3.*

Five meetings (42%) reported no other allied health professionals (physiotherapist, pharmacist, cardiac physiologist) ever attended their meetings. One cardiology MDT stated allied professionals ‘always’ attended their meetings. Researchers attended meetings in 5 (55%) of cases. The only team to ‘always’ have researcher presence was the single cardiac surgery meeting, the Heart valve MDT. We found no further differences between cardiology, cardiothoracic or joint MDT meetings. *Figure 3.4* illustrates attendance of allied professionals and researchers to MDT meetings.

Figure 3. 3 Attendance of physicians and nurses



*SpRs – Specialist Registrars

**Junior doctors – Senior house officers, house officers, medical students

Figure 3. 4 Attendance of researchers and allied health professionals

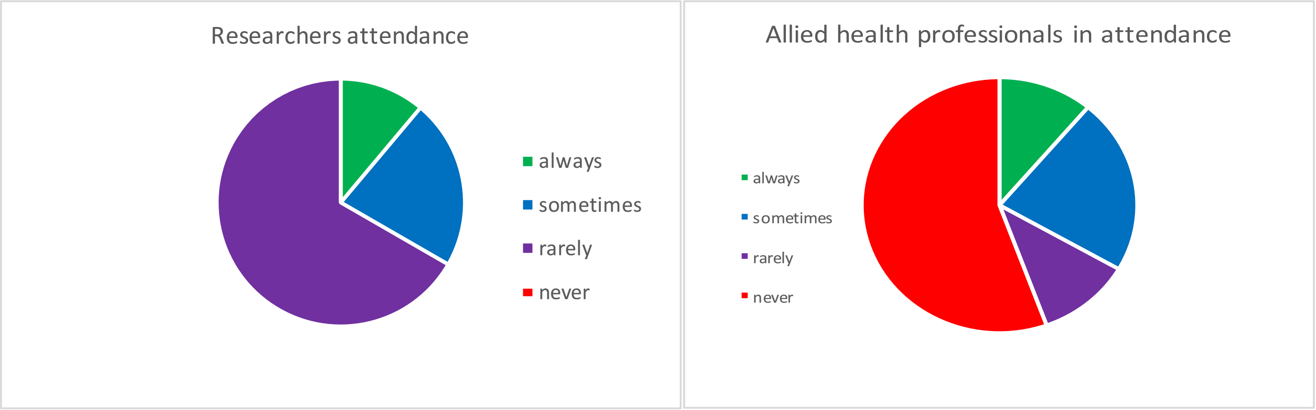


Table 3. 6 Processes of MDT meetings

Processes of MDT meeting	Response options selected	MDT meeting (n=9)	
		n	%
Formal minutes taken	Yes	5	55
	No	4	44
Outcomes documented	Yes	9	100
Where the outcomes are documented	Patient medical notes	1	11
	electronic patient records	8	89
	MDT meeting file	6	67
Patients informed prior to MDT meeting	Always	7	77
	Sometimes	2	22
Recommendation feedback to patients	In-person	6	67
	by telephone	4	44
	by post	6	67
Staff who fed back treatment recommendations	Doctor	9	100
	Nurse	2	22
Additional sources of information provided	Yes	4	44
	No	5	55
Sources of information	Information leaflets	6	67
	Internet websites	0	0
	Other	1	11
	None	1	11

Responses to the Domain 'Processes of MDT meetings,' illustrated considerable variance in meetings within and across NHS Trusts. Formal minutes of the meetings were recorded in just 5 (42%) cases. Yet all MDTs reported that their meeting outcomes were documented. Seven MDTs (58%) documented their meeting outcomes in electronic patient records. Seven (58%) documented outcomes in both the electronic patient records and an individual MDT meeting file. Not all patients were informed of the MDT meetings in advance. Most MDTs fed back treatment recommendations to patients in-person 6 (67%); 3 MDTs also fed back to patients by telephone (33%); and 2 (22%) fed back recommendations via mail. Physicians were the primary health professional responsible for patient feedback. Only two (22%) MDTs reported discussion of treatment recommendations with patients by both doctors and nurses. Four (33%) fed back treatment recommendations supported by additional health information.

However, six (67%) reported the provision of information leaflets to patients when discussing treatments. No difference between surgical, cardiology or joint MDT meetings was observed.

3.5 Discussion

More than half (55%) of the MDTs reported never having allied health professionals attend their meetings and less than a quarter (22%) followed a formalised, structured framework. It was common for MDTs to discuss large numbers of patients in a short period of time (as little as 6 minutes allocated to discuss each patient). Not all patients were informed in advance of their case being discussed. A positive finding was that teaching was integrated in to more than half of the MDT meetings. Of these, junior doctors were only present in a third of meetings and two thirds rarely had researchers in attendance. No MDTs invited patients or relatives/carers to participate in meetings.

These analyses highlight the considerable variation in the structure, function and process of decision-making by MDTs both within and across London NHS Trusts. Five of the eight largest London NHS Trusts that provide cardiology services were represented. Two additional Trusts provided data on MDT meetings conducted in South West London and North West London.

Of the nine MDT meetings, data was retrieved on five different sub-specialities. This diversity highlights the growth in specialist expertise, reflecting the move to a more personalised approach to treatment. This growth in subspecialties may potentially lead to further fragmentation of healthcare services and professional teams. There are also the impracticalities of bringing together many specialists to make clinical decisions. Too many professionals may act as a barrier to creating an environment conducive to making collaborative, high quality decisions (NHS, 2014).

3.5.1 Format of MDT meetings

These findings emphasise the lack of standardised framework and strategy used for the implementation of MDT decision-making in current practice. These findings are reflected in the literature with different guidance for MDT meeting structures for different disease groups (Nic a Bhaird et al, 2016; NCAT, 2010; NICE 2018).

Only two of the nine MDT meetings reported having documented terms of reference and less than half completed formal minutes and staff registration. Terms of reference are widely used in the NHS to facilitate meeting structure particularly when multiple stakeholders are involved (NHS, 2017; NIHR, 2018). Terms of Reference (ToR) provide details of the purpose, objectives, membership and reporting of the meeting. Measuring the effectiveness and quality of decision-making is challenging without these standards. Similarly, absence of an agreed process by the team limits their ability to audit and review practice. Few MDTs formalised their meeting aims and there was limited evidence of documentation of how and why decisions were made. This makes it a challenge for teams to reflect on and change their practice. Nearly all MDTs did have an allocated chairperson which importantly indicates a level of governance and oversight to decision-making.

Of the five MDT meetings that reported an average duration of one hour, 2 (22%) reported discussing 6 to 9 patients in that time and 2 (22%) reported discussing more than 10 patients. In these cases, it would calculate to approximately six minutes of time allocated to discuss each patient. It could be argued that such a limited amount of time is unlikely to facilitate effective collaboration among the team and consideration of management plans. Similar time allocations for patient case discussion have been reported in the literature. For example, Lamb et al (2013) conducted a prospective correlation study of cancer MDT meetings. The authors reported a mean number of cases discussed in specialist meetings as 29.9 with a mean time of 2.32 minutes per case. The study was of 7 meetings of a single MDT based in London and therefore these findings cannot be generalised. Increased time per case was associated with improved teamwork (r=0.16) but further research is required to assess time per case on decision quality and implementation. Similar findings were reported by Mullan et al (2014) from an observational study of 105 patients discussed in 10 MDT meetings. Time spent discussing each patient ranged from 15 seconds to 8 minutes (mean duration, 2 minutes).

In all cases, more than eleven members of staff attended each meeting. This included consultants, SpRs, junior doctors and specialist nurses. Only one MDT meeting reported allied professionals *always* in attendance. This number of professionals and mixture of disciplines makes pooling of opinion and agreement in a short timeframe challenging. These findings also highlight the variance in discipline representation and add to the debate in the literature over the effects of multidiscipline working in MDT meetings. The fact that nurses were not represented in all MDT meetings was an interesting finding particularly, as studies have suggested the benefits of nurse attendance. Lamb et al (2013) conducted a national survey study of cancer MDT members in the UK (n=1636). The researchers reported how respondents value nurse participation and the key role of clinical nurse specialists acting as patient advocates. This is important as research suggests that MDT meetings that discuss and take in to account patient preferences are more likely to have their decisions implemented (Blazeby et al, 2006). To improve MDT meeting processes, it is important for staff to be aware of the purpose and goals of each meeting, so staff can actively participate and challenge one another.

Formal minutes of the meetings were recorded in just 55% of cases. Yet all MDTs reported that their meeting outcomes were documented. Failure to have a formal process for documentation during the meeting could mean that some items or comments are missed. These findings also demonstrate variation in the documentation of MDTs meeting outcomes. Seven MDTs documented their meeting outcomes in electronic patient records. This was expected with the NHS move towards a central electronic system for patient records. However, MDTs also documented the outcomes in an individual MDT meeting file. Although it was unclear what was documented in these files, reducing the number of methods and sources of documentation may prevent missing data and help increase access to patient records.

There was evidence of teaching in some team meetings. Teaching was part of 6 (67%) of MDT meeting's frameworks. One third of these did not have junior doctors in attendance (senior house officers, house officers, medical students), 50% never had allied professionals in attendance and 60% rarely had researchers in attendance. These results highlight potential missed opportunities to teach and mentor junior staff. Raine et al (2014) conducted a series of observational studies of MDT meetings (n=360) to identify the factors that influence the implementation of treatment decisions. In their series of qualitative interviews, the researchers described professionals' agreement that teaching should be a function of MDT meetings. Similarly, in a national survey of cancer MDT members (n=2054), Taylor et al (2010) reported 97% of respondents agreed that MDTs have an important role in shared learning and 95% agreed they should be used for education. There is a gap in the literature evaluating the effects of teaching in MDT meetings. A set time where multiple disciplines come together regularly, offers potential for increased interdisciplinary teaching.

3.5.2 Collaboration within MDT meetings

Variation existed in the number of professionals attending each meeting. Core staff were primarily physicians with few to no specialist nurses and allied health professionals. This core group largely consisted of consultants (cardiologists, cardiac surgeons, imaging specialists); specialist registrars; less than half of the MDT meetings included junior doctors. This fits with the literature where national surveys and large observational studies have reported a predominantly physician-based core MDT group (Taylor et al, 2010; Raine et al, 2014). These data report largely on cancer MDTs and therefore, further assessment of heart failure MDT meetings is required.

In most cases (77%) at least one clinical nurse specialist attended each MDT meeting, but allied health professionals rarely attended. These findings add to the debate in the literature over the required number and involvement of professional disciplines to reach high quality decisions. An interesting finding reported by Raine et al (2014), was that increasing the number of disciplines involved in the decision-making process, the less likely treatment decisions were implemented (25% reduction for each additional discipline (95% CI 0.66 to 0.87). Alternatively, the authors reported that it was the mode of team functioning and having a structured framework for the MDT meeting that increased the likelihood of decisions being implemented.

It could be argued that without the presence of nurses and allied professionals decisions made by MDTs may neglect the wider psychosocial needs of patients. A failure to account for the impact of treatment decisions on patient quality of life, their recovery and social circumstance may result in patient dissatisfaction, reduced decisional implementation and delayed discharge. It may not be plausible to have all allied professionals and nurses attend every MDT meeting but to make effective decisions, strong leadership is needed to tailor MDT meetings to individual patient needs. The role of the chairperson and their attitude towards MDT working and decision-making is therefore paramount.

In contrast, other researchers have shown a positive effect of multidisciplinary representation on collaboration and team functioning (Hartgerink et al, 2004). For example, Powell and Davies (2012) reported the positive effect of clinical nurse specialist involvement in MDTs. Blazeby et al (2006) examined MDT decision concordance with treatment received by cancer patients (n=273 decisions analysed). The decisions that were not implemented [41 (78.1%)] were due to the inadequate exploration of patient comorbidities and personal preferences (Blazeby et al, 2006). Presenting the patient's values, goals and preferences as part of a holistic approach to treatment decision-making may facilitate better suitability of treatment and management plans.

Heart failure nurse specialists have an established role in the NHS and this may reflect the greater number of specialist nurses in attendance in the heart failure meetings compared to other specialities. A key role of the heart failure nurse is the provision of psychosocial care and support to patients and their relatives (Jaarsma et al, 2008). Nurses often have more time to spend with patients compared to physicians and with increased continuity and contact, affords them increased understanding of individual patient's needs and social circumstance. These factors play an important role in how patients make decisions about their treatments. It could be argued that professional hierarchies may undermine the benefits of bringing together multiple disciples. This is reflected in the literature with senior physicians leading the process and nurses and allied health professionals having limited input (Lamb et al, 2011). To date, little is known about the level of collaboration and its effects on decision-making in heart failure MDTs.

3.5.3 Research and recruitment

Each of the five NHS Trusts represented in these analyses have an established clinical research portfolio. Each Trust promoted their commitment to research and development through academic and commercial studies and collaboration with Higher Education Institutions (HEI). However, considering the challenges in clinical trial recruitment it was surprising that only a limited number of researchers attended the MDT meetings.

Poor recruitment to clinical trials has a significant impact on scientific quality and the decisions of organisations (both HEI and industry) to invest in Trusts (McDonald et al, 2006). Carlisle and colleagues (2015) reported nearly a fifth of registered phase II and III clinical trials on the National Library of Medicine trial register were closed or stopped early due to poor patient recruitment. MDT meetings provide opportunity to review current patient populations and determine the feasibility of study recruitment. They also offer opportunity to keep staff up-to-date on upcoming and current studies, identify any barriers or facilitators to study recruitment and discuss suitability of potentially eligible patients.

Studies conducted at these large teaching Trusts included phase II and III clinical trials. These included investigations of the effectiveness and safety of novel therapies, new treatments or advanced management strategies. Open discussion of study recruitment and trial suitability could offer patients an alternative when suitability of evidence-based guideline recommendations is unclear. Both clinical eligibility and social circumstance could be addressed in MDT meetings.

There are barriers to patient recruitment in terms of clinician workload, time and personal perceptions about research. It could be argued that not enough clinicians discuss research with all eligible patients. This is concerning when one study reported over three quarters of patients (n=885) were willing to participate in clinical trials if they were provided with further information (Ford et al, 2011). In practice there also appears to be confusion about which staff are classed as 'researchers' and which staff are 'clinical.' This distinction may be a barrier to staff involvement and perceived responsibility for who should discuss research with patients. MDT meetings could be used to encourage a breakdown of these beliefs and increase awareness of the Trust's research programme. This is an important step in shifting research practice towards a more collaborative multidisciplinary approach.

3.5.4 MDT decision feedback

It was interesting to find that some patients were not informed in advance of their case being discussed at the MDT meeting. This raises concern about the isolation of this process and distance from the NHS goal of integrated care that is patient-centred. MDT meetings provide the backbone to treatment decision-making in current practice. More needs to be done to increase the visibility of MDT meetings and potentially redesign the process to ensure a patient-focused pathway is adopted. Discussion with patients and their families about the purpose, role and process of MDT meetings may help to ensure up-to-date information is shared. Without prior knowledge of meetings, it is challenging to integrate up to date views and perspectives of the patient. These factors have shown to influence whether patients support or reject treatment recommendations (Blazeby et al, 2006).

Physicians were predominantly responsible for feeding back treatment recommendations to patients. Only two MDTs reported feedback by both nurses and doctors. Physician-led feedback was expected as consultants lead the team and are overall responsible for the final treatment plan. However, to promote a more collaborative approach combined feedback may be useful. Further research in to the best way to feedback treatment recommendations is needed to better understand how to involve patients and meet their information needs.

Patients received feedback in-person at their clinic appointment, via a letter in the post, or by telephone. There was no standardised model for feedback across Trusts. There is limited research in to the effects of treatment recommendation feedback (whether in-person or remotely) on patient satisfaction, treatment adherence or decisional conflict. However, use of technology to improve the timing and process of decision-making could be employed. There is still a lot to learn in terms of safeguarding patient confidentiality and data protection when introducing new technologies in to healthcare. Considering recent government changes (recent update, GDPR) data governance is likely to grow and whether the benefits outweigh the potential cost of healthcare technology is yet to be seen.

It was interesting to note that less than half of MDTs fed back treatment recommendations supported by additional health information. Information leaflets have shown to improve patient knowledge of their disease and information recall when provided to patients during consultations (Sustersic et al, 2017). However, some studies have found that the provision of information leaflets prior to surgery can increase levels of anxiety (Laccourreye et al, 2008). Others report patient preference for verbal information (Johnson & Sandford, 2005). The accuracy and content of recommendations reported in information leaflets have also shown to vary between NHS Trusts. Grewal (2014) demonstrated variance in the post-operative guidance literature (n= 93 Trusts) for patients returning to work, driving and exercise following inguinal hernia repair. Health information provision should not be a one size fits all practice.

There is evidence that other mediums and resources other than written leaflets can improve patient self-efficacy and health behaviour (Berkman et al, 2004). An alternative or adjunct to providing written information during consultations could include signposting patients to valid sources of online information. According to the Picker Institute (Swain et al, 2007) health professionals rarely do this and patients have been left struggling to identify valid and reliable information that is relevant to them.

3.5.5 Patient involvement

Socioeconomic deprivation is an independent predictor of adverse outcomes in heart failure. There is also evidence that this may be the case in specific treatments offered to patients. For example, previous studies have reported patients from poorer socioeconomic backgrounds having fewer indicated cardiac interventions (Bernheim et al, 2007). In contrast, researchers reported that in England the medication management of heart failure patients was found to be independent of socioeconomic status (Hawkins et al, 2012). Raine and colleagues (2014) tested these findings and reported that patients living in lower socioeconomic regions were less likely to receive the treatment recommended by the MDT. This was found to be independent of whether the patient preferences or comorbidity had been discussed. Having patients more involved in the decision-making process may reduce the effects of inequalities by assessing patients' needs, preferences and understanding of treatment.

NHS Trusts have a legal duty to promote patient involvement in decisions about their treatment and care management. This is a requirement of the Health and Social Care Act (2012) and a recently introduced pay-for-performance target (NHS, 2017). Professionals must address patients personal concerns so to adopt a patient-focused approach to decision-making. But a key barrier to this personalisation of care is that many healthcare services are standardised making it difficult to tailor care provision. To meet health policy demands increased involvement of patients is needed throughout the care pathway. A new proposal is the involvement of patients and potentially their family members/carers in MDT discussions.

Some researchers argue that adequate consideration of patient views and preferences requires patients to be present at the MDT meeting. Others have raised concern that having to modify their language may hinder decision-making (Choy et al, 2007). Researchers have examined the effect of caregiver presence during MDT meetings. In an observational study by Wittenberg-Lyles et al (2010) hospice team meetings involving caregivers via video link (n=74) demonstrated better team outcomes compared to standard meetings (n=152). This included a 50% increase in the discussion of biopsychosocial issues and improved interdisciplinary collaboration.

There are obvious impracticalities of patients and relatives attending MDT meetings. These include potentially developing a stressful environment when there is disagreement between professionals and patients/relatives; time constraints; language; practical arrangements; costs; and the resources needed to include patients (Taylor, 2010). Importantly, not all patients want to be involved in decision-making or want to attend the MDT meeting. Choy et al (2007) reported education level being a key influential factor on whether patients chose to attend the MDT meetings. It cannot therefore be assumed that involvement of patients and relatives is the right approach for everyone.

Currently, there is no evidence-based framework that can be adopted by heart failure teams to support a more integrated approach between the MDT and patients. The evidence comes from observational studies with small sample sizes often reporting data collected from a single centre study. Further research is needed to explore patient and relatives' views towards MDT meetings and potential roles for involvement.

These findings are supported by the literature. In current practice MDT meetings vary widely across and within NHS Trusts. Although many have key structures in place (such as an allocated chairperson), the number of professionals and disciplines represented vary between teams. Although little difference was found between surgical and medical MDT meetings, the lack of involvement of patients and relatives was common.

3.6 Strengths and limitations

The aim of these analyses was to evaluate cardiology and cardiothoracic MDT treatment decision-making processes in NHS Trusts across London. Due to low response rates data on nine MDT meetings were returned. Sampling relied on snowball recruitment through direct contact with clinical leads at other London Trusts. Often in these cases the clinical leads delegated data collection to junior doctors or administration staff and due to busy workloads, it was challenging to follow-up and contact these staff. There was also variance in the professional discipline of the member of staff completing the proforma. This may have led to bias particularly, with different staff describing different responsibilities and roles in the MDT meeting.

Data was collected from meetings from various institutions and settings which was useful to create a broad view of specialist's MDT meeting structures and processes. However, with small numbers the findings are not transferrable to other clinical settings. There was also limited representation from Greater London NHS Trusts likely to serve different patient populations compared to inner city, specialist referral centres. More information on the processes of each MDT may have been useful. With a limited timeframe for completion, sections on the proforma for additional comments were removed and analysis remained quantitative.

3.7 Conclusion of chapter

MDT meetings aim to improve the coordination, communication and the quality of decision-making through interdisciplinary collaboration. There is evidence that decisions made in MDT meetings are more likely to adhere to clinical guidelines. Yet it is important for professionals to challenge this guidance and accept that not all recommendations are suitable for every patient. Clinical acumen, pooled expert opinion and active input from a mixture of professional disciplines will likely support the holistic presentation of the patient. However, there is no current guidance for the process of decision-making made by MDTs.

These data provide important insight in to the current practice of MDT decision-making in cardiology and cardiothoracic meetings across London. A larger study is needed to test these findings with more sites across a wider geographical region.

On this background, a mixed-methods study was designed to further explore the factors that influence treatment decisions in practice. A holistic exploration of the views of key stakeholders involved in decision-making and decision implementation helped to identify the barriers and facilitators to a SDM approach. The following chapter details the methods used to undertake this exploratory study.

CHAPTER 4: METHODS

4.1 Introduction

This chapter details the processes of data collection and analysis used to answer the primary aims of this thesis: To explore how patients make decisions about their heart failure management; and the contextual influences on the views of patients, their families and healthcare professionals on the use of novel medical therapies and personalised medicine in heart failure. A multi-methods approach was used to examine the different facets of decision-making in heart failure. This involved a two-phase mixed-methods study design (*Figure 4.1*). The study was conducted in two parts. Strand I) a qualitative interview study that generated data about the views and experiences of patients, their family members and health professionals. Strand II) a Delphi consensus survey used as the quantitative validation arm of the study. This chapter will start by describing the study design and methods used in Strand I. It will then report the steps taken to formulate and conduct Strand II of this thesis.

4.2 Strand I: A Qualitative Interview Study

Strand I was a qualitative study that used semi-structured interviews of patients with heart failure, their family members and health professionals, to explore the factors that influence patient's treatment decisions. Interview data were collected and analysed using an iterative approach according to the principles of thematic analysis and constant comparison methodology (Glaser & Strauss, 1967). This involved a combination of deductive and inductive approaches to data analysis determined by the study aims and interpretations of the raw data. Categories were developed from the raw data into a framework that consisted of key themes that encompassed the main findings of the study.

4.2.1 Study design

Consecutive, one-to-one, semi-structured interviews were undertaken by the researcher with patients, their family members and health professionals. Interviews were audio recorded and guided by a topic guide, informed by the review of the literature. The interview topic guide was used to explore participants views towards novel therapies (such as gene therapy), treatment decision-making and personalised medicine in heart failure management. Interviews were conducted consecutively in blocks of 3 to 6 participants. This was followed by a period of data analysis and review/revision of the interview topic guide. The topic guide was fluid and evolved throughout the data collection and analysis process. Data from the interviews informed the enquiry in subsequent interviews, enabling new avenues of thought to be explored and to test the findings across the different cohorts. The primary focus on decision-making was maintained throughout data collection. This enabled the collection of rich data and the identification of the barriers and facilitators to decision-making in heart failure management. The interviews were transcribed verbatim and data were analysed using the principles of thematic analysis (Glaser and Strauss, 1967).

Analysis was assisted using the non-numerical data management programme (NVivo V12). The emergent themes described key factors that influenced patient's treatment and management decisions and their behaviours.

4.2.2 Study population

Participants from three cohorts were recruited to this study: patients, family members and health professionals. Participants were selected based on the following criteria:

Inclusion criteria:

Patients:

1. Aged 18 years and over
2. Patients who had received a diagnosis of heart failure with reduced ejection fraction (signs and symptoms of HF and LVEF <40% (ESC, 2016)
3. NYHA functional class II, III or IV (*Table 4.1*; Dolgin et al, 1994)

Family members:

1. Aged 18 years and over
2. Family members of patients who had received a diagnosis of heart failure with reduced ejection fraction and LVEF < 40% and NYHA functional class II, III, or IV

Health care professionals:

1. Healthcare professionals involved in the care, management and referral of patients with heart failure with reduced ejection fraction.

Exclusion criteria:

1. Individuals who lack capacity to consent
2. Non-English speaking (sufficient to not be able to take part in the interview)

Figure 4. 1 Study flow chart: Strand I and II

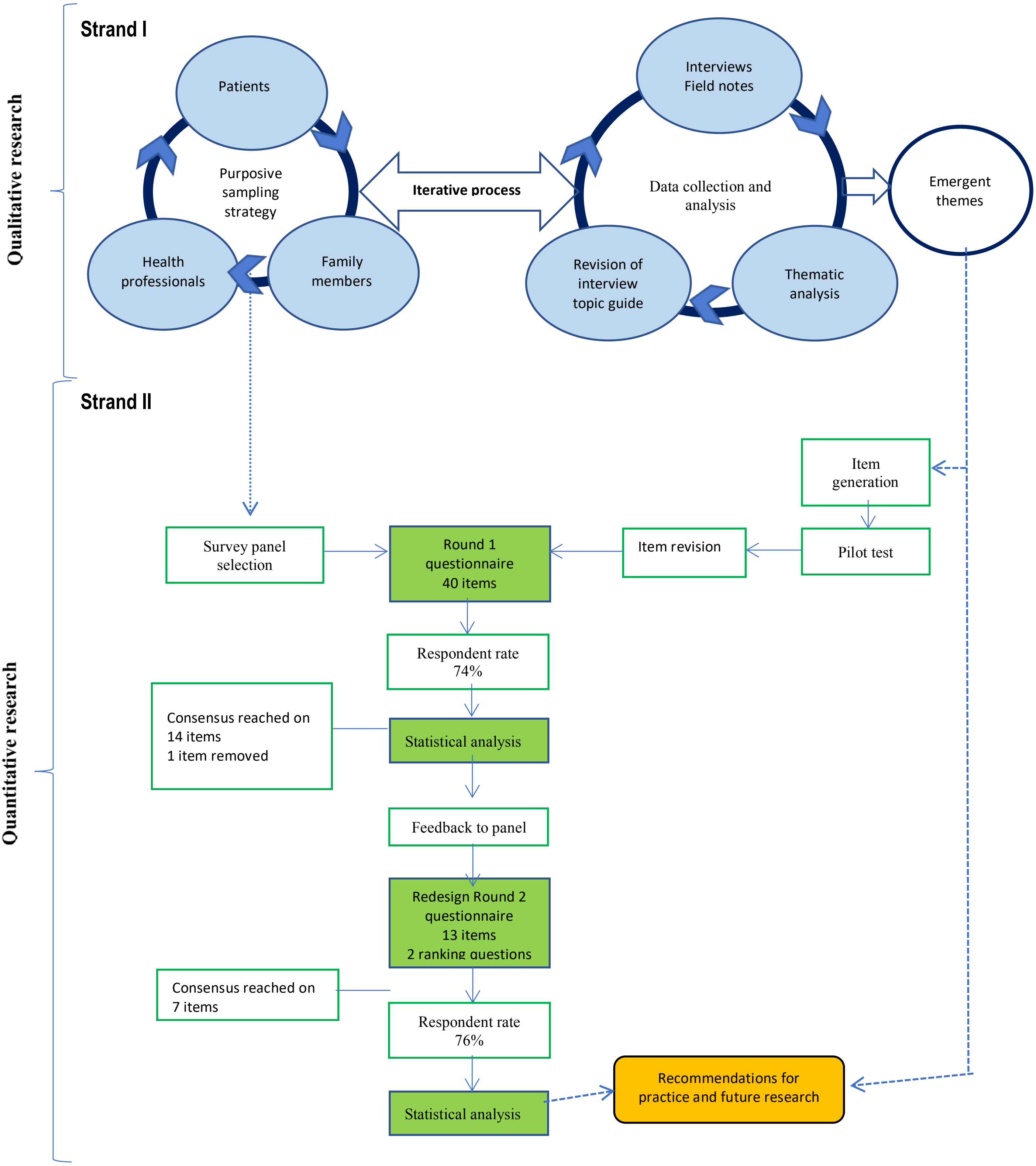


Table 4. 1 New York Heart Association Classification

Functional Capacity	
Class I	Patients with cardiac disease but without limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dyspnoea, or angina pain.
Class II	Patients with cardiac disease resulting in slight limitation of physical activity. Comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnoea, or angina pain.
Class III	Patients with cardiac disease resulting in marked limitation of physical activity. Comfortable at rest. Less than ordinary activity causes fatigue, palpitation, or dyspnoea, or angina pain
Class IV	Patients with cardiac disease resulting in inability to carry on any physical activity without discomfort. Symptoms of heart failure or the angina syndrome may be present even at rest. If any physical activity is undertaken, discomfort is increased.

Source: Dolgin M, Fox C, Gorlin R et al. (1994) New York Heart Association. Criteria committee. Nomenclature and criteria for diagnosis of diseases of the heart and great vessels 9th ed. Boston: MA. Lippincott Williams and Wilkins.

4.2.3 Study setting

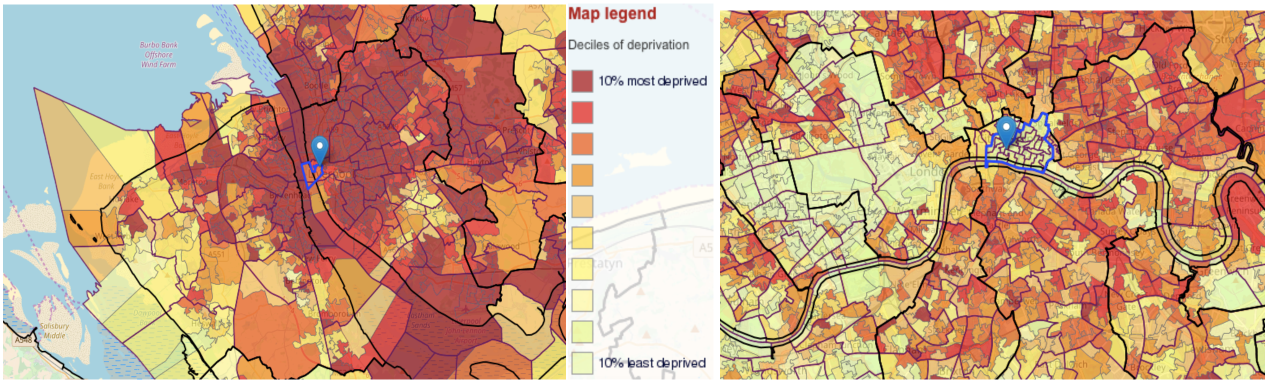
Participants were recruited from two UK specialist NHS hospital Trusts. The Royal Brompton and Harefield NHS Trust (RBHT) which comprises two hospitals: Harefield hospital situated in Middlesex and the Royal Brompton hospital situated in central London. RBHT is the largest specialist heart and lung tertiary centre in the UK. It provides specialist care and treatment to patients with complex cardiac conditions from across the Country and manages over 340 hospital admissions for heart failure a year (NICOR, 2018). The second Trust, Liverpool Heart and Chest Hospital NHS Foundation Trust (LHCH) is a single centre hospital based on the outskirts of Liverpool city centre. LHCH is a specialist hospital serving a wide geographic population of 2.8 million, extending across North West England, North Wales to the Isle of Man. These Trusts serve different geographic and socio-demographic populations (*Figures 4.2 and 4.3*) and were selected to recruit a maximum variation sample.

Figure 4. 2 Comparison of regional population demographics

Population	**Location**	
	London	**Liverpool**
Index of Multiple Deprivation (2015)	5.7%	31.3%
Identified as religious	71%	76%
Christian	48%	67%
Muslim	12%	5%
Other	10%	2%
Ethnicity:		
White	59.8%	88.9%
Asian/Asian British	18.5%	4.2%
Black/African/Caribbean/Black British	13.3%	2.6%
Employed	75.9%	68.1%

Source: National Statistics (2015) The English Indices of Deprivation Statistical Release. Department of Communities and Local Government

Figure 4. 3 Comparison of regional health deprivation



Liverpool **London**

Source: http://dclgapps.communities.gov.uk/imd/idmap.html (2015) London data store

4.2.4 Sampling strategy

Purposive sampling took place between June 2015 and December 2016. Sample size was guided by data saturation. The initial target for sample size was 60 participants: 20 patients, 20 family members and 20 health professionals**.** Participants were purposively selected to generate a heterogeneous sample**.** This allowed exploration of the effects of different variables (patient characteristics, socio-demographics) on how patients made health decisions. The process involved selecting participants based on specific variables identified in the literature as influencing health decisions. Patients and their family members were selected based on: 1) demographics: age, gender, ethnicity, education level, social circumstance; 2) disease characteristics: symptom severity, time since diagnosis. Health professionals were selected based on: age, gender, professional discipline and clinical expertise.

The researcher purposively selected 3 to 6 participants at a time, conducted consecutive interviews and then analysed the data. The findings of these interviews informed purposive selection of subsequent participants. Data were tested by selecting participants based on variables identified as potential factors influencing health decisions. This method supported the process of data saturation, where no new themes emerged from the addition of new variables.

4.2.5 Recruitment

a) Patient cohort

The outpatient clinic lists at each hospital were pre-screened to identify patients who met the study eligibility criteria. Following identification of potentially eligible patients, the researcher approached the individuals in the hospital outpatient department. Patients were invited to participate and given a verbal explanation of the study, its purpose and commitments. Patients who confirmed interest were given a patient information sheet that outlined the study rationale, interview process, ethical approvals and data protection/confidentiality. If they agreed to take part, then patients were asked to provide their contact details. The researcher then arranged an appropriate time to conduct the interview. Informed consent was obtained prior to interview.

b) Family member cohort

Family members who met the eligibility criteria were identified and approached in the hospital outpatient department. Family members were invited to participate and given a verbal explanation of the study, its purpose and commitments. Family members who confirmed interest were given a participant information sheet that outlined the study rationale, the interview process, ethical approvals and data protection/confidentiality. Patients were also invited to nominate family members who were not present at the clinic appointment. These family members were contacted and given further information about the study. If they agreed to participate, an appropriate time to conduct the interview was arranged. Informed consent was obtained prior to participation.

c) Health professional cohort

Health professionals who met the study eligibility criteria were identified and recruited from each participating Trust. Staff were identified as members of the clinical and/or research teams. Health professionals were asked to nominate eligible colleagues who may be interested in participating. They were approached in-person in the department or by email invitation and provided with a participant information sheet. Those who agreed to take part were contacted to arrange an appropriate time to be interviewed. Informed consent was obtained prior to interview.

4.2.6 Data collection and analysis

Interviews of patients and family members were conducted in their homes with only the researcher and interviewee present, unless they requested otherwise. Interviews of health professionals took place at the hospital site in a quiet room away from staff and patients in a neutral environment. Patients were offered short breaks during the interview and time to recover or stop the interview if they became symptomatic. All interviews were conducted in-person by the researcher and recorded with a digital voice recorder. Each interview lasted approximately 45 minutes (range 20 to 90 minutes).

The researcher started by interviewing patient participants. Interviews were conducted sequentially (groups of 3 to 6) to elicit key lines of enquiry. This was followed by a period of interview transcription, thematic analysis and review of the interview topic guide. The emergent findings from the patient interviews provided a framework for the interview guides and lines of enquiry for the family member and health professional interviews. A semi-structured framework was used with the same key questions and major lines of enquiry for each interview. Flexibility was maintained to alter the order and use of probes to elicit more information. Those who were interviewed as well as their family members were reassured that what they discussed would remain confidential and not divulged to their relative.

Following transcription each interview was read several times and the audio recordings were listened to so to validate each transcript. For each interview verbal signs including tone, inflections, pauses and use of humour were recorded to prevent misinterpretation. The trustworthiness of findings was assessed by participant feedback whereby participants were contacted for follow-up clarification when the researcher identified ambiguity in the meaning of their data (Creswell and Clark, 2011).

The transcripts were entered in to a non-numerical data management programme NVivo V10 and V11 that was used to manage the data (QSR International Inc.). Thematic analysis involved line-by-line review of each transcript to identify comments, words or phrases that the researcher interpreted as relevant to decision-making in heart failure management. General categories were derived from the research aims and specific categories derived from in vivo coding of the raw data.

Sections of text and phrases were given a code and sections with similar content were grouped together in the same code. Some sections of text were placed in to more than one code depending on their content. New codes were created as new content emerged in the data. The codes focused on the similarities and differences within the data and between transcripts to identify recurrent categories. Codes were grouped into categories and finally combined into themes. Data from each interview was coded and constantly compared with previous interviews within each cohort. Text that was not coded was found to be unrelated to the study aims. Relationships between codes were identified and recorded in memos (a research diary) and used to synthesise the data. This included associations and links to other codes. This formed a coding framework and development of the categories. Methodological rigor was maintained by two approaches. Firstly, codes were generated inductively from the data. This involved searching for patterns in the data (direct quotations) and underlying meaning. This approach reduced analytical bias and improved construct and criterion validity by using participant's own words. This was followed by a deductive approach where the researcher (SW) used the coding framework to identify meaningful data.

Each category was refined by identifying similarities and differences in participants' views. The 18 categories that emerged were reduced to 12 categories by merging smaller categories with similar meaning. The outcome was the emergence of summary categories which reflected the key themes in the raw data *(Table 4.2).*

Table 4. 2 Extract from coding framework

Raw data	Code	Category
"Any letter that I get…she'll (mother) just look at it and read it, then I'll find her Googling about it about ten minutes later" Patient	Health-seeking internet use	Health information sourcing
"I'll take a consultant's word for it. I mean who am I to say yay or nay…" Patient	Clinician-led approach	Treatment discussions
"I think doctors don't have so much training in talking to people openly about things because they want to fix them.." Clinical nurse specialist	Communication style	

A qualitative approach to validity and reliability was taken, whereby a proportion of transcripts were analysed by a second researcher, Dr. Jillian Riley (JR). Both researchers discussed any identified discrepancies. Codes and emerging categories were co-coded, and a coding framework was agreed upon and refined until both researchers (SW and JR) were satisfied it represented the data. When new codes emerged from the data the coding framework was revised. This process was used to conceptualise categories in to broad themes. Participant characteristics and demographic data were collected to support analysis (*Table 4.3*).

Table 4. 3 Data collected from participants

Demographics	Patients	Family members	Health professionals
Age	√	√	√
Gender	√	√	√
Ethnicity	√	√	√
Characteristics	NYHA class Time since diagnosis (years) Lives alone Education background	Relative with HF Relative's NYHA class Time since diagnosis (years) Education background	Professional role title Time in current role (years) Speciality/areas of interest Time spent in clinic (days/week)
Electronic devices owned	√	√	√

4.2.7 Interview topic guide

An individualised interview topic guide was developed for each cohort and provided a framework for exploring similar themes in each interview. The topic guide was used to direct the interview and participants were asked to go into more detail on each topic, using specific prompts to guide new lines of questioning when necessary. A funnelling pattern of questioning was followed. This involved asking broad open questions then moving to narrower topics with probing to elicit further details.

The content for each topic guide was informed by a review of the literature and the pilot study data. Each guide comprised a set of key areas of enquiry to address the study aims. For patients and family members this included: knowledge and understanding of heart failure and its management; health beliefs and behaviours; views towards novel treatments, management strategies and clinical research; sources of support for decision-making. For health professionals, this included: views and experiences of heart failure management; challenges in decision-making; role of the patient and family member; views towards clinical research and novel therapies.

Interviews commenced with a broad open question to establish a context for the participant's responses. For patients and family members, the opening question explored their knowledge and understanding of heart failure, *"Could you tell me a little bit about your/your relative's heart condition?"* For health professionals, the opening question explored their experience in heart failure management, *"Could you tell me a little bit about your role and the types of patients you care for?"* Participants were encouraged to speak freely throughout the interview and reassured that there were no right or wrong answers. Participants were encouraged at the end of the interview to ask questions or raise any issues or thoughts they might have had. This provided opportunity for participants to raise issues that they had thought about but not directly raised by the researcher. This led to the discovery of new information and lines of inquiry.

4.2.8 Pilot interviews

Topic guides were piloted by conducting interviews with three participants from each cohort. This involved conducting sequential interviews, a period of transcription, followed by data analysis. Interview topic guides were then revised according to the quality of data collected.

One of the key issues that was raised during the pilot interviews was the volume of data collected that did not relate to the study inquiry. This data consisted of participant descriptions of topics outside the remit of the study aims. These topic areas were raised by the researcher in subsequent pilot interviews to test whether further probing may unearth new avenues of enquiry. It was concluded (by researchers, SW and JR) to add probes to the broad questions to help redirect participants back to the key topic areas and promote the collection of meaningful data. Probes were added for each question to keep the line of enquiry focussed but to allow for flexibility to follow new avenues if necessary. To support this process the interviewer asked participants to provide examples of their experiences. These data gave richer meaning to participant's descriptions and provided an important context for their health beliefs and behaviours.

The development and revision of the interview topic guide was supported by feedback from each Trust's Patient and Public advisory group.

4.2.9 Observational field notes

The process of triangulation was used to support the reliability and validity of data collection and analysis (O'Cathain et al, 2010). This involved pooling information from different data sets to gain a more comprehensive understanding of the phenomenon and ensure the data were consistent. These methods included the qualitative interview transcripts, second research co-coding and the collection of observational field notes.

The field notes documented by the researcher recorded the researcher's influence on the research process and on the construction of data. Following each interview, the researcher documented observations and memos in the form of a research diary. This included the researcher's initial thoughts about the context of each interview; observations of participant's appearance, gestures, home environment, presence of and interaction with family members.

Field note extracts:

Female patient aged 57 years

"The patient was interviewed in her own home. The home was very clean, tidy, everything was ordered (had its own place). There were multiple (15 plus) large photos on display in the living room – on the wall and on the cabinets. These were of her sons and their family, their wedding photos and her grandchildren. She also had 3 large framed pictures in the middle of her living room of her and her husband's wedding day. One was a very glamourous photo of the patient. These were placed in a central position – suggesting highly valued by the patient as her husband had died around 10 years ago at a young age. The patient showed me her balcony which overlooked the sea. She described sitting in the sun and enjoying chats with friends outside – this was very important to her and her quality of life. The patient's home environment and mannerisms suggest that she is a very proud lady, who likes to keep things ordered maintaining a sense of control. Importantly and to provide a social context for her views and experiences, she has a large family support network and socialises regularly with friends."

Male patient aged 46 years

"Patient lives in a hostel and chose to have the interview at the hospital. He had recently attended an outpatient clinic where he talked to the HF nurse about transplantation, medication, life-style changes and potential DCCV/ablations. The gentleman talked about his suicide attempt last year and said he is not depressed now, although low in mood at times, but now talking to people and his friends are aware. The interview took place in one of the consultation rooms. I chose a room that was quiet and away from the main reception desk and other rooms in use. Chairs were placed at a 45-degree angle to promote an equal relationship between the patient and the interviewer and away from the desk, to encourage the patient to talk openly and not be influenced by previous experiences of clinical consultations."

Prior to data analysis the researcher reflected on these observations and explored personal assumptions. These assumptions were set aside 'bracketed' (Fischer, 2009) so the researcher could pursue a fresh perspective when analysing and interpreting the data.

4.3 Ethical considerations

4.3.1 Ethical approval

This study was approved by the Yorkshire & The Humber, Leeds East Research Ethics Committee (REC) on 30th April 2014 (REC reference: 14/YH/0151). Local Research and development office approval was gained from both Trusts prior to study initiation. The study was conducted in accordance with the Declaration of Helsinki. The researcher worked within the boundaries of her professional framework, adhering to the Nursing and Midwifery

Council (NMC) code of professional conduct and the principles and values of each NHS Trust. *(REC approval letter available in Appendix 4.1; NHS permissions available in Appendix 4.2, 4.3).*

4.3.2 Informed consent

Informed consent was obtained from each participant prior to interview. Participants were provided with a participant information sheet in person, by email or by post. Participant information sheets and consent forms were written in English in language intended for the lay public. The information sheet provided clarification of the purpose of the study, the aims and objectives, participants' commitments, confidentiality and details of how participant's data will be used. Each person was given time to review the information and there was no upper time limit for consideration of study entry. Contact details of the researcher were included on the information sheet to give participants an opportunity to ask any questions they might have. The information sheet was also explained verbally in-person, prior to obtaining consent.

Process consent was used by the researcher to reaffirm consent throughout the interview. The researcher asked questions such as, "Are you happy to tell me a little more about that?" It was made clear that the study was voluntary and if individuals changed their mind they could leave the study at any time without giving any reason. Informed consent was obtained by the interviewer. The researcher was appropriately qualified and had completed informed consent training and Good Clinical Practice training.

4.3.3 Research burden

To reduce the burden of participation, the study participants were reassured there were no right or wrong answers and offered short breaks or discontinuation if they became tired or breathless. Some of the interviews raised sensitive issues that at times made the interviewee emotional. The researcher intuitively determined whether to interrupt or stop an interview if required. Participants were advised on how to access their appropriate Trust's Patient Advice and Liaison service (PALs) if they had any concerns.

4.3.4. Privacy

Participant's privacy was maintained by conducting one-to-one interviews in a private setting and contacting participant's individually for follow-up clarification. Pseudonyms were used when reporting quotations from the interviews.

4.3.5 Nurse-researcher relationship

To minimise potential conflict raised by the dual-role relationship, the researcher disclosed her professional background prior to interview and outlined her primary role as research-related where therapeutic communication would be sought from the patient's clinical team.

4.3.6 Safety

When interviews were conducted in participant's homes then the researcher adhered to the lone worker policy (RBHT, 2018). This involved a buddy system where a designated colleague at the hospital was provided with details of each interview in advance and real-time feedback of progress. This included participant's details, address, time and date of interview (estimated time of arrival and departure); actual time of arrival and departure. A risk assessment was completed in advanced and approved by the department manager. Regular contact was made between the researcher and the appointed colleague whilst collecting data in the field.

4.4 STRAND I Summary

In Strand I of this study the researcher conducted an in-depth qualitative exploration of the views and experiences of patients, their family members and health professionals of treatment decision-making in heart failure management. Thematic analysis of these data highlighted important factors that influenced patient's treatment and disease management decisions. The sourcing of health information emerged as a key theme from these data. To extend these findings a second phase of this thesis was developed as the quantitative validation arm of the study. Data from Strand I was used to design and develop a Delphi consensus survey. Strand II involved the exploration of the similarities and differences in views between cohorts towards the provision of health information in heart failure.

4.5 STRAND II: Delphi Consensus Survey

The Delphi process was used to gain consensus across the three cohorts on the main factors (priorities) for consideration when tailoring treatment discussions in heart failure management. The survey process was guided by three principles: the discovery of similarities and differences in opinions; the process of determining the most important issues; and managing opinions.

To maintain transparency and increase usability a framework for reporting the Delphi survey was used. This combined survey reporting checklists (Bennet et al, 2011) and guidance for internet survey reporting (Eysenbach, 2012). The objectives of the Delphi survey were:

4.5.1 Objectives

1. To explore the views of patients, family members and health professionals towards the provision of health information in heart failure management.
2. To identify the barriers and facilitators to health information provision in heart failure management
3. To gain group consensus that will inform practice recommendations to improve the tailoring of treatment discussions and information provision in heart failure management.

4.5.2 Recruitment

Participants were recruited from the two sites at the London NHS Trust selected in Strand I: The Royal Brompton hospital and Harefield hospital sites. Recruitment took place between October 2017 and February 2018.

Inclusion criteria:

Patients:

1. Aged 18 years and over
2. Patients who had received a confirmed diagnosis of heart failure with reduced ejection fraction and LVEF ≤ 40% (*Table 1*; ESC, 2016)
3. NYHA functional class II, III or IV (*Table 4.1*; Dolgin et al, 1994)

Family members:

1. Aged 18 years and over
2. Family members of patients who had received a confirmed diagnosis of heart failure with reduced ejection fraction and LVEF < 40% and NYHA functional class II, III, or IV

Health care professionals:

1. Healthcare professionals involved in the care, management and referral of patients with heart failure with reduced ejection fraction.

Exclusion criteria:

1. Individuals who lack capacity to consent
2. Individuals who cannot access the internet to complete the online survey

To test the interview findings, purposive sampling was used to select participants and generate a sample representative of the sample selected in Strand I. To enhance the credibility of the Delphi outcomes it was important to reflect the full range of stakeholders who had an interest in the results of the study. Participants were selected based on socio-demographics, disease characteristics and professional discipline/clinical experience and together formed a diverse survey panel (*Table 4.6*).

Patients and family members

Potentially eligible patients and family members were identified and approached in the hospital outpatient department. Patients were invited to participate and given a verbal explanation of the survey, its purpose and commitments. Patients who confirmed interest were then given a participant information sheet that outlined the study rationale, Delphi process, ethical approvals and data protection/confidentiality. If they agreed to take part patients and relatives were offered the choice to complete the survey at that time using a tablet or receive an email with a link to the electronic survey. Contact details and an email address was collected for each participant.

Health professional cohort

Health professionals who met the study eligibility criteria were identified and recruited from each hospital site. Professionals were approached in-person or by email and provided with the participant information sheet outlining the purpose of the survey, ethical approvals, data protection/confidentiality, study commitments and the study outcomes. Those who agreed to take part were sent an introductory email with a link to the survey. Due to initial low level recruitment of health professionals, snow ball sampling was used to increase enrolment.

All participants who agreed to complete the Delphi survey were also invited to nominate relatives or colleagues who met the eligibility criteria. Participants were informed of how their information would be stored and that no identifiable information would be entered in to the electronic Delphi survey. It was emphasised to all participants that participation required completion of multiple rounds of questionnaires. This was necessary to clarify the level of commitment if they agreed to participate and increase response rates to subsequent rounds.

Table 4. 4 Survey panel selection

Sample selection and recruitment process		Outcome
Step 1	Identify the most appropriate stakeholder groups for the survey panel	Three identified – patients, relatives, health professionals
Step 2	Identify criterion for each stakeholder group based on demographics and characteristics	Reviewed sample of interviewee cohorts
Step 3	Identify eligible health professionals Identify eligible patients	Sent invitation with PIS through Trust email Pre-screened heart failure clinic lists
Step 4	Approach patients and their relatives in clinic	Invited to participate, provision of PIS
Step 5	Option offered to complete the Round 1 questionnaire via web-link or email Collect participant's contact details	Survey data entered manually on the electronic tablet onsite or email invitation sent
Step 6	Ask individuals to nominate other participants	Relatives and health professionals only

4.6 Ethical considerations

The Delphi consensus survey was approved by the Leeds East Yorkshire and The Humber REC committee on 4th October 2017. Health Research Authority (HRA) approval was awarded on the 6th October 2017. No changes to protocol recruitment method were submitted. Written consent was not a requirement. Informed consent was implied through participant response to the survey. The researcher explained the nature of the research, its purpose, commitments and the participants had the opportunity to deliberate. *(REC approval of substantial amendment available in Appendix 4.4; HRA approval confirmation available in Appendix 4.5).*

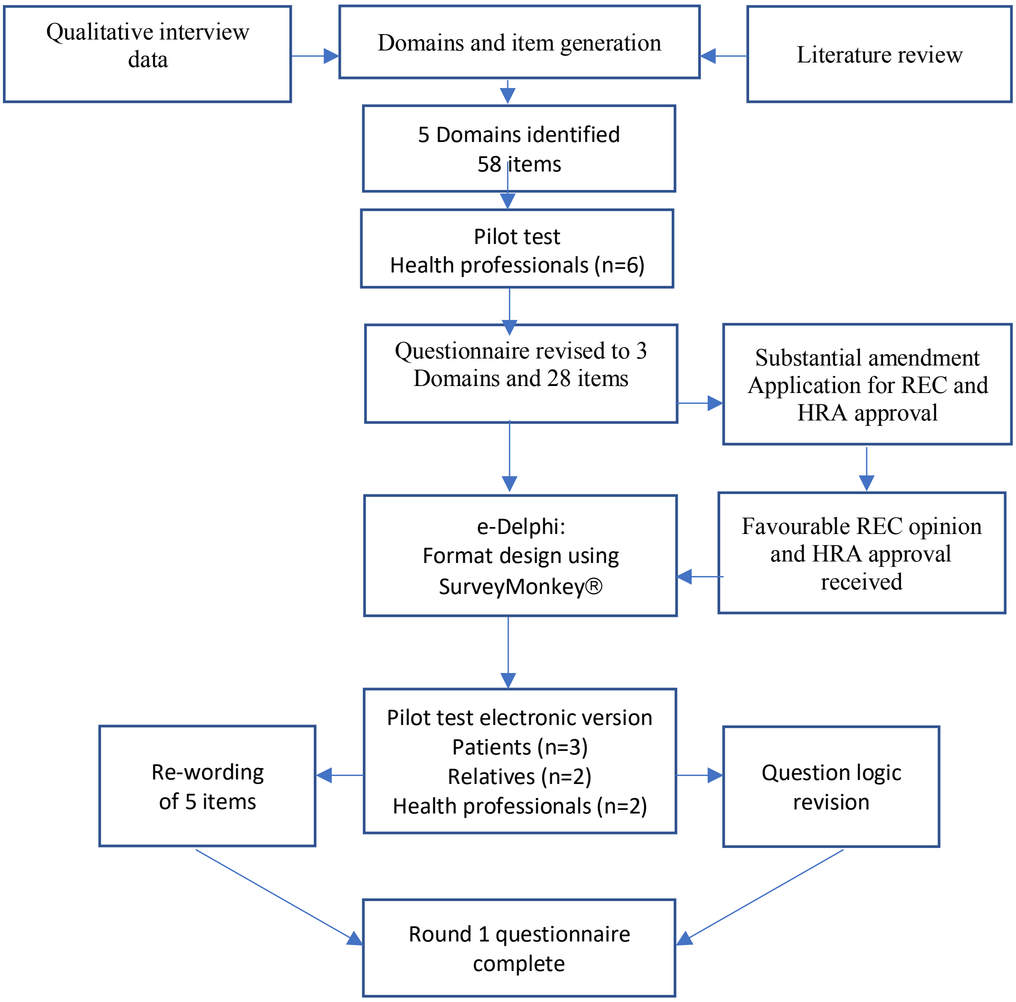
4.6.1 Data protection and confidentiality

The Delphi survey was designed and distributed using the survey software SurveyMonkey®. The survey used 'quasi-anonymity' where participants were known to the researcher, but their responses remained anonymous. The researcher had to know the identity of respondents to send non-respondents email reminders. Participants who agreed to join the Delphi panel provided their full name and email address to the researcher. This was used for identification of participants who completed the survey, circulation of the survey feedback and link to the Round 2 questionnaire.

4.7 Round 1 Questionnaire development

The questionnaire for Round 1 of the Delphi was developed in four phases: 1) item generation informed by a literature review and analysis of interview data (Strand I); 2) pilot test evaluated content validity of the questionnaire and reduced the number of items; 3) design of the electronic questionnaire; 4) preliminary cross-sectional pilot test to check design software *(Figure 4.4)*. The survey was conducted in English.

Figure 4. 4 Round 1 survey design and development



The primary aim of the Delphi was to test and extend the findings of the qualitative interview study in Strand I of this thesis. To do this, the Round 1 questionnaire was divided into three domains based on the themes that emerged from the interview data to ensure meaningful and relevant domains were used. Perspectives from each cohort were represented in the final questionnaire.

The survey title page included a definition of terms and instructions on how to complete the survey.
For the purposes of the survey 'health information' was defined as, 'all information related to heart failure and its management in verbal, paper or electronic form. This included information about heart failure diagnosis; prognosis; treatments; investigations; lifestyle advice; monitoring; identification of symptoms; self-management techniques.'
The instructions to participants included:

1. Please rate your level of agreement for each statement by putting an X in the box
2. We use a 5-point Likert scale for rating the statements from 'strongly agree' through to 'strongly disagree'
3. Please choose only one score on the scale for each statement
4. There are no right or wrong answers

Data were collected on participant demographics and patient characteristics. Data collected were based on the variables associated with health information provision and preference from the literature. Demographics and patient characteristics questions required selection from multiple choice options. Additional data on the type of electronic devices owned by participants was collected. The survey was voluntary with no financial incentives. It was only open to the panel which the investigator knew.

4.7.1 Item generation

The Round 1 questionnaire was divided in to four domains: value of information; information need; involvement in decision-making. Each domain comprised a list of statements (items). Domains were developed from the key areas within the 'health information sourcing' theme that demonstrated disparity in views between cohorts. The qualitative data was used to identify areas that were important to each cohort and determine the scope of each domain.

Each statement was designed to present a key finding/viewpoint of one of the cohorts reported in the qualitative data. The statements reflected some of the barriers and facilitators to health information provision raised by each cohort. This included: patients and relatives' behaviours and preferences towards health information provision; and health professionals' opinions of patients and relatives' motivations and behaviours. Each statement posed a question to the Delphi panel asking for their level of agreement with a view or preference of 'patients' or 'patients and relatives' towards health information or treatment discussions. This format enabled the testing of the qualitative data and the identification of key disparities between each cohort. Some items were formatted as negative statements to support testing. A technique that has proved useful in maintaining participant engagement and attention.

Statements were then placed into a traditional survey format. Participants were asked to rank each item on a five-point Likert scale (strongly agree to strongly disagree). A 'don't know' option was not included to promote the collection of relevant data and encourage group consensus. Content validity was addressed through pilot testing and identifying statements that each cohort considered relevant and important. The definition of 'health information' was included on the survey cover page to ensure clarification across cohorts. The final questionnaire contained questions on health information sources; health information need; provision of health information in practice; and patient involvement in decision-making.

4.7.2 Pilot testing

Pilot testing of the survey was necessary to maintain reliability and validity. Pilot testing was performed at integral stages of survey design: following item generation, following electronic formatting and design using SurveyMonkey® software. Pilot testing was conducted with a small group of six participants who met the eligibility criteria. Participants from the pilot sample were excluded from participation in the Delphi survey to mitigate response bias.

Refinement of statements, wording and format changes occurred over two iterative cycles before Round 1 was distributed to the Delphi survey panel. The reviewers assessed clarity of the questions, relevance of the statements, importance of the topic and ease of interpretation. Following feedback, the pilot questionnaire was revised and reduced in length to minimise time burden. All questions and statements were examined by the research team to ensure readability and face validity prior to administration.

4.7.3 E-Delphi

Round 1 of the electronic survey addressed 40 individual items over 5 pages. The SurveyMonkey® platform was used to perform ‘completeness checks’ prior to survey submission. This enabled the collection of complete data with the ability to use response required options and a ‘completeness check.’ Mandatory items were highlighted to participants and response required options were used to force participants to choose a response before they could move to the next page. To minimise entry errors the survey was designed so respondents could review and change their answers before final submission. The logic question function was used to reduce the number of questions and respondent fatigue. This allowed participants to be automatically directed to the demographic questions relevant to their cohort. Once participants answered the initial screening question, ‘Which of the following best describes you? I am a patient, I am a relative, I am a health professional,’ patients were directed to the relevant survey page.

Only panel members who completed the Round 1 questionnaire were sent the Round 2 version, which was administered using the same methods.

4.7.4 Reliability and validity

The Delphi survey process was exposed to both researcher and subject bias. The researcher followed measures to maintain the reliability and validity of the method: attention was paid to the phrasing of the statements and items designed to reflect thoughtful responses rather than emotional. The design and language used supported completion by participants with low literacy skills and the five point Likert scale with some reversed scored statements encouraged deliberation by the participant.

Content validity was increased by purposively selecting participants who had experienced treatment decision-making and to whom changes to practice would directly impact. Each individual survey item was assessed to ensure the key avenues of enquiry that emerged from interview data were present. This included review of the clinical meaningfulness and relevance of items to treatment decision-making in practice. Statements on topics shown in the literature to be viewed differently by patients, family members and health professionals were included. Demographic factors known to be influential to patient's decision-making were collected. The ability of the survey to identify the between group differences for each questionnaire statement (concurrent validity) was addressed by assessing opinions on the questionnaire items where patients had shown to differ: by age, health status, symptom burden. Responses for each item were compared between the three cohorts: patients, family members and health professionals.

For verification of data entry information specific data was collected from participants. This included IP and email address, data automatically generated following participant access of the web-based survey. This was used to track survey responses using email and web link origin. Data that was passively generated by participants as they responded to the survey questionnaires included length of time needed for survey completion, data and hour survey submitted.

4.8 Data collection and analysis

4.8.1 Level of consensus

The level for reaching consensus for this Delphi survey was set at ≥ 65% of the participants selecting the responses (strongly agree/agree or strongly disagree/disagree). This was agreed following adjustment for a mixed cohort panel. When a statement reached consensus the remaining 35% of responses were assessed for distribution across the remaining categories. When these were evenly distributed the definition of consensus was accepted. When >20% of the remaining responses were clustered in one response category only, consensus was not achieved and was further explored in Round 2 of the survey.

For each statement the level of consensus was examined for all participants as a group and by cohort (patients, family members, health professionals). Comparisons between cohorts were proportionate to response rates of each cohort completing each round. Statements in Round 1 where responses as a group reached consensus but the difference between subgroups for consensus was more than 20%, were explored in Round 2.

4.8.2 Statistical analysis of Round 1

Quantitative data from the survey were entered to SPSS Statistics for analysis. Response rates and respondent characteristics were assessed using data on the entire sample. The statistical tests used for non-parametric data analysis were percentage of agreement (PA) for nominal data, medians and IQR for continuous variables and the number (%) for categorical variables. Descriptive statistics including the mean, standard deviation, frequency and proportion were calculated to present the respondent's demographics and characteristics.

Variance in level of agreement was measured as the percentage of each cohort. The 20% cut-off for 'marked variance in agreement' was calculated as the difference between the subgroup responses to a category (proportion of each subgroup).

The Delphi survey was set up to require a response for each statement. The response rate was calculated by the ratio number of people who were approached to participate (in-person or via email invitation)/ the number that completed the questionnaire. This included those who partially completed the questionnaire.

Round 2 required the data from the responses to Round 1 to be summarised and fed back to the Delphi panel. Graphical representation of the results was used to provide participants with information about the group's collective opinion and their own response to individual statements.

4.8.3 Survey administration

The questionnaires were administered over two rounds to all panel members who agreed to participate. Two data collection avenues were created within the Surveymonkey platform. The first was an email invitation used to send the survey link to participants. Personalised emails were used for participants that had not received face-to-face invitation. Surveymonkey software enabled the tracking of email invitations by collecting data on recipient receipt. The initial screening question for the survey was embedded in the email invitation to maximise respondent rate and usability. When answered participants were directed to their relevant demographics page in the survey.

The second option for data collection was the use of a web link collector. These required participants to enter their responses manually into the survey using an electronic tablet (a single tablet was used belonging to the researcher). Participants whom were approached in the outpatient department were given the option to complete the survey using the online web link or the email invitation. Participants were encouraged not to discuss the Delphi survey with other participants. Informed consent was implied through completion of the survey.

Reminder emails were created and sent using the SurveyMonkey software to enhance response rates. Round 1 of the survey was administered to participants followed by a window of 1 month for their completion. Email reminders were sent at one week intervals with a maximum of four reminders per participant. Analysis of the responses to Round 1 was made over 8 weeks following completion of the final panel member. Non-responders were excluded from Round 2.

The results of Round 1 were analysed and fed back to participants accompanied by an electronic link to Round 2. Participants were encouraged to use the findings of Round 1 to inform their rankings/ratings to the statements in Round 2.

A title page outlining the purpose of the Delphi survey was provided at the start of the survey:
"Thank you for agreeing to complete this survey which is part of a student PhD study at Imperial College London. The purpose of this Delphi consensus survey is to explore the views of patients, family members and health professionals towards the provision of health information in heart failure management. The survey aims to gain group agreement on recommendations to improve the provision of health information in practice."

4.8.4 Individualised results feedback

Individualised feedback of the results of statements were emailed to each participant who completed Round 1. Feedback included a summary of the statements that the entire group agreed upon (reached consensus); and the remaining statements that reported 'marked variance' in responses between subgroups (>20% difference between groups in agreement/disagreement).

A standardised feedback format was created for all cohorts. For ease of interpretation across subgroups a series of column graphs (*Figure 4.5*) were used to present the distribution of the subgroup responses (patients, relatives, health professionals) to the statements that showed greatest variance in opinion. Each bar chart included indication of the participant's own response to that statement in Round 1. This provided a comparison of participants' own responses with that of the group and their individual subgroup. Participants were encouraged to review their own response considering the group response to inform their ratings/ranking of the statements in Round 2.

Individualised feedback reports included the following explanation to participants:

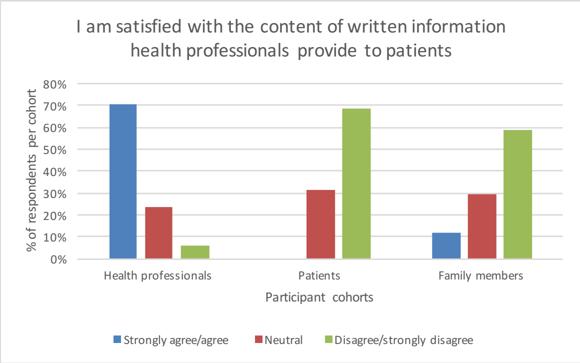
"Patients, family members and health professionals agreed on 14 of the 40 statements in the first questionnaire (Round 1). Of the remaining 26 statements, 15 showed marked variation in responses between the groups (more than 20% difference in agreement/disagreement). Your responses and those of the group to the remaining 26 statements were used to develop the second questionnaire (Round 2).

Figure 4. 5 Graphical representation of individualised feedback Round 1

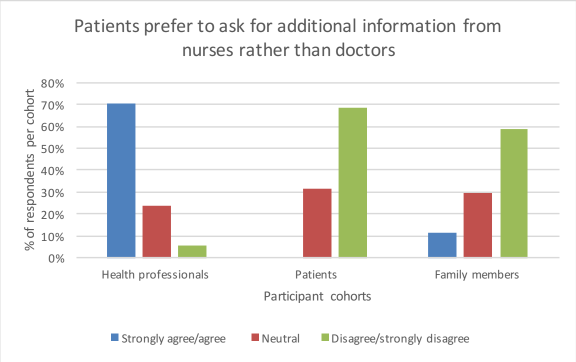
"To help you decide on your ratings in Round 2, we have displayed the results of the 15 statements which showed the greatest variation in agreement/disagreement between the groups. Your answer is presented below each graph, so you can see where your response fits within that of the group."

Domain 1a: Sources of health information

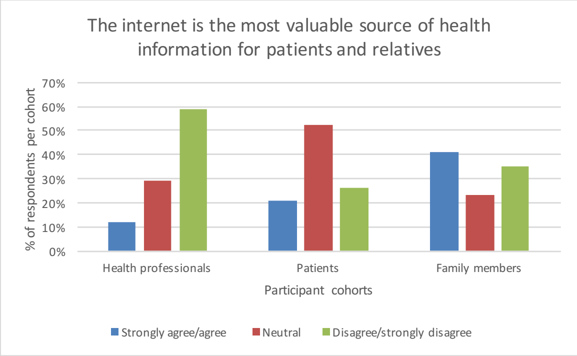
Please rate your level of agreement for the following statements:



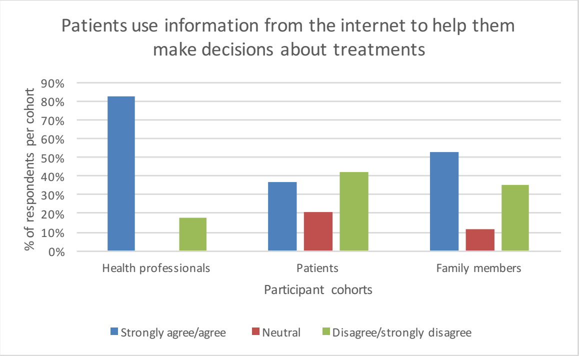
Q6. You answered:



Q4. You answered:



Q14. You answered:



Q15. You answered:

4.8.5 Round 2 questionnaire development

The results from Round 1 informed revision of the questionnaire in Round 2. Statements that reached group consensus highlighted areas of agreement about current health information provision. To minimise participant research burden, it was necessary to decrease the range of answers to reach group consensus. The questionnaire for Round 2 was reformatted in to a set of statements to be rated and ranked by the Delphi panel members. This was required to gain consensus among patients, relatives and health professionals on key components to be included in health professional's approach to information provision and treatment discussions in heart failure.

The statements that did not reach group consensus but demonstrated marked variance in agreement were retested in Round 2 of the Delphi process. The statements that demonstrated disagreement in the group were compared to those statements that reached consensus. To further explore areas of agreement and disagreement these statements were condensed in to items to be ranked in Round 2.

Two scales were used: 1) a 5-point Likert scale rating from 1= extremely important to 5=not at all important; 2) item ranking in order of importance, 1 = most important to 10 = least important. The new format consisted of 33 items within 3 domains: Health information sources; Treatment discussions; and Health information need. Participants were asked to rate or rank the statements considering their initial answers in the context of the group's response.

The questionnaire opened to a title page outlining the purpose of the second round and instructions on completion:

Instructions:

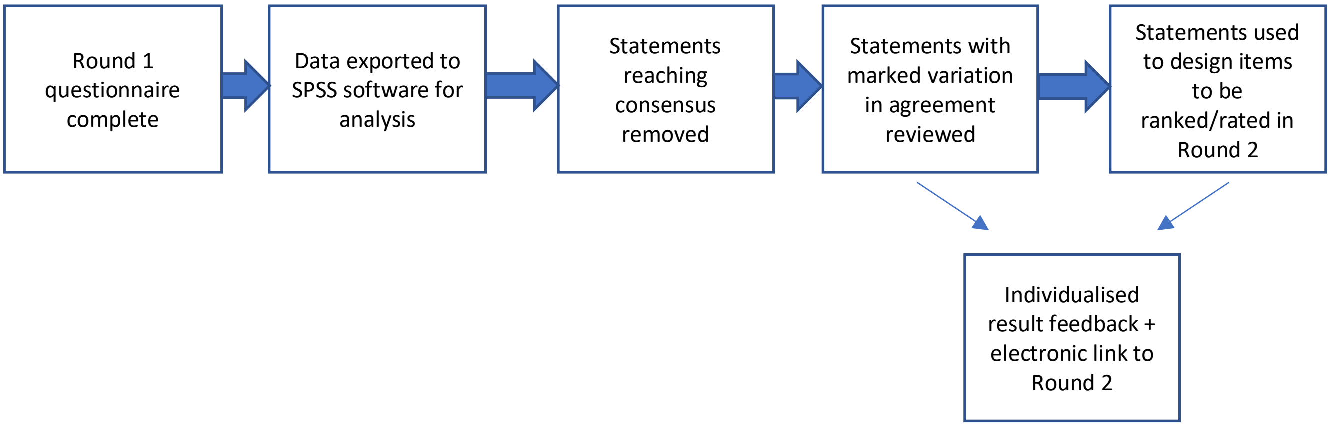
- *Question 1: please rate each statement from extremely important to not at all important*
- *Questions 2 and 3: please rank 10 items in order of importance*
- *1 = most important item, through to 10 = least important item*
- *Each item requires a different number*

Feedback:

Instructions were added based on feedback from three participants who stated that it was unclear how to rank the items in questions 2 and 3.

An additional screening question was added prior to the 3 Domains. Asking participants to select which group best describes them: patient, relative of a patient or health professional. This was to assist in data analysis phase so to collectively group cohort responses.

Figure 4. 6 Round 2 survey design and development



4.8.6 Distribution of Round 2

An invitation email was sent to all participants who completed Round 1. It was stated that the survey will only be open for two weeks. It was explained to participants that the second questionnaire was based on their individual responses and those of the group to the first Round. Individualised feedback forms for the results of Round 1 were sent as attachments to each participant invitation email. Weekly email reminders were sent to each participant who had not responded.

4.8.7 Statistical analysis of Round 2

Items rated on the 5-point Likert scale were assessed as reaching consensus using the same parameters as Round 1. For each item, descriptive statistics were used to identify variance in agreement and disagreement. The mean, median and proportion (%) were calculated for each item as a group and for each subgroup (patients/relatives/health professionals). Ranked scores were calculated using the median and IQR.

4.9 Conclusion of chapter

This chapter outlines the methods undertaken to collect, analyse and report both the qualitative and quantitative data in this mixed-methods thesis. It is important to note that with its mixed methodology design data collection and analysis was an iterative process, where qualitative findings informed quantitative exploration. The following chapter presents the results of these studies in accordance with the mixed methods framework that characterise this research paradigm (Creswell and Clark, 2011).

CHAPTER 5: RESULTS STRAND I: QUALITATIVE INTERVIEW STUDY

5.1 Introduction to chapter

This thesis used a mixed methods approach involving the collection of data sequentially using methods drawn from both qualitative and quantitative traditions. A qualitative exploration of the contextual influences on patients' treatment decisions and health behaviours was conducted to determine the applicability of a shared decision-making (SDM) approach in heart failure. By collecting data on the views and experiences of patients, their family members and health professionals, the barriers and facilitators to SDM were explored. These findings were then extended using the Delphi consensus method to identify priority areas for recommendations for practice and future research.

This chapter presents the qualitative findings of the interview study (Strand I). The chapter begins by reporting the sample characteristics of the interview study sample and an overview of the key themes that emerged from inductive thematic analysis. Each theme is presented with evidence of the raw data 'direct quotations' and comparison of data within and between each cohort.

The subsequent chapter (Chapter 6) presents the quantitative results of the Delphi consensus survey (Strand II). The panel member characteristics of the Delphi and the statistical analysis of its two rounds are reported.

5.2 STRAND I: Qualitative Interview Study

This section presents the findings of the qualitative interview study. The aims of the study were: to explore how patients make decisions about their heart failure management; and to explore the contextual influences on the views of patients, their family members and health professionals towards novel treatments and personalised medicine in heart failure.

5.2.1 Study sample

5.2.2 Recruitment

Participants were recruitment to the study and interviewed between March 2015 and December 2016. Participants were recruited from the Royal Brompton and Harefield NHS Foundation Trust (RBHT) (site 1) and Liverpool Heart and Chest Hospital NHS Trust (LHCH) (site 2). During this period participants attending the cardiology outpatient clinics were screened for eligibility. Purposive sampling was used to select individuals to be approached for study participation. Interviews took place in the homes of patients and family members 16 (57%) and at the hospital site 12 (43%). All interviews with health professionals took place at the hospital sites.

Forty-one participants signed a consent form and agreed to take part in the study. Of those approached 4 (15%) of patients and 5 (45%) relatives declined to be involved. One patient stated their reason for non-participation was due to their symptom burden. The remaining stated they were unable to commit to the time requirements of the interview. Patients were screened for eligibility and first invited to participate. If accompanied by a family member, the family member would then be approached. Due to the time commitment of the interview (approximately 45 minutes), few family members attending the clinic agreed to be interviewed at that time. Three family members (50%) were interviewed at their own home following interviews with their relative (patient cohort).

Seven patients were identified as eligible but were not approached to participate at the request of their clinical team. The primary reason to not approach patients was their increased frailty. Five patients and six relatives were identified as eligible but unable to participate due to having insufficient English to be able to undertake the interview. Most recruitment was conducted at Site 1 due to travel restrictions and time available to recruit at Site 2 *(see Tables 5.1, 5.2, 5.3).*

5.2.3 Sample characteristics

Patients

Twenty-two patients with a mean age of 62 years (range 34 to 91), and 9 (41%) were aged 65 years and over. Seventeen (77%) were male, 21 (95%) were White British and 4 (16%) lived alone. Functional capacity was measured using the NYHA classification at the time of interview and eleven patients (50%) described experiencing symptoms on moderate exertion, NYHA class II. Seventeen patients (77%) described moderate to higher education backgrounds (College/technical training to University) and the mean time since patient's heart failure diagnosis was 6.4 years (range 1-16 years). *See Table 5.1.* The baseline characteristics of the patients from both sites were similar, although more female patients were recruited from Site 2 and more symptomatic patients (NYHA III) from Site 1.

Family members

Six family members were interviewed, 2 (33%) from site 1 and 4 (67%) from site 2. The mean age was 66 years (range 54 to 78), all were spouses, 5 (83%) were female and 5 (83%) were White British. Half had relatives that received their heart failure diagnosis more than 8 years ago and all family members described moderate to higher education backgrounds. *See Table 5.2.* The baseline characteristics of the family members from the two sites were similar.

Health professionals

Thirteen health professionals were interviewed, 7 (54%) from site 1 and 6 (46%) from site 2. The professional disciplines of the health professionals interviewed included: Four (31%) consultants, four (31%) specialist registrars and five (38%) clinical nurse specialists. Six (75%) of the physicians were male and the nurses were all female. Heart failure was an area of interest for all health professionals and the discussion of treatments was part of the clinical role. Six (46%) reported an interest in pacing/devices; one (8%) in Left Ventricular Assist Devices (LVAD) and one (8%) in Inherited Cardiac Conditions (ICC). The mean number of years, health professionals had worked in their speciality was 10 (range 4-15). Nine health professionals (69%) reviewed patients in the outpatient clinic >2 days/week. See *Table 5.3*. More nurses were recruited from site 1 and physicians from site 2.

Table 5. 1: Patient characteristics

Patient characteristics at each recruitment site				
Variables	**Site 1**		**Site 2**	
	N	**%**	**N**	**%**
Mean age (years) **Range**	62.1 (34-91)		61.5 (48-70)	
Male	9	(90)	8	(67)
Ethnicity				
White British	9	(90)	12	(100)
NYHA Class				
II	5	(50)	7	(56)
III	5	(50)	5	(42)
Time since diagnosis (years)				
0-2	0	(0)	5	(42)
3-7	5	(50)	2	(17)
≥ 8	5	(50)	5	(42)
Lives alone	3	(30)	1	(8)
Educational background				
High school	3	(30)	2	(17)
College/trade/technical	5	(50)	3	(25)
University/Polytechnic	2	(20)	7	(58)
Total	**10**		12	

Table 5. 2 Family member characteristics

Family member characteristics at each site				
Variables	**Site 1**		**Site 2**	
	N	**%**	**N**	**%**
Mean age (years)	71.5		63.3	
Range	(65-78)		(54-68)	
Female	1	(50)	4	(100)
Ethnicity				
White British	1	(50)	4	(100)
Relationship				
Spouse	2	(100)	4	(100)
Currently employed	0	(0)	3	(75)
Time since relative's diagnosis (years)				
0-2	1	(50)	3	(75)
3-7	0	(0)	0	(0)
≥8	1	(50)	1	(25)
Education background				
High school	0	(0)	0	(0)
College/trade/technical	1	(50)	3	(75)
University/Polytechnic	1	(50)	1	(25)
Total	**2**		**4**	

Table 5. 3 Health professionals' characteristics

Variables	**Health professional characteristics from each recruitment site**					
	Site 1 **N (% of total cohort)**			**Site 2** **N (% of total cohort)**		
	Consultant	**SpR**	**CNS**	**Consultant**	**SpR**	**CNS**
Male	1 (7)	2 (15)	0 (0)	1 (7)	2 (15)	0 (0)
Female	0 (0)	0 (0)	4 (30)	2 (15)	0 (0)	1 (7)
Areas of interest:						
HF	1 (7)	2 (15)	4 (30)	3 (23)	2 (15)	1 (7)
Devices	1 (7)	1 (7)		2 (15)	1 (7)	1 (7)
Mean number of years working in specialty	15	8.5 (7-10)	11 (4-16)	11 (10-12)	6 (4-8)	8
Mean number of clinics per week	4	1.75 (1.5-2)	2.3 (2-3)	2.5 (1-3.5)	2.5 (2-3)	3.75

*SpR – Specialist Registrar, CNS – Clinical Nurse Specialist

5.2.4 Thematic analysis

National health policy promotes the integration of a shared decision-making (SDM) model of care in routine clinical practice. As discussed in Chapter 2, the evidence for an effective way to do this is lacking. Key themes emerged from the interview data provide important insight in to the core processes of SDM and its application in heart failure management. The findings of the qualitative interview study are presented in three themes:

1. Preferences for involvement in decision-making
2. Health information-sourcing behaviour
3. Ability to deliver an SDM approach

The first two themes present the different views, preferences and approaches of patients, their family and health professionals to decision-making. The final theme emerged from data focusing on the practicalities of the adoption of a SDM approach. The findings of the qualitative interview study identify important factors that professionals need to consider to better tailor their communication about treatments to individual patient needs.

Sixteen categories emerged from these analyses and combined to form these themes *(Table 5.4)*. The categories and subcategories that were identified through the process of constant comparison and thematic analysis. *Table 5.5* provides an example of how this data reduction process was conducted.

The participant's words provide the raw data and the analysis frames their views and experiences. Each theme is reported individually where the raw data are presented as direct quotations from participants. Participants were given a pseudonym to maintain confidentiality when reporting the raw data. *See Tables 5.6, 5.7, and 5.8.* Literature is used to explore the concepts underpinning the data and to draw inferences. A process commonly used in mixed methodology paradigms (Creswell and Clark 2011). The results of the interviews are supplemented by data from field notes collected during home visits for interviews and following interviews on site.

Three key processes influenced how patients made decisions about their heart failure management (primary research aim): patient involvement, the sharing of information, and the treatment discussion. These data emerged as the three main themes from these analyses. The first theme, 'Preferences for involvement in decision-making,' emerged from data describing patients' preferences and approach to decision-making. Focus was on the process of the clinical consultation and the discussion of treatments between patient and professional. The second theme, 'Health information-sourcing behaviour,' emerged from the data relating to patient's knowledge needs and the value they attributed to different sources of information. The third theme, 'Ability to deliver a SDM approach,' evolved through the identification of barriers and facilitators to the process of treatment decision-making in practice. These data illustrate the role of the multidisciplinary team and the effects of service organisation and delivery on how decisions are made.

The secondary aim of this study was to explore the contextual influences on the views of patients, family members and health professionals towards novel therapy and personalised medicine. This was achieved by exploring the views and experiences of patients, family members and health professionals towards decision-making in contemporary heart failure management. This involved exploration of patient's views toward novel treatments such as gene therapy in heart failure, clinical research and evidence-based treatment recommendations. Exploring participant demographics and disease characteristics identified different types of patients.

Table 5. 4 Data reduction generated in thematic analysis

Categories	***Themes***
Approach to decision-making	**Preferences for involvement in decision-making**
Preferences for involvement	
The decision-making pathway	
Making the final decision	
Knowledge of heart failure	**Health information-sourcing behaviour**
Knowledge need	
Understanding of heart failure	
Internet	
Friends	
Written information leaflets	
Media	
Treatment value	**Ability to deliver a SDM approach**
Service delivery	
The treatment discussion	
Patient-professional relationship	
Patient engagement	

Table 5. 5 Example of coding in to categories

Raw data	Code	Sub-category	Category
"Well because he's a top top man, he lectures, I looked him up on the Google.. he had a very good write up.." **Patient**	Internet	Health information seeking behaviour	Value of different sources of information

A direct quotation presents the raw data, the code used to sort the data, the sub-category/category used to describe the data and the description of its contents.

Table 5. 6 Patient interview cohort

Pseudonym*	Site No.	Age	Gender	Ethnicity	NYHA	Time since diagnosis (years)	Lives alone	Education Background
Janet		68	F	WB	3	4	Y	College/trade/technical
Blaine		56	M	WB	3	4	Y	College/trade/technical
Paul		62	M	WB	3	8	N	High school
John		52	M	WB	3	8	N	University/Polytechnic
Bruce		74	M	WB	3	12	N	College/trade/technical
Nick		34	M	WB	2	4	N	College/trade/technical
Daryl		70	M	WB	2	16	Y	High school
Simon		42	M	WB	3	3	N	High school
Fred		72	M	South Asian	2	3	N	University/Polytechnic
Donald		91	M	WB	2	5	N	College/trade/technical
Paula		55	F	WB	2	4	N	University/Polytechnic
Adam		48	M	WB	2	2	N	University/Polytechnic
Bill		64	M	WB	3	2	N	University/Polytechnic
Steven		60	M	WB	3	8	N	University/Polytechnic
Sarah		63	F	WB	3	1	N	High school
Beth		68	F	WB	2	14	N	University/Polytechnic
Andrew		58	M	WB	2	14	y	University/Polytechnic
George		67	M	WB	2	2	N	College/trade/technical
Mary		61	F	WB	2	3	N	College/trade/technical
Jonah		69	M	WB	3	8	N	College/trade/technical
Brian		55	M	WB	3	5	N	University/Polytechnic
Albert		70	M	WB	3	1	N	High school

*WB = White British

Table 5. 7 Family member interview cohort

Pseudonym	Age	Gender	Ethnicity	Relation with HF	Time since diagnosis (years)	Currently employed	Education background
Nadim	65	M	Indian	Wife	1	No	University/Polytechnic
Sandra	78	F	WB	Husband	8	No	College/trade/technical
Pam	65	F	WB	Husband	12	Yes	University/Polytechnic
Karen	54	F	WB	Husband	2	Yes	University/Polytechnic
Jane	66	F	WB	Husband	2	No	College/trade/technical
Chris	68	F	WB	Husband	1	No	College/trade/technical

*WB = White British

Table 5. 8 Health professional interview cohort

Pseudonym	Gender	Job role	Specialty	Area of interest	Years working in specialty	No. of clinics per week
Charlie	M	SpR	Cardiology	HF, devices	7	1.5
James	M	Cardiologist	Cardiology	HF, pacing	15	4
Diane	F	HF nurse	HF	HF	15	2
Samuel	M	SpR	Cardiology	HF	10	2
Sally	F	LVAD nurse	LVAD	LVAD	4	1
Kathryn	F	HF nurse	HF	HF	12	3
Sharon	F	HF nurse	HF	HF	16	3
Linda	F	Cardiologist	Cardiology	HF, community cardiology, rehabilitation	11	3.5
Tina	F	Cardiologist	Cardiology	HF, devices	10	1
William	M	SpR	Cardiology	CM, ICC, CMR, HF	8	3
Jim	M	Cardiologist	Cardiology	HF, devices	12	3
Anna	F	HF nurse	HF	HF, devices	8	2.5 -5
Tim	M	SpR	Cardiology	HF, devices	4	2

*SpR – Specialist Registrar, LVAD – Left Ventricular Assist Device, CM – Cardiomyopathy, ICC – Inherited Cardiac Conditions, CMR – Cardiac Magnetic Resonance imaging

5.3 Themes

5.4 Preferences for involvement in decision-making

Chapter 2 reported patient and public patient demand for greater involvement in their care as a major driver of health policy change. In this study, some patients did not want to be involved in decision-making and did not want their family members to be involved in decisions about their care. These findings add to the literature by illustrating key differences in the views of patients, family members and health professionals toward involvement in decision-making.

This theme presents the factors found to influence patient preference for involvement in decision-making. The similarities and differences in views between patients, their family members and health professionals highlight key barriers and facilitators to a SDM approach. The findings are discussed under three subheadings that represent the main influential factors that emerged from the interview data: the clinic consultation; type of treatment decision; and family involvement.

5.4.1 The clinic consultation

The literature reports three main categories of patient preferences for involvement in decision-making: active, collaborative and passive (Hubbard et al, 2008). These definitions are widely used in the literature and based on use of the Control Preferences Scale. This scale categorises patient preferences based on their level of perceived responsibility for making the final treatment decision. The findings of this study identified two different types of patients. Patients who preferred health professionals to take the lead in the discussion of treatments; and patients who preferred a more collaborative approach to the discussion of treatment. A collaborative approach was defined as patients who asked for more information, shared their own views and/or challenged the advice of professionals. Ultimately, all patients made their decisions based on their own experience and disease beliefs. The categorisation of patients as simply *'passive recipients of care'* was not supported in this study.

A key finding was that patients' behaviour during the clinic consultation (when treatment decisions are discussed), was not a true reflection of patients' wider decision-making processes. A multitude of factors were found to influence whether patients chose to act on the advice of professionals, take their prescribed medications or adopt healthy lifestyles and self-management behaviours. Patient preferences for involvement were influenced by several key variables including their age, education background, the time since their heart failure diagnosis and the type of treatment decision being made. In contrast to the literature, patient preferences were not found to be influenced by gender or symptom severity (Goggins et al, 2014; Mansell et al, 2000).

Patients who preferred professionals to take the lead in treatment discussions described them as the *"experts"* and placed their trust in the knowledge and expertise of their heart failure team. These patients commented, *"it's up to Dr X or his team to say that's what you need"* and *"Dr Y said it's the best one for me, which I will take, he's the expert."*

In support of the literature, age was found to be a key factor that influenced patient preferences for involvement (Murray et al, 2007). Older patients showed preference for a physician-led approach. Donald was a 91-year-old gentleman who lived with his partner in an apartment in the city. When describing discussions, he had with professionals about treatments, he commented, *"I don't argue with them, I don't question."* Donald's preference to let his consultant cardiologist lead decision-making discussions was based on his positive experience of his care. In the five years since being diagnosed with heart failure Donald had undergone surgery (CABG), had a CRTD inserted and had been optimised on his heart failure medications. During this time, Donald had been managed by the same heart failure team. He did not describe any complications or side-effects of the treatment he had received.

Donald lived with his partner and despite being symptomatic on mild exertion (NYHA III) he described regularly getting out of his flat to socialise with friends. Donald was a proud man who valued his sense of control. He described the importance of being independent and not relying on others. His willingness to pass responsibility to others was only evident in his approach to his healthcare, not in other aspects of his life. This behaviour was mirrored in interviews with other older patients (those aged >70 years).

As described in Chapter 2, the literature reports an association between older age and preference for a professional-led approach to decision-making (Chung et al, 2012). Social isolation has been described as an important factor influencing older patient preferences for this approach. This was not found to be the case in this study sample. An alternative explanation for these patient preferences may be their wider views towards healthcare and the role of the physician. The literature suggests that older patients view physicians as a highly respected and valued profession. Older patients have shown to value a trusting relationship with their physician over participation in decision-making (Wrede-Sach et al, 2013).

Daryl, a 70-year-old gentleman, commented on how only physicians are trained to give medical advice. He viewed the medical profession as an expert trade. If he had an issue with his car he would go to a mechanic. This pragmatic view may reflect his behaviour and the tendency for him to appear *'passive'* and less likely to challenge the advice of professionals during the clinical encounter.

Simon was one of the youngest patients interviewed aged just 42 years. According to the literature, younger patients are more likely to prefer an *'active'* role in decision-making (Hamelinck et al, 2018). Alternatively, in this study, professionals believed younger patients were less likely to want involvement in decisions. They commented that young patients, *"frequently don't want to engage."* Physicians used terms such as *"they're often in denial"* or *"not accepting the fact they've got a cardiac condition."*

Like Donald, Simon did not ask many questions during discussions about treatment with professionals. This behaviour was perceived by health professionals to be Simon not wanting to be involved in decisions about his treatment. When further exploring how Simon made decisions he described his preference to listen to the advice of professionals and then go home and do his own research. He would then carefully consider the information provided by professionals and the information he had sourced independently to make his final decision. Simon stated: *"So then the next option was a pacemaker... I looked into it and I thought it was the best thing to have it done."*

Simon was young, high school educated and breathless on mild exertion (NYHA III). He described feeling anxious and depressed with little sense of control over his life. He was unable to work due to his symptoms and lived with his wife and young son in a small council house. Despite spending much of his time in his house and not wanting to socialise, Simon described wanting to improve his functional ability with the goal to walk his son to school. According to the literature Simon's depression, social isolation and low educational background would suggest preference for professionals to make decisions. This was not the case. Searching for additional health information was an important part of Simon's decision-making process.

Simon's behaviour in the clinic consultation and the views of professionals may partly be explained by younger patients being less likely to access health services and contact professionals for advice. Barriers to accessing services for young patients included getting time off work and childcare commitments. Younger patients were often considered as being more isolated from professionals. In this study sample these patients chose to make decisions about their care based on information they sourced independently. Although younger patients may not appear to want to be involved in decision-making (less likely to engage in treatment discussions), their health behaviour was greatly influenced by the information they sourced outside of the clinical encounter.

The relationship between education background and preferences for involvement was also raised in interviews with health professionals. There was a common belief that educated patients preferred greater involvement in decision-making compared to patients from lower educational backgrounds. Charlie was a cardiology SpR with 7 years of experience working in heart failure. His experience was that patients from higher educational backgrounds were more involved in treatment discussions. Charlie commented:

> *"Patients who have a better educational background tend to ask a little bit more questions and they want more evidence, so that's what I have heard, because they might be coming a little bit more prepared for this type of discussion... patients with lower educational background have less questions about the procedure."* Charlie

This view was shared by nurses and physicians regardless of their years of experience. Patients in this study with higher education backgrounds (university educated) tended to be more vocal and engaged in treatment discussions because they felt confident to challenge the advice of professionals. These patients viewed health professionals as the experts but were arguably less influenced by any power-dynamic. They valued their contributions to making decisions and their ability to problem-solve and consider complex information. For many, this was based on their employment background with most working in professional roles in business, industry and education. Yet for both Donald and Simon, their preferences for involvement were influenced by a combination of factors, not just their age and educational background. Their relationships with professionals and motivations for treatments were important influences on the decisions they made about their care.

Professionals' views toward patient preferences are likely to be influenced by the fact that patients adapt their approach to treatment discussions depending on who they are talking to. Professional discipline was found to influence what information patients shared during treatment discussions. Patients and family members frequently tailored the information they shared. Patients and family members often restricted the information they shared with physicians to biomedical issues. These patients were more likely to be female and chose to share information relating to other symptoms, comorbidities, psychological health and personal circumstances with nurses. This tailoring of information was based on their perception that doctors will view this information as *"something silly," "they'll think I'm pathetic."* Most described doctors as not to be *'bothered'* with *'trivial matters,'* they are *"too busy."* Janet was a 68-year-old lady who had been diagnosed with heart failure 4 years earlier and lived alone. Janet commented, *"Sometimes I'll think, you know I said to you (nurse) about my legs, they'll think I'm pathetic, you know, and I don't, and I could say it to you, but I don't think I'd ask them (doctors)."*

These findings contrast to those reported in the literature, whereby females have been found to be more likely to report psycho-social issues to physicians (Doherty and O'Doherty, 2010). These findings highlight patient perceptions of physicians and how many view their role as primarily focusing on disease needs. Importantly what this means is that physicians may not be receiving the 'full picture' of a patient's health status. As discussed in Chapter 3, the combined input of both physicians and nurses in treatment decision-making is important so all facets of the patient health and well-being are considered.

This behaviour was also raised in the interviews with nurses. Diane (an experienced CNS) described similar experiences to Janet:

> *"Sometimes people will disclose things that they don't say to the doctor because the doctor's busy or they know they're just going to talk about the particular complaints. They'll tell you all sorts of other issues, which sometimes are relevant."* Diane

Patients' decision to restrict the information they share may in part be explained by their experience of how physicians approach treatment discussions. Physicians described the purpose of clinic consultations to gain patient agreement with their recommendations. They had a short time in which to communicate results, treatment recommendations and put a management plan in place. Giving patients time to consider different options was viewed as important. But there was an expectation that patients would eventually accept their advice and adhere to their treatment plan. This view was shared by experienced consultant cardiologists and junior SpRs, but not by nurses. Tina, an experienced consultant described this process as, *"often you just could chip away at the resistance but slowly."* Others favoured a positive approach to gain acceptance. Tim, a junior SpR with 4-year experience in heart failure commented, *"if you talk about the positive side, they'll usually comply with all the management plan quite easily."* On occasions when patients had challenged treatment advice, the common approach adopted by physicians was to arrange a future appointment to revisit the decision. Jim was an experienced consultant cardiologist and described his process:

> *"If they want to have time to go away and think about it, that's absolutely fine… And if they have some misconceptions and go through that with them. Sometimes, they can be adamant, and that's the time to say, well, let's just accept that right now, let's come back to it in six months."* Jim

In contrast to physicians, nurses approached treatment discussions differently. Nurses viewed their role as managing patient expectations of treatment and explaining the rationale of treatment recommendations and service provision. Diane, a specialist heart failure nurse, commented:

> *"If there's someone elderly and frail but wants to have every option, that's their decision, and everything's bespoke. But there are limits to care, because even if someone said, I want everything, you can be limited by obviously the physicians and surgeons and the ITU team, if there's no realistic, so sometimes we'll get a second opinion."* Diane

The different approaches adopted by nurses and physicians may in part be explained by each professional's differing roles, the amount of time they spend with the patient and the information they share. Yet perceptions of the clinic consultation both from the patient, family member and physician viewpoint appear to retain an element of paternalism. The result is that many patients were less likely to challenge physicians or disagree with their advice. Increased time spent with nurses (facilitated by longer clinic appointments and increased continuity) may have encouraged confidence for patients to share more information.

The literature suggests that gender influences how patients trust professionals and therefore may explain patient behaviour during treatment discussions. Trust in health professionals has been reported as an important influence on the doctor-patient relationship. Banerjee and Sanyal (2012) conducted a mixed methods cross-sectional study to explore the doctor-patient relationship. The researchers conducted interviews with patients (n=198) and focus groups with physicians (n=10) and found that females had lower trust in physicians compared to male patients (measured by the Trust in Physician Scale). No other determinants were found to be statistically significant (socioeconomic status, education, religion, language). The researchers utilised techniques of triangulation to validate their thematic analysis of the qualitative data and further explore the determinants of doctor-patient concordance. These findings may in part account for the females in this study preferring to share their concerns and anxieties with the nurse rather than the doctor. This tailoring of information was less apparent in the interviews with male patients. Whether these actions were based on a lack of trust in physicians, increased trust in nurses or different views towards the role of each discipline is difficult to determine. Nevertheless, it is an important finding that requires further exploration.

5.4.2 Type of treatment decision

Patients and family members were supportive of novel treatments in heart failure such as gene therapy. Their decision whether to participate in clinical trials of novel therapies were based more on the study commitments and duration of follow-up rather than their views towards the type of treatment itself. Patients with young children and in full-time employment were less likely to enrol in clinical trials. It was patients who remained symptomatic on optimised medical and device therapy who were motivated to undertake *"anything that can make me feel better."*

A key finding of this study was that patients and their relatives demonstrated limited understanding of their heart failure aetiology. Particularly its basis for the suitability of treatments they were offered. Most patients did not understand how or why they were being offered different treatments compared to those offered to their friends or family. This lack of knowledge and understanding was a strong influence on how patients viewed different types of treatments and their preferences for involvement in decision-making.

In general, a professional-led approach to decision-making was preferred by patients when deciding on complex interventions such as coronary interventions (PCI) and device implantation (PPM, CRTD, ICD). Alternatively, a collaborative approach between patient and professional was favoured when making decisions about treatments that required a trial-and-error approach. Patients who preferred a collaborative approach used terms such as *"we discussed"* or *"we tried."*

Sarah was a 63-year-old retired GP receptionist who lived with her husband. She described having symptoms of breathlessness on moderate exertion (NYHA II). Sarah was actively engaged in her heart failure management and described managing her medications by adhering to a strict daily routine. Her primary concern was the effects of her medications on her blood pressure. Sarah described discussions with her heart failure team about changing to an alternative regime that she felt would minimise these effects.

> *"Well I've discussed it with the team, because my blood pressure was coming down and I was really suffering and I thought well it's not worth me taking them all at once because that would just devastate it… So, we did discuss about splitting them up."* Sarah

John was a 52-year-old gentleman diagnosed with end-stage heart failure and experienced symptoms of breathlessness at rest (NYHA III). Like Sarah, he described a collaborative approach with professionals to tailor his treatment to his needs. In John's case, this collaboration related to optimisation of his pacemaker settings:

> *"We tried different pacing modes between the leads as well, some are worse and this seems to be the best configuration, where it's pacing ring to tip off the same lead..."* John

Sarah and John were both well-educated (university level education). As previously discussed, the literature reports education level as a key factor influencing patient preference for involvement in decision-making (Chung et al, 2012). Despite Sarah and John being at different stages along the disease trajectory and having different levels of symptom burden, both showed preference for a collaborative approach to decision-making. There is limited evidence in the literature reporting the influence of symptom burden on patient preferences for involvement in decision-making. In Sarah and Johns case, a higher education background may have given them confidence to openly discuss different options with professionals. This was likely to have greater influence than their symptom burden or age.

The influence of type of treatment on patient preferences for involvement were also raised by professionals. Pacemakers and defibrillators were viewed by professionals as treatments where it was important for patients to make the final decision. James was an experienced cardiologist who had specialised in heart failure for the past fifteen years. James commented:

> *"Treatment decisions it's very important to make sure that the patient knows what they want and we can understand what the patient would like to have, especially when it comes to invasive procedures…the patient has to make the decision themselves as to whether they want a defibrillator or not, or a special type of pacemaker or not"* James

Similarly, Diane, an experienced senior CNS in heart failure commented: *"We're not there to force them into a decision about CRT because actually that patient fitted the criteria on paper for CRT. It, but it's just a discussion."*

James and Diane were experienced in device therapy in heart failure. They regularly reviewed heart failure patients (4 clinics and 2 clinics per week respectively) and were involved in weekly multi-disciplinary team (MDT) clinics for patients with device therapy. Regular discussion with patients about devices and a MDT approach to treatment decision-making may help to explain their emphasis on the patient role in decision-making.

A further explanation of their views may be underpinned by the indications and expected outcomes of device therapy. Primary prevention ICD implantation is considered in patients at high risk of sudden cardiac death (ESC, 2016). The eligibility criteria include: NYHA II-III, LVEF ≤ 35% despite ≥ 3months of optimal medical therapy, prognosis of >1 year and IHD or DCM (ESC, 2016). Unlike recommendations for secondary prevention ICD, patients without a prior ventricular arrhythmic event may find it challenging to weigh the risks and benefits of ICD implantation. CRT insertion aims to improve patient symptoms and reduce morbidity as well as mortality (Class I, Level A evidence; ESC, 2016). According to studies of CRT efficacy, approximately one third of patients will be 'non-responders' and see no improvement in their heart failure symptoms (Daubert et al, 2017).

Health professionals found it challenging to explain the rationale for these treatment options to patients whilst emphasising that they may not feel any improvement in their symptoms. This may account for James and Diane's comments. By handing over the responsibility and ownership of the decision to the patient when the outcomes are variable. This belief was shared by professionals when they were met with the challenge of not knowing the best treatment. Professionals referred to this as the *"grey zone"* in clinical guidelines. This made treatment and management decisions more complex for both physicians and nurses.

This may in part be explained by the changing heart failure clinic population. Professionals are seeing more elderly, frail patients often with multiple comorbidities. In a situation where there is not a single treatment offering the best therapeutic effect, health professionals had increased readiness to share the responsibility of treatment decisions with patients. Samuel, an experienced SpR in cardiology, commented:

> *"Sometimes the guidelines are not very clear, so, especially when it comes to age or frailty, so they're not that detailed. So, what usually happens is that patients, who would qualify as for guidelines, would not qualify as per our criteria when we meet the patients…So, on that occasion it's up to them to decide, because there's always a grey zone and the guidelines do not say yes or no always."* Samuel

In contrast, professionals with less experience in heart failure (≤4 years) described using a more direct approach to treatment discussions about devices. One SpR described using fear to shock patients so they understood the importance of having a device implanted.

In contrast to invasive procedures, patients preferred greater involvement in decisions about their medications. Most patients felt confident to challenge professionals about their medication management regardless of their age, gender or education background. These challenges originated from decisions to stop their medications, to increase doses or to tailor their own regime. Simon strongly opposed stopping one of his medications. He could not recall the name of the medication, but he understood its importance in managing his chronic pain. Simon stated:

> *"I can't remember which one now but they tried to take me off one of my medications and I totally refused it. I said no, because I need that. I knew that was one that I needed for pain."* Simon

Similarly, George a 67-year-old gentleman who described a recent improvement in his symptoms (from NYHA III to II), questioned the continued use of one of his medications. George asserted, *"Do I need to be on this medication? I don't get angina now, so do I need to be on the rosaniline?"*

This was because patients viewed themselves as the experts when it came to their medications. They knew their own reactions to the medications, what relieved their symptoms and what suited their lifestyle. This confidence and willingness to challenge professionals was only evident in decisions about medications.

In contrast to Simon and George, Paula was university educated and demonstrated a high level of engagement in her heart failure management. She described how she self-referred to specialists and managed her condition at home by weighing herself daily and monitoring her blood pressure. Paula was a 55-year-old business manager who worked in a busy company and lived with her husband. She had minimal symptoms (NYHA II) but was concerned that her beta blocker and ACE inhibitor were dropping her blood pressure. Paula understood the important role of her heart failure medications and rather than wanting to stop the medication she offered a personalised titration plan:

> *"I was then saying well look, it's a big step to do from, I don't know whether it was 10 to 20 or something grams, and so I said why can't I take 5 and do it gradually, you know, get my body used to it and take it in stages, and she (nurse) said, oh we don't do that, we don't do that, we can't do that."* Paula

Importantly when Paula was met with disagreement from the heart failure nurse she admitted she changed her regime anyway, *"right, and I've got to be honest, I did it quietly myself."* Paula's decision to go against the advice of the heart failure nurse and act on her own beliefs was based on her confidence in her own management of her heart failure. She felt she knew what was best for her. Going against the recommendations of professionals in terms of medications was largely influenced by patients experience of symptoms.

However, many patients did not demonstrate this same level of involvement. Some chose not to discuss the problems they were experiencing with their medications with health professionals. These patients were likely to be more symptomatic and from higher education background. The level of patient involvement in discussions about their medications did not influence their behaviour. Patients would do what they thought was best in terms of starting, stopping or continuing with their advised medication regime. Patients valued their own views about medications more than the advice of professionals, regardless of age, gender, education background or symptom burden. Patients described medications as, "*if it works, fine, if it doesn't, then you stop taking it, no point."* Many patients viewed the effectiveness of medications on their level of symptom relief. *"To feel normal"* was a reason for some patients to stop taking their medications. For others, it was to *'feel better.'* Blaine, a 56-year-old patient whose symptoms had worsened over the last year disclosed, *"you can feel great without them. And I do stop taking them now and then."*

Professionals raised this issue of medication compliance in their interviews. Jim, an experienced consultant cardiologist commented on different types of patients and their degree of engagement in their medication management.

> *"So, some will take them and accept the side effects because they know in the long term it's going to make them feel better and they can see the end game and they're really on board really quickly. And then there are other patients who you try and you do it, will get to that stage. And then there are a group of patients who just won't try at all."* Jim

Hibbard and Mahoney's (2010) Patient Activation theory helps to explain this behaviour. Patients' experience of emotion is related to their level of activation. Negative self-perception and negative effects of medications are likely to result in low levels of activation and therefore, patients are less likely to adhere to recommended medication regimes.

In contrast to device therapy and interventions, medications were an ongoing treatment managed by patients and their relatives at home. This was important to patients and relatives to gain a sense of control. Patients would come to scheduled clinic visits to see the heart failure nurse. The purpose of these appointments would be for the nurse to assess the patient's response to medication titration through monitoring and review of symptoms. Patients often spent more time with nurses in clinic than they did with physicians. Similarly, patients were more likely to contact nurses by telephone to discuss their medications and symptom management. Their unique experience of medications, regular monitoring and discussion with professionals gave patients the confidence to share their views and concerns.

5.4.3 Family involvement

The literature reports family member preference for greater inclusion in the decision-making process (Laryionava et al, 2018). Family members played an important role in helping to manage patient's heart failure. From managing the patient's medications, encouraging patients to seek medical advice and supporting patients to engage in self-management activities and healthy lifestyle choices. Family members described the effects of disease burden, how they adopted new roles in the family and the strain of caring for a patient with heart failure. Family members had a pivotal role in patient disease management and acted as an advocate for the patient. Yet the role of family members in the decision-making process has not been widely explored. Sharma et al (2011) conducted a cross-sectional survey of 52 dyads (patients and relatives) to assess whether family members could identify patient preferences for family involvement. Agreement in preferences was reported in only 56% of the sample. This was a small study but to date the only one of its kind. This reinforces the disconnect between professional assumptions and the reality of patient preferences for decision-making.

The involvement of family members in the clinical consultation varied dependent on the patient's characteristics and their relationship with their relative and health professional. Patients who described leading the discussion with professionals viewed their relative's role as *'filling in the gaps.'* These patients tended to be younger, male and from moderate to higher education backgrounds. These patients preferred one-to-one communication with the physician, where the focus was on them and the information they wanted to share. These patients viewed the consultation as a time to listen and consider the advice of professionals. Involvement of their family members in discussions was often viewed as a barrier to them getting the information they wanted. Most male patients preferred to speak to health professionals or friends about their health and heart failure management rather than their families.

Many patients described value to independent decision-making often searching for additional information online or discussing treatments with friends, in isolation from their relative. These patients were proud and valued their independence. Older, male patients described relatives as *'fussing,'* *"we're not invalids"* and little value to their views towards treatments. These patients expressed preference for a physician-led approach to decision-making. Daryl was a 70-year-old patient who was a retired strawberry farmer and lived alone in a small bungalow. He commented:

> "*(Partner) often talks to me about how I'm getting on with my heart and everything like that, but we don't harp on it all the time the two of us…. They're not doctors. They're not doctors or nothing, they don't know nothing, do they?"* Daryl

Daryl's symptoms had recently worsened (NYHA III) and he expressed frustration at no longer being able to go to his archery club and becoming more isolated. He was a proud man who prided himself on DIY around the house, helping his friends with odd jobs and socialising with his friends. He had no children and previously described physicians as 'the experts' with preference for a physician-led approach to decision-making.

The rest of the patients that shared this view were husbands and fathers viewing their role in the family as the lead decision-maker. Having a chronic disease like heart failure often lead to increased reliance on family members and this resulted in patients feeling a loss of control. Regaining that control in consultations with professionals (particularly with physicians), meant that patients could retain a level of responsibility for their disease. When at home they often felt their relatives (wives or children) were taking on more responsibilities and this impacted negatively on their self-image. The literature reports that male patients with chronic disease often feel a loss of dignity and demoralisation (Vehling and Mehnert, 2013). Male patients in this study demonstrated demoralisation through their loss of control with no longer being able to undertake duties that they perceived to define them as a husband/father.

Female patients described not wanting to burden their spouse or partner with discussions about their heart failure*, "don't want to upset him" "don't want him worrying."* In contrast, female patients were more likely to talk to their children and view their opinion as valuable when deciding on treatments. No influence of symptom severity or education background on these preferences was observed. Interestingly, all patients valued the advice of family members who worked in healthcare, regardless of their profession. Patients looked to these relatives for validation of their symptoms, views towards medications and treatments and confirmation of advice they had received from professionals.

The literature reports lower levels of concordance between younger patient preferences and their family member preferences for involvement in treatment decisions (Shin et al, 2013). Young patients in this study were more likely to act on the advice of family members. Nick was the youngest patient interviewed at 34 years, commented:

> *"I was quite happy just to not do anything about it, I was like, I need to get a bit of rest and that but I was forced, by my parents, to go to A & E, because they said it's not normal, you should be able to walk up that hill without being as bad as you look, and you look awful."* Nick

Nick had recently moved out of the family home. He had started a course at University but following his diagnosis he moved back home after finding it difficult to cope and accept his condition. His mother was a key source of support and accompanied Nick to his clinic consultations at the hospital. Nick's close relationship and reliance on his parents increased how he valued their advice. Nick was much younger than the rest of the patient study population. Compared to other patients who were older and described less consideration of their relative's advice.

In contrast to these findings, professionals viewed older patients as valuing the advice of relatives more than younger patients. Tim, a junior cardiology SpR commented: *"Very elderly patients trust their families, especially if they have anybody working in the NHS or anybody working in the healthcare sector…. younger patients more likely to act on advice of health professional."*

Tim's views may be based on professional observations of patients and relatives' behaviour during the clinic consultation. Patients who described family members as being involved in clinical consultations were more likely to be older. Yet, the level of involvement of family members in the treatment discussions was not reflected in the value patients placed on their advice.

Most family members perceived their role as being an advocate for the patient during clinic consultations. Relatives expressed a sense of authority and confidence when discussing medications with health professionals. One patient's wife, Pam, commented, *"Well (patient) doesn't really like to make a fuss."* She went on to offer her own views and advice on his medication: *"Do you think we should try him on water tablets?"* Family members highly valued this inclusion in the treatment discussion. For many, it provided them with a sense of control and responsibility in the management of their relative's heart failure.

Family member preference for involvement was also influenced by the time since their relative had been diagnosed with heart failure. Jane was a 66-year-old lady whose husband had been diagnosed with heart failure two years previous. She described being *"guided"* by professionals and the sense of relief that gave her during the first few months following her husband's heart attack: *"Because it's a new experience in a way, you are guided very much by them… they're the experts and everything."* Jane had a college education and described earlier in her interview how she researched different treatments using the internet to find out more information. Despite this proactive information-sourcing behaviour, Jane described preference for professionals to lead the decision-making process during the early stages. This need for relatives to feel 'part of their relative's disease management' to feel *'useful'* was raised in other interviews of patient's spouses.

Nadim was the 65-year-old husband of a patient who was recently diagnosed one year earlier. He was an Indian gentleman, university educated and used to work in the public sector. He had a supportive family (some of whom worked as health professionals) and lived with his wife acting as her primary carer. Nadim challenged his wife's GP over her medication treatment plan:

> *"Have you received reports? She says yeah, I said when? She looked in her computer, 15th January and I was ... 18, 19 January. I never heard from you anything. I says I'm getting worried because her Ramipril should be increased and hasn't been increased, right?"* Nadim

Nadim was the only male spouse interviewed and was strongly involved in the management of his wife's heart failure. Early in the interview he described leading conversations with professionals during clinic consultations. His wife spoke limited English (insufficient to be interviewed) and took a 'back seat' during discussions about treatments. She described her symptoms to the physician but had little input into the discussion of different treatment options and medication regimes. This may in part be due to her limited English but may also have been influenced by cultural factors. The population sample in this study was predominantly White British therefore, cultural comparisons could not be explored. Further examination of culture and religion and their influence on views towards treatments and approach to decision-making is needed.

Like Nadim, Sandra had an important role in managing her husband's medication at home and described organising his *"pill box"* and reminding him when to take his tablets. She had also taken on additional responsibilities around the house. As Tom's symptoms had worsened he was unable to manage activities such as the gardening and home DIY. Sandra adopted increased responsibilities at home but commented on her role in the clinic consultation as:

> *"Tom's policy has always been, it is my body, if there are any questions to be asked you be quiet Sandra, I will ask the questions, when I have finished if there's anything you think I haven't covered, then you ask, but it is me to do the asking."* Sandra

Similarly, John stated that his wife would be angry that he chose to share his 'part truth' with the doctor, *"Julie still gives me a row, she says, no you didn't tell them you were that bad like this or that bad like that."* Despite wives taking on important roles in managing patient's heart failure at home, their level of involvement in treatment discussions with professionals did not reflect this.

In the interviews with health professionals, physicians described highly valuing the role of family members in retaining information as well and supporting their recommendations through reinforcing compliance. Jim (consultant cardiologist) commented:

> *"Sometimes patients don't even comprehend what you've said. They're so busy worrying about whether they're going to die or have a cardiac arrest that they don't hear half the things but the relatives do."* Jim

He went on to explain:

> *"Involving family members is really important, because, whilst a patient might decide he's not, or he or she's not going to take something, their family might decide they are…. recruiting some support from the family to reinforce the benefits of long term compliance and adherence strictly to things is really important."* Jim

Physician's focus on treatment outcomes and adherence to professional advice may partly explain their views. Other described the challenges of family member involvement in treatment discussions. Charlie (experienced SpR) stated, *"I think it might be easier for us to just have the patient in the room but I think it's probably not easier for the patient in the long run."*

Physicians viewed the relatives of older patients as more challenging due to their, *"anxieties and agendas of their own"* and *"telling them what to do."* This may in part be due to the conversations about treatment, prognosis and end of life and the higher risks of treatments due to multiple risk factors and frailty of older patients. James (experienced consultant cardiologist) who specialised in device therapy was frequently referred complex cases to discuss device treatment in his specialist clinic. James described occasions where treatment outcome preference varied within families:

> *"The patient himself didn't really know what he wanted and was quite happy to defer the decision making to his children. The son was, yes, he must have everything and the defibrillator may help save his life and so he should have that. The daughter was much more, how can we improve the quality of life and what's the risk of the device and so on, so a bit more measured."* James

Nurses perceived family members as an important source of information, *"I've been told about someone's mental health problems, which, they haven't really been in the notes."* They viewed involvement of family members as necessary to gain a holistic picture of the patient. These nurses would see patients and relatives in their clinic to review their symptoms, medication management and to provide health education. Knowing how the patient is managing at home was an important part of their assessment to support self-management. Nurses found relative's presence useful and helpful in supporting patients to self-care. Anna (CNS) commented:

> *"A lot of my patients are elderly patients so they are sometimes carers. And obviously, towards the end stage, they take on more of a clinical role. So, they are sometimes, when the patient's cognition starts to fail, they are taking the lead on making sure they medicate, making sure that they alter their dose, they're weighing them for me, they're making sure that they're reporting that and they're recording that. And then ringing me and negotiating changes in diuretics so it is quite a big role and a big responsibility."* Anna

Most relatives interviewed were wives. As previously described, females may be less likely to share information with physicians compared to nurses. It was also these family members that frequently accessed advice about medications and their relative's symptoms by contacting the heart failure nurse. Nurses therefore were more likely to see the benefit of family member involvement through increased contact.

These differences in views are likely to stem from the different purpose of consultations with the nurse and the physician. Physicians have limited to time to communicate treatment options, the rationale for recommendations and the intended benefits and risks. Nurses often have longer appointments with patients where assessment of how patients are coping at home, their social circumstances and psychological health are important to nurses in supporting their self-management.

Better understanding of the views of relatives is important to provide context for how each patient makes decisions. Family member support has demonstrated positive influences on patient's uptake of self-management techniques (Dunbar et al, 2008). However limited guidance for professionals on how to involve and support family members is currently available.

5.4.4 Summary of theme

This theme illustrates the differing views and approaches to decision-making favoured by patients, family members and health professionals. Importantly it builds upon the literature by providing a deeper understanding of the factors that influence patient preferences. In addition to socio-demographics, these findings illustrate the combined influence of multiple factors that underpin patient approaches to decision-making. Importantly, the clinic consultation only forms part of the patient decision-making pathway. The assumptions and often misconceptions held by professionals fail to account for the external factors that influence patient's final treatment decisions and their health behaviours.

These differences in views and approaches to treatment discussions are a key barrier to the adoption of a SDM approach in heart failure management. Importantly, these findings highlight potential missed opportunity for professionals to support patients to make treatment decisions based on clinical evidence, disease needs and personal preferences. The clinic discussion is a core part of the treatment decision-making pathway. Focus on ways to improve current practice could lend itself to a more shared approach to decision-making.

5.5 Health information-sourcing behaviour

Health information provision has typically been the role of the health professionals through providing patients with professionally-derived written literature. Yet with increased access to information via the internet and technological advances making mobile phones, tablets and computers more accessible, patients and turning to alternative sources to meet their information needs.

This theme identifies key differences in the views of patients, family members and professionals towards health information sources. Health professionals, patients and family members were found to have different views about their information needs. A disparity emerged between patient preferences for health information and the information provided by health professionals in practice. The need to tailor health information provision is a key part of a SDM approach.

This theme helps to increase understanding of how patients view their heart failure and the factors that influence their preferences for health information. The theme emerged from the data illustrating patient knowledge and understanding of their heart failure, perceived information needs, and the value attributed to four key sources of information: the internet, friends, written information leaflets and the media. The findings are presented under two subheadings that reflect the main differences in views between cohorts: Health information need; Value of different information sources.

5.5.1 Health information need

Patients described their heart failure by several means. Most referred to their experience of the initial onset, the investigations they had undergone and treatments they had received. Interestingly, few patients who experienced an acute cardiac event accurately identified their symptoms. Bill described in detail the initial onset of his symptoms: *"It was July 2014. Literally just got up out of bed, and felt this tightness across my chest. So, I thought, something's wrong."* Others described their diagnosis as a series of treatments they had received. Donald commented, *"the understanding of my heart is that I had a triple bypass 20 years ago... I have now had a valve replaced. I have a pacemaker. I have had a clip, and I think that's it."* Both Bill and Donald viewed the effects of their treatments in isolation. This view was reflected in most patient interviews whereby patients viewed their heart failure management as a series of independent treatments, rather than a combined approach to improve their symptoms and functional ability.

Patients identified and described their symptoms of heart failure but demonstrated limited knowledge of its cause. We found no influence of age, gender, or symptom severity. Most patients knew their primary indicator of deterioration, *"I suppose the main thing is to see whether the feet are swollen," "I think a lot of my trouble now is my weight."* Older patients often associated these symptoms with the normal progression of aging.

Patients were knowledgeable about their medication regime including the names, doses, the need for titration and regular monitoring. This is likely based on the provision of services in heart failure where regular in-person and remote communication is often focussed on medication management. Pharmacological therapy is the backbone of heart failure treatment and optimisation requires regular contact with health professionals, particularly nurses who take a lead role in medication management. Nurses reviewed patients in regular scheduled clinics to review their symptoms, assess their health status and perform blood tests, whilst attempting to up-titrate medications to their target guideline doses. Patients and their relatives are encouraged to contact the heart failure nurse if they identify a change in their condition or if they had any concerns. Often this would mean nurses giving advice to increase or decrease certain medications.

Patients measured their health status by the number of medications they were taking. They were aware of the need to increase certain heart failure medications. Most patients were content to attempt up-titration (albeit with their own requests to tailor the regime) to their experiences and lifestyle. Nick (the youngest patient interviewed at 34 years) described managing his medications as giving him a sense of responsibility and control. He viewed reaching the target doses as a reflection on his health status and improvement in his condition. Nick commented:

> *"Well I've been sort of the optimum one isn't it, going up to 10mg for that and 10 for Ramipril and lower my diuretics…. I'm only on two of them a day now. I was on four. And that's working out well and I'm up*

> *to my Bisoprolol to 7.5, but they're trying to push that a bit further maybe in the next few months as well to get that up to ten."* Nick

In contrast to the literature, the accuracy of patient's understanding of their heart failure, appropriateness of treatment and its effects was not strongly influenced by education background (Poureslami et al, 2017). Paula (a 55-year-old patient who was university educated) compared her treatment to that of her friend's husband and commented: *"I mean my friend's husband had a new aorta valve not long ago, but the mitral valve can't be replaced, which is damaged with me."*

Patients' limited understanding of their heart failure aetiology was raised in the interviews with health professionals. Professionals agreed that patients often based their understanding of treatments on information provided by their family and friends. Linda (consultant cardiologist) stated:

> *"There's an awful lot of people who pick information, take information, from friends and family and neighbours and not understand that there are different sorts of heart conditions for which different treatments are relevant."* Linda

Patients' knowledge and understanding of their heart failure and treatment is likely to be explained by the information they source independently. Patients with higher education backgrounds tended to search for more detailed and analytical information. In contrast, patients from less educated backgrounds searched for additional information but were less critical of their findings. Despite this information sourcing behaviour, most patients demonstrated limited understanding of their heart failure aetiology with many having limited knowledge of the indications and actions of their treatment. For device therapy, knowledge was limited to the name of the device or the manufacturer, terms that are likely to have originated from discussions with professionals. Patients described their device using terms such as, "*DDD Medtronic"* and *"It's C, R, T, I know I heard him say, defibrillator."*

How patients viewed treatments and the value they attributed to them, was influenced by the language professionals used to describe them. Feeling *'almost mechanical in a way,'* feeling special *"it's the posh one."* These patients felt privileged to be offered treatments that their consultant considered highly. Regardless of their age, gender, education background or symptom severity. Patients described these treatments in a sense that they were giving them hope. This is likely to have originated from physician preference to be positive and 'try to sell' treatments. This may be cause for concern if this positive slant leads to misunderstanding and high expectations of treatment. Yet none of the patients that voiced this view described unrealistic outcomes.

Most patients had limited knowledge of the criteria and suitability of different treatments. Steven's consultant had discussed with him about having a CRT upgrade in the past but then stated it was no longer indicated. Steven interpreted this as that the consultant was waiting for his heart function to worsen before they did the procedure. This caused a great deal of confusion for Steven and reduced the value he attributed to the treatment.

> *"It was discussed some time ago, 18 months ago the next step would be to have another lead. But they said not now we'll wait. It's not bad enough."* Steven

Steven's attitude was mirrored by several patients. The value they placed on treatment was reduced due to their confusion over eligibility and suitability of treatment to their heart failure aetiology.

In contrast, health professionals perceived patients to be knowledgeable of the rationale for treatments, particularly for device therapy. Many described detailed conversations they had had with patients explaining the indications and expected outcomes of treatments. Professionals' misinterpretation of patient level of knowledge highlighted a discrepancy between their perceived information need and the information they were providing to patients. Physicians often felt challenged by the limited time they had to explain complex information to patients in a way that was meaningful to them. They frequently used medical terminology to describe treatments. This may in part be explained by how some physicians viewed the value of information they provided about treatments. Some believed the information discussed during consultation had little impact on patient views. Charlie (an experienced cardiology SpR) commented, "*how much the patients remember and take home, I suspect is probably not a huge amount."* Others emphasised the difficulty in translating scientific information in a way that patients could comprehend. Tina (consultant cardiologist) commented:

> *"The biggest barrier for me is the fact that a lot of the patients actually do not understand the complexities of the matters we're delving into. And sometimes, much as we want to give them all the information there is available, they might not be able to process that information in a way that's rational."* Tina

The views of professionals may have been influenced by patients tendency to focus on the expected outcomes of treatment rather than the indications and functions. Tim (SpR specialising in devices) commented, *"they wouldn't know how they work, but they would know why we are putting them in."*

Patients used medical terminology as a tool to make sense of their heart failure and measure their health status. Terms most commonly used originated from verbal communication and written correspondence with health professionals. Commonly used terms included: "ejection fraction," and "moderate to severe/mild to moderate." Few patients demonstrated accurate understanding of these terms. Alternatively, they were used in the context of describing the function of their heart. LVEF values were commonly misinterpreted: *"only 29% of his heart that's working,"* and *"half heart was not working."*

Despite misinterpretations, patients and relatives valued the use of medical terminology. This was because they could use it to classify and quantify their health status. Some perceived this method to gain respect from health professionals. For many this served the purpose of finding common ground. Use of these terms enabled patients and relatives to discuss their heart failure with others, their friends and family as well as other professionals. Little empirical evidence exists about how patients interpret medical terminology and its role in their understanding of their disease. One study by Wernick and colleagues (2016) used a randomised, crossover trial design to assess the effects of reducing medical terminology in clinic letters on patient understanding, anxiety and depression scores. The authors reported a statistically significant improvement in patient understanding and perceived ability to manage their illness ($p<0.001$).

Use of medical terminology to make sense of their disease was not influenced by age, gender or education background. Importantly, patients and relatives used these terms to compare their health to others. One patient, Fred, a 72-year-old gentleman spent time actively searching for information online to improve his knowledge and understanding of his condition. Fred described a time when he compared his symptoms to another patient based on ejection fraction alone:

> *"I was reading an article where there was somebody with the heart failure at, yeah, she was, her EF had come down to 20, she couldn't climb any steps. So I, my case made me think of it, I'm 30 to 35."* Fred

Similarly, patients used these classifications to judge the effectiveness of treatments. Adam stated, *"they've actually brought me from being moderate to severe up to moderate which is good."*

In the interviews of health professionals, it was only the specialist nurses that raised concerns about patients limited understanding of these terms. Diane (experienced heart failure CNS) reviewed patients 2 days/week in her nurse-led clinic. Diane commented:

> *"Sometimes, they get, people can get very fixated on figures and then they think, if the EF has got worse or gone down or the BNP has gone up, it can mean something terrible. And it might not be very much of a change. Now, I've had people that will say, but my ejection fraction was 35 last time and now it's 32 or it's 30. And I think it's actually really not very much, it depends how it's measured or whatever else. It's not significant."* Diane

Nurses spend more time with patients, allowing them greater insight in to patients knowledge and understanding. Nurses were more likely to recall individual patient's level of understanding compared to physicians. In contrast, the treatment discussion between patient and physician during clinic consultations often involved complex information about investigation results and risk communication.

Patients were aware of their own mortality. This was expressed in a variety of ways with older male patients often using humour and a matter-of-fact style: *"if you die, you die and that's the end of it"* and *"well if I pop it... there's a funeral director on the corner."* Others focused on the practicalities of preparing their effects, *"doing an archiving exercise... just supposing I die off."* In contrast, younger patients described their commitment to living a long life. They used terms such as *"I'll prove them wrong" and "I'm one of these people that can get through anything."* Most knew the nature of decline in heart failure, but they wanted to know how long they had left.

This gap in knowledge may be due to how professionals approach the discussion of mortality and prognosis. When interviewed, consultants preferred a positive approach to communication about prognosis. There was a preference to give hope and offer treatment to extend life. Jim (consultant cardiologist) stated:

> *"I can't give them false hope but, equally, I don't want to give them no hope. So we talk about extending life and how important that is, but also the quality of life, which is equally as important."* Jim

Patients and relatives wanted health professionals to provide them with more information. Most wanted to know more about the cause of their heart failure and greater specificity regarding prognosis. Some patients believed that health professionals were purposefully withholding information. Adam was a 48-year-old husband and father of two. He was diagnosed with heart failure 2 years previous and described symptoms on moderate exertion (NYHA II). He expressed the view that physicians have the tools to quantify and predict longevity and quality of life but chose not to share it with patients. Adam commented:

> ***"****I can probably appreciate that most doctors not wanting to say something but they're all saying that well we can't really diagnose how long you've got or what quality of life you'll have, well you've got plenty of statistical analysis that let you know what your broad outline is."* Adam

Younger patients valued information related to practical information such as mortgages and insurance advice. Knowledge they deemed valuable to supporting their normal activities and family life, their ability to work and go on holiday.

These findings highlight that patient information needs are arguably not being met by health professionals. One reason for this may be related to how professionals assess patient information needs. Most health professionals interviewed determined patient information needs by the patient's level of engagement in treatment discussions, with many taking a reactionary approach to information provision. If patients asked for more information or raised queries about information they had sourced elsewhere, professionals would provide additional information or clarification. Patients who did not ask, did not get.

This behaviour was reflected in the interviews with patients whereby there was a common perception that patients had to be assertive in discussions so to *"get something back."* Paula believed she needed to *"push a bit where we feel things aren't right."* Similarly, Donald (91-year-old patient) commented:

"But if you go in like a mouse, right, you come out with nothing. But if you go in and you're positive and you say, I want this, or I've got this and I don't feel, I feel something, I don't feel well, or I'm getting swollen ankle, or whatever it may be, if you are positive to the doctor or practice nurse, you get something back." Donald

Physicians described educated patients as wanting a *"long-term plan or long-term prognosis."* Conversely, less educated patients were assumed to be more interested in their quality of life. Professionals viewed their role in meeting patient information needs differently, depending on their professional discipline. Physicians viewed information provision and patient education as a primary role of the heart failure nurse. Charlie, an experienced cardiology SpR commented:

> *"I think we doctors are extremely bad at lifestyle advice, and I think that heart failure nurses are great at it… Whereas doctors, we tend to be very medication and device focused, so we spend a lot of time fussing over how best to program the CRT, but don't spend very much time not telling them lose the salt on the chips, shall we say."* Charlie

This is likely due to physicians focussing on treatment during clinical consultations. The time constraints and complexity of explaining the rationale, risks, benefits and relevance of treatment meant that physicians were less likely to engage in health education. Jim commented on the importance of patients understanding the combined approach of treatment, medication and healthy lifestyle choices to manage their heart failure:

> *"Making sure they understand the risk benefit ratio, that not every treatment saves life immediately and that some treatments take a very long time to work and some treatments need a bit of persistence on their part, like taking the tablets, like doing exercise rehab, like losing weight or controlling diabetes."* Jim

Professionals agreed that patients' inaccurate knowledge was one of the greatest barriers to treatment discussions. Samuel commented:

> *"Maybe some patients might have heard about the CRT and from other doctors, or GP's, or other specialties possibly, but still we have to be firm in our advice, but we always need to explain to those patients that, and spend a few minutes with them explaining clearly why they're not candidates for that type of treatment"* Samuel

Many physicians described their time spent in clinic was overshadowed by the time taken to explain why certain treatments were not appropriate for individual patients. With a short time to discuss treatment and management plans, it's clear to see why many physicians had negative views towards patients independently sourcing information.

5.5.2 Value of different sources of information

Certain socio-demographics and patient characteristics have shown to influence individual's health information-seeking behaviour (Chung et al, 2012). The findings of this study add to the literature-base. What emerged from the interview data was the value patients and relatives attribute to different sources of health information and the reasons for their preferences. Key sources of information were raised in the interviews. This section focuses on how each source is viewed and valued by individuals within each cohort and the influence of the information sourced on patient health beliefs and behaviours. These data are presented in the order of greatest influence on patients' decision-making processes. Firstly, the internet, then friends, the media, followed by written information leaflets.

Patients and relatives valued the internet as an important source of information. For many, use of the internet was integrated in to their daily lives. Patients and relatives described using the internet to do shopping, searching for holidays, purchasing flights and tickets to events. Most described having access to at least one internet-enabled device (commonly a smartphone). Patients and family members used their mobile phones for general internet searches to *"look things up"* and for keeping in contact *"send emails."* The process of searching for health information on the internet varied. Patients and relatives had differing views about the trustworthiness of information. Of key importance was the value of the information sourced depended on how they perceived the information to align with their own beliefs. Patients who preferred a professional-led approach to decision-making also described value to the internet. This behaviour of self-directed 'checking' or 'validation' of information provided by health professionals was common regardless of age, gender, symptom severity or education background. However, no patient or family member viewed the internet as a replacement for health professionals.

In the interviews with patients, 16 (73%) referred to health information that originated from the internet. Thirteen of these patients described independently searching for health information online *(see Table 5.9).* Five patients described not using the internet of which two, referred to online health information their family or friends had sourced. Patients who searched the internet for health information were more likely to be younger (mean age 53 years, range 34-72 years), symptomatic on mild exertion (NYHA III) (7 (54%)), all college or university educated and had been diagnosed with heart failure two to five years ago. Few patients who lived alone described using the internet to search for health information (2 (15%)). These patients were older and valued the advice of physicians over other sources of information. Patient and family member's health information sourcing behaviours are summarised in *Table 5.10.*

Table 5. 9 Patients health-seeking internet use

Characteristics	Total sample n (%)	Patients who searched the internet for health information n (%)	Patients who did not use the internet n (%)
Male	17 (77)	11 (85)	2 (40)
Mean age (years) (age range)	62 (34-91)	53.7 (34-72)	67.6 (63-70)
Ethnicity: White British	21 (95)	12 (92)	5 (100)
Symptom experience: NYHA II NYHA III	 11 (50) 11 (50)	 6 (46) 7 (54)	 4 (80) 1 (20)
Years since diagnosis of HF: ≤1 2-5 6-9 ≥10	 2 (9) 12 (50) 5 (18) 3 (18)	 0 (0) 9 (69) 3 (23) 1 (8)	 2 (40) 1 (20) 0 (0) 2 (40)
Lives alone	4 (18)	2 (15)	1 (20)
Education background: Low - High school Moderate - College/trade/technical Higher - Higher Education Institution	 5 (18) 8 (68) 9 (4)	 0 (0) 5 (38) 8 (62)	 3 (60) 1 (20) 1 (20)
Total:	**22**	**13**	**5**

Table 5. 10 Patients and family members' internet searching behaviour

What health information	How	Why	When
Information about health professionals	Google search, Hospital Intranet	Self-referral Reassurance	Prior to clinical encounter
Diagnoses	Google search BHF, CMA websites	Clarify/verify information discussed during consultation	Change in symptoms Post consultation, on receipt of clinic letter
Medications	Google BHF, CMA websites	Further information, side-effects	Pre and post clinic consultation
Treatments/ interventions	Google, manufacturer website	Practical implications, recovery, risks	Ongoing
Investigation results	Google	Clarify/verify health status	Post clinic consultation
Novel treatments and clinical research	University/hospital websites	Improved QOL/longevity when medically optimised	Ongoing

Responses listed in order of how frequently they were raised in the interviews.

‘Google’ was the primary search engine used to source health information by patients and relatives. Terms searched for included diagnoses, treatments, investigation results and research. In the early stages following diagnosis, these searches often fuelled anxiety. Relatives described lists of complications of heart failure they had found online and their shock when reading about *“sudden death.”* This negative experience did not stop them from using the internet to search for information but did make them more cautious of the websites they used.

Janet (68-year-old patient) raised concerns about information she had found online about her gallbladder condition. As well as searching for information about her heart failure she also searched for information about other conditions. Like most, she started with a general search of the internet using google. This was the search engine she valued most as she used it as part of her everyday life. Janet was anxious about her findings but chose not to share this information or her concerns with her heart failure team. Janet commented:

> *“I looked it up and they said it can go cancerous, porcelain gall bladder, and you should get it, have it taken out straight away. That’s what it tells you on Google, they don’t mess around, got a porcelain gall bladder, out it comes…. cause it is at the back of my mind, that it’s there, and it doesn’t give me any discomfort or pain, but I don’t particularly want it to go into cancer, you know? And it does say that when I Google it, I told you I Google everything.”* Janet

Patients also used Google to search for information about their consultant’s expertise and reputation. This information was used by patients to make decisions about self-referral. Most searched for information about treatments and medications including searching the manufacturers of devices (PPM, ICDs) and pharmaceutical companies. Few patients described limited value of general search engines, “*not Google, Yahoo or anything like that.”* These patients preferred accessing charity websites to search for information. The most frequent sites used by patients were the Cardiomyopathy Association (CMA) and the British Heart Foundation (BHF) websites. Patients and relatives chose to use these particular sites because they believed the information was reliable. This is likely to have stemmed from conversations with professionals who described signposting patients to these specific sites. Patients that searched these validated websites were from higher education backgrounds and interested in novel treatments and research. We found no influence of age or gender.

Most patients and relatives did not trust information on American websites. This was based on limited trust in the credibility of large American pharmaceutical companies. There was widespread agreement that American sites *“exaggerate”* and are *“almost scaremongery”* whereas British websites were viewed as *“honest.”*

Patients and relatives frequently used the internet to search for information about their symptoms, medications and treatments before seeking medical advice. Following the clinic consultation patients used the internet to confirm the validity of information provided by health professionals. Additional information was sort to satisfy their own views towards the advice of professionals. Paula used the internet to search for further information to relieve her anxiety after speaking with her cardiologist, *"and of course it's why you then go on to the computer and start looking things up."* Family member's main motivation for searching the internet for health information was to seek reassurance. Their actions were to clarify and/or verify information discussed during clinic consultations, often prompted by receipt of clinical letters. Similar findings relating to the timing and motivations for internet use have been reported in the literature (Tan et al, 2017).

Patients who used the internet to search for health information were more likely to live with a spouse who did the same. Yet searches were commonly conducted independently. Some patients would then share the information they had sourced with their relative. Conversely, family members often chose not to disclose their internet findings with their relative. The main reason for this was not to worry their relative or burden them with negative information. Karen (54-year-old patient's wife) worked as a teacher and often used the internet for work and at home to research her husband's treatments. Karen described 'covertly' using the internet to review her husband's blood results and compare them to the 'normal ranges.' Karen did not mention the particularly websites or tools she used to make this assessment. She did describe this as a regular behaviour that helped her to make sense of her husband's condition. Karen stated:

> *"When they've done tests on him and they'll say the levels of his kidneys and things, so then I'll be like, I always do it when he's not here as well, because I always think, oh God, if it's not good, I'm not good at hiding things on my face."* Karen

Patients who did not use the internet to search for health information commented on a family member or close friend who did. These patients tended to be older. Beth was a 68-year-old retired patient who kept socially active by running a local flower group. She lived with her husband and had grown-up children who were all active in her heart failure management. Beth did not have access to the internet but commented on the information her son provided:

> *"Michael (son) had been doing his nose in on there again, on his computer, and he phoned me up and he said, mum, I don't want you to take those tablets, he said, there's not a good write up."* Beth

Although Beth described her son as *'fussing,'* when his advice was confirmed by her physician she described value to the internet. Patients relationship with their family member influenced how they valued the information. Mary, a 61-year-old patient who relied heavily on her daughters for advice and support, carefully considered the information they had sourced online. She saw this process as helping her to include her daughters in her heart failure management:

> *"I would leave it with Wendy and Steph, this is what they want to do, this is the tablet what do you think? They'd look upon it, they'd look it up and they'd go through all the pros and cons, and then they'd tell me*

> *if I, if it's advisable, and I'd get their opinion from the both of them, because I trust them two with my life."* Mary

Others who described the internet as *"rubbish"* still described occasions when they had sought health information online. Patients would cherry pick information that reinforced their own views. Nick (34-year-old patient) commented on his mother's use of the internet, *"(she) would be googling…all this new medication."* Nick described negative views toward the internet but did admit to occasionally searching online. Nick commented:

> *"No, I'll always try and follow what she (heart failure nurse) says to me really. I don't want to start looking up on Google or stuff... Because it's just all crap. Basically. I'll probably have a look at what it does and everything."* Nick

Interestingly, patients who had previously shown preference for a professional-led approach to decision-making also searched for health information online. Bill commented on using the internet to find out further information after speaking to the nurse. He considered health professionals to be *"the experts*" but also chose to 'check' the information they provided by searching the internet. This was an important process in helping him to decide whether to act on the nurse's advice. This process of validation was common regardless of age, gender, education background or the professional providing the information. Bill commented:

> *"I'll do bits on, so long as I can do it through by phone, but I've never used a tablet or anything like that…. anything that the nurses tell me, then, yeah, I'll take it in and I'll even look it up and try and find out… I'm interested the way anyone would be interested, but I'm not going to be knocking the hospital's door saying, oh, there's a new drug out, I want to try that. I'll follow what they tell me. They're the experts, they know if it'll be good for me."* Bill

Patients who did not use the internet to search for health information preferred to rely on the information provided by their physician. These patients were more likely to be male. We found no influence of age, education background or whether patients lived alone. Blaine stated, *"years of experience rather than the internet giving you bits and bobs. No, I'd rather hear it from the doctor."* Similarly, Daryl responded, **"***why muck about taking advice from people who don't know, and internet, you do all this, when it's got to boil down to your GP at the end of the day."*

In the interviews with health professionals, few raised questions about patient use of the internet. These findings are likely to reflect the limited number of patients and relatives who chose to discuss this information with professionals. The primary reason for this was patients not wanting to *"waste their (health professionals) time."* In contrast, nurses and physicians described regularly sign-posting patients to validated websites, commonly the *"British Heart Foundation," "Arrhythmia Alliance," "Cardiomyopathy Association."* Recommendations often stemmed from each health professionals own experience working with that group or charity. One consultant based his recommendation on his experience of writing the health information literature for the charity.

Physicians viewed the ease of access to health information online as taking away their sense of control, "*you don't quite know what source they're looking at, it could be dreadful."* Physicians described their role as trying to *"demystify what this actually means for that individual patient."*

Only two health professionals shared the belief that the internet was a positive source of health information for patients. William was an experienced cardiology SpR who specialised in inherited cardiac conditions (ICC), cardiomyopathy and clinical research. He often discussed treatments with young patients and their families in his ICC clinic. William viewed the internet as an important source for patients to validate information he provided, "*then it reinforces, it means that they have a little trust in what their cardiologist was saying."* William's positive view towards the internet may in part be explained by the young patient population he saw in clinic. These patients were often young couples with children who were likely to use the internet frequently as part of their everyday lives. These patients may be more engaged in discussions about the internet.

Health professionals described patients '*health interest'* as a factor influencing their internet use. Patients who were more engaged in their heart failure management (self-monitoring at home, adopting healthy lifestyle choices) were believed to be more likely to use the internet. Professionals also viewed patients from higher education backgrounds as more likely to source information online. They were less likely to discuss internet use with patients from lower education backgrounds.

Friends were an important source of information for patients and relatives both by enabling access to information online and by validating patient symptoms. There was agreement among health professionals that patients highly valued the advice of their friends. Professionals believed the recommendations of friends influenced patients' views toward treatment, *"people relate very strongly to anecdotes, so I had a neighbour or a friend who had this procedure."* As discussed in Chapter 2, this view is reflected in the findings of the recent report of the Academy of Medical Sciences (2017), who conducted an observational study which reported 65% of the public trusting advice from their friends and families about medications, compared to only 37% that trusted evidence from clinical research (Hawkes, 2017).

Patients frequently compared their health status to that of their friends. Karen was concerned her husband would end up like her friend's husband who had a *"similar thing"* and *"just gone onto dialysis."* Similarly, friends experience of treatment directly influenced patients' own beliefs about treatment. Bruce was a 74-year-old patient who talked about his close friend who chose not to listen to his doctor's advice and refused to take his medications. His friend's experience emphasised the importance of medication compliance to Bruce:

> *“I have a mate of mine who died didn’t he? Well he was a diabetic, but he wouldn’t do as the doctor told, he said that they’re rubbish and of course the next thing… But they changed his tablets and he just wouldn’t take them”* Bruce

Patients also described their friends initiating discussions about treatments and clinical research. Janet referred to her close friend her prompted her to self-refer for a clinical trial and contact the Principal Investigator directly:

> *“Because my friend who’s interested in all these trials phoned me up and I said, well I’m not going on a trial, and she said, what’ve you got to lose… She said the NHS have just said you’re stable and that’s OK and I wasn’t in a good place, and so she said if I didn’t do it she’d never speak to me again. A very close friend.”* Janet

Patients and relatives particularly valued the advice of friends that worked in healthcare, regardless of their professional discipline. This was reflected in interviews with health professionals. Linda (consultant cardiologist) was concerned about the quality of the information patients were sourcing. She commented:

> *“I once had a lady who was taking notes and I said, I can see you’re taking notes, is there a particular reason for this? And she said I’ve got a friend who’s a doctor, and I said I’m more than happy to send you a copy of the letter if your mum is happy for that to be shared by your friend who’s a doctor. I said are they a cardiologist? She said no, they’re a psychiatrist, and I went OK.”* Linda

There were some patients that preferred not to talk to their friends about their heart failure, *“if my friends comes in I’m not going to tell them look, this is my file.”* This decision was often based on their experience of a friend’s negative comments, “*there was a couple of them (friends) that said, oh I wouldn’t do that, blimey, because naturally you can have a tooth out and die can’t you?”* These patients were male and preferred to seek health information directly from the health professional. We found no influence of living alone on the value patients placed on the advice of their friends.

The media was a further source of health information described in patient interviews. Patients and relatives had different views towards the media. Younger patients had limited trust in the media and described not taking it *“too seriously.”* Regardless of age, most patients valued information publicised about new clinical trials and novel treatments. Patients and relatives commented on information they had read in newspaper articles and watched on the news. Treatments and medications publicised in the news were referred to as *‘the new cure,’ ‘new possibility.*’ The type of medium (tabloid, broadsheet, television) did not influence how patients valued the information. Alternatively, patients viewed the publicity of novel treatments and clinical research to increase their value: *“excited to be in the trial as seen it mentioned on the news”* and *“the X trial we were really excited about that and it was on the telly.”*

Interestingly, patients were more likely to ask professionals questions about information they had seen in the media compared to information they had sourced from the internet. Information from the media prompted patients to raise questions in the clinical encounter, particularly about medications. There remained negative views about the use of statins. Steven referred to watching a news bulletin discussing the benefits of novel oral anticoagulants (NOACS). Steven commented:

> *"I saw this drug on television about six to nine months ago and it supposed to be everything that you would require and it's expensive. They did say that and I go back to the doctors and he says I think you would be better off staying on Warfarin"* Steven

During the time that health professionals were being interviewed the new medication Entresto® was added to the ESC guideline recommendations for the treatment of heart failure (ESC, 2016). This drew global interest and was publicised nationally and internationally. Health professionals perceived the media to be more influential than the internet on patient views and behaviour. Some physicians viewed media publicity as helpful, giving patients knowledge about new drugs. James (an experienced cardiologist) explained, *"so he (patient) read in the Daily Mail about Entrestro, was reasonably knowledgeable about it although it was the Daily Mail and wanted to know about whether he could actually have the drug."* Others described the media as "*sensationalistic and frightens patients."*

Nurses described the challenges of managing media publicity about new medications. They perceived patients as blindly following the recommendations of the media regardless of previous experience of side-effects. The role of nurses in medication optimisation and the close titration and monitoring required by Entresto® made them the key contact for patients and relatives. Nurses received frequent phone calls from patients wanting to start a new medication publicised in the media. Many found it challenging having to explain the suitability of that drug for that individual person. Diane stated:

> *"When a new drug or new treatment comes out, or something's in the Daily Mail, and people will ask and they'll phone… we have patients that'll come to clinic because there'll be something in the press about the latest tablet. At the moment it's Entresto… "it's quite amazing how people will have side effects from everything else but they'll want to try, can't take this, this, this, have a reaction to this, but I want this new tablet that I've seen in the paper."* Diane

The information that health professionals provided to patients was primarily in the form of written information leaflets. This is common practice in the UK and forms the primary source of professionally-verified information literature supplied in hospitals and clinics. There are many leaflets developed for heart failure patients with various content on specific diagnoses, management, medications, treatments, lifestyle advice and self-management techniques. The importance of the latter two in particularly have been emphasised in the 2016 update of the ESC clinical guidance for patients with heart failure (ESC, 2016).

Both hospital Trusts involved in this study provided written information leaflets to patients. Many had been developed (often co-written) by health professionals and were disseminated throughout the hospital wards, outpatient departments and by specialist teams. The choice of leaflet provided to patients was often based on the preferences of consultant cardiologists, many of whom were affiliated with specific organisations.

Only a third of patients (32%) and two relatives (33%) described a 'general interest' in these written information leaflets. Patients who were older or recently diagnosed commented, *"you go have a look."* Most did not share this view. For some the content of the information leaflets caused panic and anxiety with terms such as *"palliative care"* and *"lasting power of attorney."* Others felt *"overloaded with leaflets."* These patients tended to be younger. Brian was a 55-year-old patient who commented, *"I think leaflets are a waste of time… you're given a leaflet and you put it in your bag, you get home and you think, what's all this about?"* No patient or relative mentioned the specific content of the leaflet that they found useful or how that information influenced their decisions about treatment.

In contrast, all professionals highly valued information leaflets as a primary source of information for patients. Their value was based on their accessibility, the information felt to be accurate and that leaflets could be read in the patient's own time. All physicians described regular provision of information leaflets to patients. Physicians described the importance of having information they could provide to patients that they felt was accurate and helpful. It also provided a sense of control in shaping patient knowledge about their heart failure. Control that was reduced when patients turned to the internet. There was a consensus that written information leaflets were useful to patients and their relatives. Only one professional (a nurse specialist) described concern over whether people found leaflets helpful or not.

5.5.3 Summary of theme

This theme highlights both demographic and situational factors found to influence patient preferences for health information. All patients regardless of age, gender and education background had limited understanding of their heart failure aetiology. This knowledge need led to misunderstanding and misinterpretation of treatment indications, suitability, their effects and their health status.

Patients are making decisions about their treatment based on information that validates their disease beliefs. These beliefs evolve primarily from their own experiences. Their knowledge and understanding are informed by information sourced from the internet, friends, family and the media. This information helps to shape their beliefs. Information provided by health professionals either confirms their beliefs or prompts them to seek out more information. The checking and validating of professional's advice by searching the internet, speaking to friends and family is often the final step before patients make their decision.

Patients require further information to improve their knowledge and understanding of their heart failure. The challenge is finding the best way to do this in practice. Only patients who ask for information seem to receive it. The majority turn to the internet to meet their information needs. Professionals' preference for the provision of information leaflets and limited discussion of internet use, means that current practice is unlikely to meet patients information needs. Key opportunities for information provision are being missed. To support patients to make decisions based on clinical evidence, disease need and personal circumstances, information needs to be provided in a meaningful way. Consideration of the contextual factors that influence patients' decision-making is needed to better understand their disease beliefs and health behaviours. This will allow for better tailoring of information to individual patients.

5.6 Ability to deliver a SDM approach

This theme explores the barriers and facilitators to delivering a SDM approach in heart failure management. A focus on the decision-making pathway, service delivery and patient-professional communication illustrates the challenges of integrating SDM in to practice, as well as opportunities for change. Key facilitators that emerged from the data include: Knowing patient motivation and value of treatment; a trusting relationship between patient and professional. Barriers identified include: the isolated process of MDT meetings; time constraints of clinic consultation; in-person versus remote patient management; and access to services. Differences and similarities in the views within and between cohorts are illustrated. The findings are presented under the two subheadings: Barriers to a SDM approach and facilitators to a SDM approach.

5.6.1 Barriers to a SDM approach

Complex treatment decisions in heart failure are made following discussion by the MDT, in dedicated meetings where different options are considered. As discussed in Chapter 3, the benefits of this process are in the input of multiple professionals from different disciplines and specialties, who come together to make high quality decisions. One of the key findings of the MDT meeting analyses was that this process is not always implemented in an inclusive way. Of interest was that no MDT involved patients in their meetings. Patients being excluded from this core process of decision-making may account for their limited awareness of how treatment recommendations are made.

The view of the MDT meeting as a medically-driven process was highlighted in the interviews with professionals. This emphasised the isolation of this core part of the decision-making pathway and likely accounted for the limited discussion of MDT meetings with patients. Only four health professionals described the role of the MDT in treatment decision-making in heart failure management. Their focus was on its usefulness in making decisions when guideline recommendations were unclear. James was an experienced cardiology SpR and commented, "*think is where the MDT is very helpful, certainly if we're prescribing or recommending treatment that's outside the guidelines and the MDT is a very powerful tool."* Others described its usefulness when managing, *"patients that are coming to end of life."* No health professional described discussing the process of MDT meetings with patients and their relatives.

Themes 1 and 2 illustrated the core role of the clinic consultation in discussing treatment options and the importance of the information shared on patient decisions. It was interesting to find that some professionals reported patients often not knowing why they were coming for a clinic appointment. This lack of knowledge was a barrier for professionals as it required increased time to explore patient perceptions and expectations. Tina commented *"you'd be surprised the number of patients who turn up saying, well I'm not really sure why I'm here."*

Both patients and professionals referred to the negative effects of short consultation times and busy clinics. Janet described the *"depressing"* nature of attending her hospital outpatient clinic with the long waiting times. Both nurses and physicians felt time constraints were the greatest barrier to a collaborative approach. There was a strong belief that patient needs could not be met with current resources. To overcome this burden, some physicians created their own strategies to allow for flexibility and the tailoring of care to individual patients. Jim, a senior consultant cardiologist described having to manage his appointments to meet policy requirements. Jim commented:

"You're allowed two follow ups to one new, so you might have to work round some patients having quite a few more to get right and others just being discharged after one appointment." Jim

This tailoring of outpatient appointments was also made by nurses. Heart failure nurses would often be in contact with patients by phone and, *"judge when I'm (nurse) going to see them."* Jim described this process as a game, *"and we're all in the game where you have a limited number of appointments."* Jim had previously used humour to voice his anguish with current practice and the pressures on the services he provided. He made light of the issue of having to work around a 'broken system' most likely due to his experience of the pressures for many years working in the NHS (12 years). Jim went on to share his disagreement with health policy and his concerns about discharging complex patients back to the community:

"I completely disagree with government policy for two follow ups to one new appointment, then I'll bounce you back out to your GP, who's got no bony notion about the complexities of the issue, who feels frightened of treating that issue, who would much rather you did it anyway." Jim

For patients and relatives, limited time often meant not having the opportunity to ask questions. This included patients who engaged in treatment discussions and who prepared a list of questions prior to the clinic appointment. Debbie a 63-year-old patient who had been diagnosed one year earlier commented, *"I do write a list of questions, but I never get a chance to ask them."* This experience of *"having to rush*" was reflected in the interviews with physicians with Charlie (SpR) comparing these pressures to, *"chasing rainbows," "you never have enough time."*

A further barrier to the process of treatment discussions was the difference in views between physicians and nurses towards the need for in-person consultations. Nurses strongly supported seeing patients in-person which they felt was necessary to gain the full picture of the patient. This is likely due to nurses having longer consultations with patients. Nurses described this time as gaining a more holistic picture of the patient and their condition, there personal circumstance, time for education and psychosocial support. Diane was an experienced heart failure CNS and commented on the importance of 'seeing' the patient in terms of developing a relationship with the patient and assessing their condition. Diane stated:

"I actually think you gain more when you see someone. Because there are lots of, as I say, you make the, get a relationship that way… But actually nothing really beats seeing a person, because a patient can tell you or you can see on telemonitoring the way it's stayed the same. But then when you see them, the, you actually find they've actually lost weight and they have got oedema or they've not picked it up. Or if they're a little bit unkempt or something like that, you find out more about patients." Diane

Diane referred specifically to the role of tele-monitoring in heart failure and her belief that this management strategy can provide misleading information to professionals. Diane had worked in the past on clinical trials using remote monitoring in heart failure and in her clinical role with patients who had devices implanted. She was experienced with the technology but believed in-person consultation was more valuable. In contrast physicians described the number of unnecessary clinic appointments and the need for better monitoring. Samuel, an experienced cardiology SpR working in heart failure for the last 10 years commented: *"I don't think that a visit to see the doctor every few months is going to make much difference, provided that there is a plan in place."*

He went on to highlight the inefficiencies of current service provision and need to focus on remote monitoring which he felt patients would favour: *"I think that bringing the patients for unnecessary appointments doesn't necessarily add to their quality of life either. Since we cannot provide this efficiently at the time being, so I think that it is quite important to try to see them on a regular basis, but in part we would need to try to improve our monitoring system... I think patients would like less visits to the hospital and more communication, another type of communication, remote monitoring would be an option."* Samuel

One physician described initiating 'skype consultations' in his service. *"For one part of the service people come from all over the country and it's difficult to justify coming from Glasgow to say how are you? In the new clinic restructuring we're going to be able to do Skype consultations, the clinic will be set up for Skype."* William

These views were based on the different delivery of services between physician consultations and nurse-led clinics. Nurses valued the in-person consultation as they could discover new issues that previously had not been reported, only through observation in-person. Nurses were frequently the first port of call to patients and their relatives and therefore often arranged unscheduled clinic visits to review patients who were deteriorating. Seeing patients in clinic meant that nurses could discuss any issues with physicians, who may be called upon to review these patients and commence/alter treatment. Nurses described occasions where they had been frustrated that patients had not accessed help sooner and their symptoms had deteriorated. Nurses likely felt safer seeing patients in-person in the hospital, where they could call upon assistance from physicians and admit the patient if necessary.

In contrast physicians would see patients in clinic as new referrals, for follow-up or for new treatment discussion. Physicians were more supportive of alternative strategies that could free-up their time to deal with complex patients. Tele-monitoring and remote consultation were favoured. We found no influence of age on support for technology. Interestingly, all physicians viewed patients as valuing fewer visits to hospital and increased use of technologies such as tele-monitoring and skype.

New methods of service provision have been developed in heart failure management in attempts to streamline resources and reduce the number of patient visits to hospital. One of these systems has been referred as, *'the one stop shop'* where patients attend the hospital as a 'day case' and undergo scheduled tests and investigations and then are reviewed by their physician and nurse specialist. The aim of this service is to streamline care for heart failure patients and increase patient satisfaction. In cancer care these clinics are well established and have shown to improve patient anxiety levels (p<0.00011) (Dey et al, 2002).

Both nurses and physicians had concerns about the efficiency of these clinics. Nurses highlighted the emotional and mental strain placed on patients and their families having to undergo a full day of consultations and investigations. The practical impact of patients having to take time off work to attend a full day at the hospital. Diane commented on the MDT device clinic she was involved in:

"Because if you've got to see three people on the one clinic visit and three different people, that's really challenging from a patient perspective. I'm not sure a lot of patients would want to engage for that length of time. And I'm not sure, as an individual, I would want to engage with a new diagnosis with three different takes on it, from a nursing perspective and the genetic counsellor perspective. That's a lot to ask some patients to take in. " Diane

Sally was a CNS working with LVAD patients and involved in their weekly day case clinic. Sally was concerned that their one stop shop clinic was not set up for those patients with limited family support. Sally described these patients preferring regular visits to the hospital. She commented: *"it's just one day up here, they get it all over and done with in one go. But then we do have patients that haven't got a lot of family support, and they like to come in every week. And so they're like oh, can I just come in for that this week, and then I'll come in for the echo and the exercise next week? Because I think they like the contact."*

Physicians raised concerns about the complexity of setting up this service and ability to tailor services to individual patient needs. Some patients would need to return for follow-up tests and investigations. Tim was a cardiology SpR and commented:

"Other factors to consider how we are booking the patients and whether the patients are willing to stay for a few hours to have all the checks done, and in some cases it's not even convenient for a patient, because we might go through all the investigations and we might not get the answer we're looking for so we'd have to consider referring them for an MRI or a CT thereafter and then we'd bring them back on a following day, so it might not be as convenient as we think it would at the end of the day." Tim

Patient preferences for how services were delivered were influenced by the practicalities of attending the hospital. Cost of travel was found to be an important barrier for patients. Chris was the wife and primary carer of her husband. With limited finances, she described the cost and effort for her husband to have to attend the hospital appointment with his heart failure nurse whilst she was at work, *"Carl used to go to the hospital to see the heart failure nurse, but it was quite difficult for him to get there, it was two buses or it was a taxi and the taxi cost £10 each way."*

This issue was raised by professionals. One consultant Tina observed an association between patient socio-economic background and their attendance at clinic. Tina worked both in the specialist heart and lung hospital receiving referrals from all over the country and in community heart failure services in a low-income region of inner city Liverpool. Tina commented:

"Income area, and those people do struggle and it does cause a relative high DNA rate to clinic. I don't know if that directly relates to the cost of the bus to get them there but there is a mind-set that doesn't allow them to come out that much and I think some of that is related to finance. Asking somebody to come back on very frequent basis is a challenge for those patients. Other people embrace it. So the retirees who are, we deem to be the upper, the higher socioeconomic classes are very intelligent and involved in their care, I know they relish coming back and there's no problem bringing them back and cost doesn't seem as much an issue to them." Tina

Age was also a factor found to be associated with how patients valued a day clinic. Janet was happy to attend a day clinic but was aware that younger patients may find it difficult.

"At our age, whether it's half a day or a day, doesn't matter very much, because we're not going to do very much anyway. I suppose younger people that have got work to go to or kids to look after or something else, yes, they have a different priority. And so, visiting hospital for half a day is a major trauma, whereas for a retired person it's not.' Janet

Professionals were concerned that some patients were not accessing healthcare services. Anna commented:

"It's not your patients who maybe aren't as well educated who maybe don't engage or maybe have mental health issues and don't visit the GP because they just don't like being in that environment. We have some of them but we also have the other extreme of highly functioning individuals who just ignore their own health." Anna

Young patients were less likely to access services as they thought they were too young to be having health problems. Nick commented, *"It's been a blur, I suppose. In that sense that you, and being young, you don't really think it's anything bad, it's just, oh I'm all right."*

Despite the differences in value of in-person consultations all patients highly valued being able to speak to health professionals to ask their advice. Many contacted nurses and physicians by phone and email. Patients described value in calling the nurse specialist for advice on their symptoms and medications. Simon commented: *"I'd like to see someone and keep in contact with them to let them know that what's going on, so I've got someone to talk to really."*

Many patients and relatives were frustrated with the poor access to medical correspondence. Andrew was angry that he had to keep contacting the hospital staff to get his next appointment letter sent out. He described feeling let down by the staff:

"*I've had to phone them up and say, you've not sent this letter out or this letter, or when's my next appointment. I get transferred over to a heart transplant co-ordinator who, to put it mildly, are very nice to you on the phone but they don't seem to be doing anything for you. As soon as you put the phone down they forget or they don't pass the message on."* Andrew

A further barrier to service delivery raised by patients and their relatives was poor continuity in health professional. Bruce was 74-year-old patient and described his frustration about being moved under the care of another doctor who wished to change his medication regime. Bruce stated, "*but they've put me under another doctor now that I've not met yet so I don't know what he will be like yet. Yeah because they all seem to want to swap things."* Similarly, Jane (wife of patient) commented, "*I suppose my frustration is, and it's no-one's fault, but you get into a system, you get into a hospital or doctor's system and people come and go and you get left and that's what happened with Charles."*

This lack of continuity was mirrored in interviews with health professionals, particularly in relation to community services. One heart failure CNS commented:

"In the community teams they're seeing patients quite a lot now, and the way that the community teams are commissioned, they discharge patients for six months and they get them back and then they discharge them, they get them back in and they discharge them. So I'm getting a feel of the patients who are coming back to clinic saying, the nurse has discharged me. Patients are getting the impression that actually nobody wants to care for them past that point." Anna

Others found referring patients for services in the community challenging. Jim, consultant cardiologist commented, *"the catchment area in our population is diverse and knowing and understanding what support there is in all those other areas is still quite a challenge."*

Reduced trust in health professionals, lack of regular follow-up and poor continuity of care were all found to influence patients' health-seeking behaviour. Nick described how he would wait until his symptoms became so bad they would "show up" when he went to the hospital. He had previously been turned away and told to go home when he was experiencing palpitations. He returned the next day with worsening symptoms and was then admitted: *"Yes and I'll wait and wait and wait, until they get as bad as they can, so they do show up."*

Many of these barriers that emerged from the interview data are not new. Rather they are well established problems that affect chronic care management across all healthcare services. Current service provision in heart failure management follows a rigid path, with limited room for flexibility to tailor care provision to individual patients. Changes have been made in attempts to overcome some of these barriers. Such as the 'one-top-shop' clinics, developments in remote monitoring strategies and the recent integration of 'virtual' clinics. Importantly, these findings demonstrate that different patients have different preferences and needs. Involving patients in the development of new systems of care delivery is important to ensure resources are efficiently used and supported by patients.

5.6.2 Facilitators to a SDM approach

This section presents the findings of the interview data that offer potential support for adoption of a SDM approach in heart failure management. Taking account of the barriers to service delivery and the realities of cost and resource constraints, these facilitators offer realistic changes that can be adopted into current practice. The findings presented aim to increase professionals' understanding of how a supportive and collaborative partnership with patients can be made. Focus is on the communication of treatments during the clinic encounter. This includes: the discussion of treatment options; building a trusting relationship with patients; and styles of communication.

Knowing patients' motivation for treatment and how they value different treatments is important, so professionals can adapt their approach to decision-making and tailor how services are delivered. Patient views towards treatments were influenced by their effects on the quality of life of their friends. Factors influencing how patients valued different treatments included: waiting time (time-to-treatment); understanding of eligibility (guideline recommendations); perceived outcome of treatment (life-saving ICD, one-off interventions); symptom relief and quality of life.

Patients interviewed in this study were supportive of research and novel treatments however, not every patient wished to participate in clinical trials. Patients' decisions were influenced by their experience of symptoms and stage of disease trajectory. Older patients were less likely to want to be involved in therapeutic trials requiring long term commitments. Those patients that were less symptomatic preferred not to change the status quo. Those patients that had been enrolled in clinical trials, found the process of regular follow-up visits and monitoring reassuring, they felt *"looked after."* Janet who was involved in one of the gene therapy trials for patients with advanced heart failure commented, "*I think it was, I great comfort when I'm having a blood test every three months."* Blaine, a 56-year-old patient enrolled in the same gene therapy trial commented on the benefits of being regularly assessed and reviewed by professionals:

"Yeah, you come along and you're having a scan, you're having this, you're seeing people at the top of their field, which is quite, yeah, as far as confidence. So yeah, you just know that you're being monitored, rather than waiting for a six months appointments or once a year appointments." Blaine

Patients viewed the effects of treatment in isolation rather than a combined response to multiple treatments and management strategies. The type of treatment, whether it was a one-off intervention or on-going management influenced the value patients attributed to it. Those who experienced immediate symptom relief from a one-off intervention described value to those treatments. These included PCI, Device therapy and radiofrequency ablations. Many attributed their improvement in symptoms and quality of life solely to the effects of one of these interventions.

Patients frequently described device therapy when talking about treatments. Patients and relatives referred to their devices using terms such as *"I feel almost mechanical"* and *"we call it the gadget,"* reflecting their limited understanding of the device function, but their trust in its effects. In contrast, ongoing treatments such as medication management were not afforded the same value, as patients did not experience an immediate improvement in their functional ability. Patients understood the importance of medication adherence and need for titration. Barriers that influenced patients views toward adherence included: regular monitoring, blood tests, clinic visits and side-effects. Patients described treatments that maintained the status quo (medication optimisation) as ineffective. Paul, a 62-year-old patient who was diagnosed with heart failure eight years ago, commented, "*Well we're in the same place as we were when we started really, I mean I still take the same medication the only difference is some of the diuretics."*

Paul had not experienced any improvement in his symptoms and viewed his medications as having little effect. At the time of the interview Paul had been optimised on all his heart failure medications and for most, had reached the target dose. He was unaware of the effects of his medications and their role in minimising his deterioration and prolonging life. Paul was classed as NYHA II and had not experienced worsening symptoms over the past year. Like many others, he viewed treatment effectiveness based on symptom relief.

Most patients were concerned about the effect of treatment on their ability to work, to drive, and possible changes to their insurance. Patients described wanting to *"feel normal"* as their primary motivator for treatment. 'Normality' was viewed as not *"feeling ill"* and being symptom-free. This was viewed as their ability to perform simple tasks such as walking up the stairs without stopping, doing the gardening and walking to the shops. Patients were willing to accept short term side-effects or pain, if the treatment would likely improve their functional ability. Nick a 34-year-old patient commented, *"you think you're going through the pain because you think it might make you better so you've had a shitty time but you take the rough with the smooth don't you I suppose."*

In the interviews with health professionals, older age and stage of disease trajectory were perceived to be factors that influenced patients views towards invasive treatments. Tim commented:

"If I'm a 60 or 70-year-old patient coming in for a huge or open heart procedure or even like device implant procedure, I'd be very reluctant and I'd be very anxious about it because at that age I wouldn't want to expose myself to any risks and being in a hospital would make me more anxious, but with younger patients I think it's not as horrendous as it sounds." Tim

Tim may have had this view as he was also young, with only a few years of experience as a cardiology SpR (4 years) in training. Sixty or seventy years was a long way off for him. Conversely, sixty years old is young for a patient with heart failure with reduced LVEF. This view was shared by other young physicians and influenced their approach to treatment discussions with patients. In contrast, more experienced physicians focussed on the importance of managing patient expectations. Linda an experienced cardiologist commented, *"I think it all depends really on the desperation of the patient and the expectation, which I think you have to manage as well. Because a lot of people, if they've been told there really is nothing else for you, and you put something to them that they may benefit from, they just grab with both hands."*

In contrast to the views of professionals, age was not found to influence patients views towards invasive treatments. Symptom severity was a far greater influence on patient decisions. Bill was 64 years old and symptomatic on mild exertion. He had only recently been diagnosed with heart failure (2 years previous). Bill stated, "*As I say, if I go, I go. I wouldn't want to go into serious stuff, serious operations, or heart replacements or, I wouldn't want to do that."* Nick also described preference for not taking additional risks with treatment. Nick was much younger than Bill (34 years old) and was satisfied with his current health status. Nick commented: *"I lead a normal life, and why, at this stage why take that, why take a risk?"* Nick was currently symptomatic on moderate exertion and felt 'well' in himself.

Interestingly, the value patients placed on treatments was influenced more by the health professional who recommended the treatment rather than the treatment itself. The development of a trusting and empathic relationship was very important and influenced how patients interacted with professionals and whether they agreed with their treatment recommendations or not. The language professionals used to describe treatments was an important factor in how patients viewed treatments. Bruce commented, "*Dr X says I'll give you the posh one."* Here Bruce was describing a new CRTD device. He described it as, *"all singing, all dancing,"* a phrase used to describe the device by his consultant cardiologist. This positive description gave Bruce confidence in his physician's advice and reassurance the treatment would benefit him.

Patients and relatives were more likely to engage in treatment discussions and act on the recommendations of professionals if they had a trusting relationship. Conversely, patients who described limited trust were less likely to follow their advice. Importance of the patient-professional relationship has been reported in the literature and shown to influence patient satisfaction and their compliance with treatment choice (Kornhaber et al, 2016; Chipidza et al, 2015). Trust was built through positive past experiences of treatments. Janet commented, "*Well because he thinks I'd have a better quality of life and he was 100% right."* But past experiences only formed part of patients' views towards treatments. Even patients who had negative experiences of treatments (both interventions and medications), would trust the recommendations of a professional they had grown to trust.

Trust in health professionals developed when professionals displayed certain attributes. Health professionals that *"know you so well"* was important in building trust. These involved professionals knowing the patient's medical background, their personal circumstance and showing interest in the patient's personal life, *"to have someone who is interested in what you're going through."* For patients this required time, continuity and an environment where they felt, *"put at ease and making you feeling as though you are a person."*

Patients and relatives described professionals they valued by name. Knowing something personal about their health professional (such as how many children they had or a recent holiday experience) was highly valued by patients. Some patients used humour to personalise communications. Donald commented, *"I pull his leg, or I say something, I like your hair. As a typical example I do that, because it's a way of getting to know people."*

Good communication skills helped to build positive and trusting relationships. This included being a good listener, the attributes of which included active listening skills, acknowledgement and normalisation of patients' views, a friendly disposition and being made to 'feel special.' Professionals who practiced these skills and behaviours were more likely to have patients engage in their treatment discussions.

Many patients expressed a loss of confidence following their diagnosis and the importance of reassurance, honesty and clear explanations by health professionals in the early stages. Patients valued professionals who were, "*very forthcoming," "explained everything," "nice to be reassured."* For others, value was given to a blunter communication approach. These patients tended to be middle-aged male patients. Steven was a 60-year-old businessman. He stated:

> *"I think a doctor that spends a little bit of time and tells you what you're going to get even if he says, even if I do this it's not going to make a difference. You know where you are."* Steven

Professionals agreed it was important to develop a trusting relationship with patients. Health professionals believed providing explanations of the rationale for treatments led to increased patient compliance. Charlie an SpR of 7 years in heart failure commented, *"I think if you take your time to actually talk them through it and explain why they're doing it, and what the rationale is, I think it's much more satisfying for the patient and I'm sure it improves their compliance."*

Physicians used different communication styles and language to tailor these explanations. Jim (consultant cardiologist) who specialised in device therapy described the indication for ICDs in a matter-of-fact style to highlight the severity of the situation and need for the device. Steven stated:

> *"So it's an idea of whether they've had any dangerous heart rhythms, and I use the word dangerous a lot, to describe why it's important. And sometimes it's a matter of saying that the reason that this device is in is to save your life in case something really bad happens."* Jim

Charlie took a similar approach: *"Patients who are eligible for CRT, as long as they're up for the procedure, as it were, they don't mind having the risk associated with the actual operation and putting in CRT you can normally be pretty frank and say, look we know that people that have hearts like yours and electrical conduction like yours do better if they have one of these special types of pacemaker put in, they feel better, they live longer."*

Some patients were less amenable to such a direct approach. Simon was a 42-year-old patient from a lower education background (High school). He found the directness of his consultant's communication style quite frightening.

> "*Ever since then they've been fretting with a pacemaker, you're going to need one, and all of a sudden he mentioned sudden death and, we're going to give you one whether you want one or not, basically, you haven't really got a choice in the matter otherwise you're going to drop dead*." Simon

Previously in the interview Simon described not wanting a pacemaker, he did not value it. Then he felt professionals wanted to shock him in to having it. The 'pacemaker' he was referring to was an ICD indicated for his diagnosis of Dilated Cardiomyopathy (ESC, 2016). Without previous experience of a sudden cardiac event, it was difficult for Simon to see the value in this invasive procedure. At the time, Simon had commented that his new physician was 'quite young.' This may have partly contributed to why he had limited trust in the device and negative views towards his communication style. Other patients shared this view. With limited trust being attributed to younger, less experienced physicians. John commented on his negative experience of younger physicians:

> *"Young doctors, they're not going to be knowledgeable about heart failure or heart failure drugs and I knew from the start that he wasn't that up on it because he told me that my main problem was right side failure, and it's actually left side failure"* John

Continuity in professional and access to them was important and increased levels of trust. Patients and family members highly valued the option to call the nurse specialist if they wanted advice or had concerns. Most family members described contacting nurse specialists if they had any questions regarding their relative's health. Karen was a 54-year-old wife of a patient and commented, *"if we did ever have a question, the heart nurses have been wonderful, you could always just ring."* Similarly, Sandra, a 65-year-old, referred to her husband's heart failure nurse as, *"Fiona's been a very stable force."* Sandra commented:

> *"Say if he thought, like he split one tablet that he takes, 3.75 I think in the morning... chat with (the nurse), would that be all right then, can I do that, that sort of thing."* Sandra

Importantly, patients and relatives that formed a trusting relationship with their heart failure nurse were more likely to seek their advice before altering their medication regime. These findings demonstrate the strong influence of a trusting relationship on patient access to services, compliance with medication and self-management and monitoring behaviour.

5.6.3 Summary of theme

It is important for professionals to know why patients value different treatments. This provides a better understanding of how to approach treatment decision-making with different patients. Despite different patient motivations and values, their views toward treatments were largely influenced by their relationship with their physician or nurse. The role of a trusting patient-professional relationship should not be undervalued. This theme has illustrated the key factors that can support professionals in adopting a shared approach to decision-making in practice. Despite the time constraints and limited resources, greater understanding of the needs and preferences of patients is needed. This will lead to better service management that can meet the needs of patients and health policy.

5.7 Synthesis of results

5.7.1 Different types of patients

The SDM model of care described in health policy focuses on patient and professionals' behaviour during the discussion of treatment (Coulter and Collins, 2011). In practice, the clinic consultation is the primary point of communication between the patient and professional about treatments. As described in Chapter 2, there is a continuum of styles of consultation that extend from a paternalistic approach through to a consumerist or an 'informed consent' approach. The SDM model assumes a collaborative approach between patients and professionals. The findings of this qualitative study challenge this classification with patients' approach to decision-making not always falling in to one of these distinct styles.

Two types of patients emerged from the interview data. Patients who preferred health professionals to take the lead in treatment discussions and patients who preferred a collaborative approach to treatment discussions. Patient characteristics were found to influence their approach to decision-making and their value of different information sources. Patient preferences were influenced by their age, gender, education background and symptom severity. *See Table 5.3*. Four types of patients were identified based on the two variables found to have the greatest influence: age and education background. Age was found to be the greatest influencing factor for patients ≥70 years and for patients <45 years. For the remaining patients, education background was found to be the greatest influencing factor. *See Table 5.4.*

Table 5.1 1 Patient preferences based on demographics and disease characteristics

Patient attributes	**Patient characteristics**							
	Age		Gender		Symptom severity		Education background	
	≥70 years	< 45 years	Male	Female	NYHA II	NYHA III	High school	HEI
Preference for a physician-led approach to decision-making	X	X	X				X	
Preference for a collaborative approach to decision-making								X
Preference for involvement in decisions about medications	X	X	X	X	X	X	X	X
Patients who were involved in treatment discussions*			X					X
Influenced by media publicity about health services and treatments	X	X	X	X	X	X	X	X
Used the internet to search for health information	X	X	X	X	X	X	X	X
Valued written information leaflets provided by professionals								
Valued advice of family members		X		X				

HEI = Higher Education Institute – University, technology institute

*Patients who asked questions, requested further information, challenged the advice of health professionals

Table 5.1 2 Different types of patients based on age and education background

Patient preferences	Older patients	Younger patients	Education background	
	(≥70 years)	(<45 years)	Patients aged 45-69	
			HEI	High school
Level of involvement in treatment discussions	Older male patients preferred to take the lead in treatment discussions Valued professionals using a direct, blunt approach to communication about treatments	Less involved in treatment discussions More likely to share information with nurses	High level of involvement in treatment discussions More likely to ask questions, ask for more information, offer their own views and share their findings from the internet	Limited involvement in treatment discussions Less likely to raise information they have sourced elsewhere More likely to share information with nurses
Value of information sources	Valued the advice of professionals above all Less likely to use the internet Older male patients attributed limited value to the views of their family	Valued the internet as a primary source of health information More likely to act on the advice of family Valued advice of family/friends who worked in healthcare	Valued the internet as a source of health information Valued the advice of family/friends who worked in healthcare	Valued the internet as a source of health information Valued information from friends and family Valued advice of family/friends who worked in healthcare
Treatments	Valued treatments that were expected to improve Quality of Life	Valued treatments expected to improve longevity	Willing to share their own ideas about treatments and medication regimes Valued novel therapies	Valued treatments recommended by professionals and treatments that had improved the quality of life of their friends
Service delivery	Valued in-person consultations Happy to attend a whole day in clinic	Less likely to access health services Limited value of whole day clinics – childcare and work commitments	Middle-aged male patients less likely to access health services	Valued regular follow-up and access to health professionals by telephone

* HEI = Higher Education Institute – University/Polytechnic

Age

Older patients (≥75 years) were more likely to prefer a physician-led approach to decision-making regardless of their gender, education background and symptom severity. This may in part be explained by how older patients viewed the patient-physician relationship. Older patients viewed the purpose of the clinic consultation to seek the advice of a respected professional and leave with a treatment plan. Physicians were considered *'the experts'* and patients trusted their opinion. These patients valued the advice of physicians above all sources of information. Challenging physicians or patients sharing their own views about treatment, was not viewed as part of this process. How professionals communicate information about treatments to older patients is therefore critical. Greater encouragement of older patients to share their views in treatment discussions is important so professionals can address their preferences and better understand their information needs. As discussed in Chapter 2, a shared approach to decision-making requires patients to share their views with professionals to make quality decisions and encourage adherence to treatment choice (Coulter and Collins, 2011). Older patients have been found to be compliant with clinic appointments, but less compliant with behavioural advice (diet, fluid restriction, exercise and weighing) (Van der Wal et al, 2010).

Older patients valued in-person consultations and most were generally happy to attend a half day or whole day clinic. However, long days did lead to increased fatigue. This may explain some of the limited interactions between patients and professionals during their consultations. Studies have shown that patients don't always absorb all the information provided by professionals, particularly information on lifestyle advice and medications (Richard et al, 2016). This is unsurprising as patients are often anxious following multiple tests and tend to focus on details of their results. Information that patients retain is often condensed to measures of their health status. In helping patients to better understand their heart failure and suitability of treatments, the timing of information provided to older patients needs to be reviewed. Professionals may view this 'one stop shop' model as beneficial, but older patients may feel overloaded and important information is not retained or misunderstood.

A positive finding was that older patients supported clinical research and novel therapies. In practice, there is a tendency for professionals to refrain from approaching older patients to recruit to studies. This is often based on concerns for their frailty and assumption that they would not want to be involved. The inclusion and exclusion criteria of clinical trials often exclude elderly patients. In this study, seven patients were found to be eligible to participate in the interviews, but their clinical team recommended they not be approached. All were aged >70 years. The challenges of recruiting older patients to clinical trials is well documented (Ridda et al, 2009). These findings may encourage professionals to discuss research possibilities and novel treatments more openly with older patients.

Older patients frequently had access to online information provided by their family. Many professionals believed that older patients do not use the internet and were therefore, less likely to raise internet use during the consultation. This highlights the potential missed opportunity for professionals to better understand the information that informs older patients' beliefs.

Younger patients (<45) tended to be less involved in treatment discussions but showed greater use of the internet to source additional information. These preferences for limited involvement contrast with previous reports in the literature. Mah et al (2016) reported younger patients with hypertension (<60 years, n=210) and those with higher education backgrounds preferred a SDM approach ($p<0.01$). The 'young' patient population was older than this cohort, but similar findings are reported in both qualitative and quantitative paradigms. With a variety of patient groups including patients with cardiac disease (Deber et al, 2007). These younger patients regarded written information leaflets as *"a waste of time"*. Arranging childcare and taking time off work meant that younger patients found it difficult to attend long clinic appointments. Like older patients, they valued in-person consultations but were less likely to contact professionals for advice. Young patients were therefore more isolated from professionals. A shared approach may encourage professionals to adopt more open discussion with younger patients about their health-information sourcing behaviour. Family members are a strong influence on their views therefore, involvement of family members in the clinic consultation may help gain support for patient self-management and encourage access of services.

Symptom severity

This study reports limited influence of symptom severity on patient preferences for involvement in decision-making. This is in contrast with findings presented in Chapter 2, where researchers reported association between patients' preferred decision-making role and their stage of disease trajectory and symptom burden.

Gender

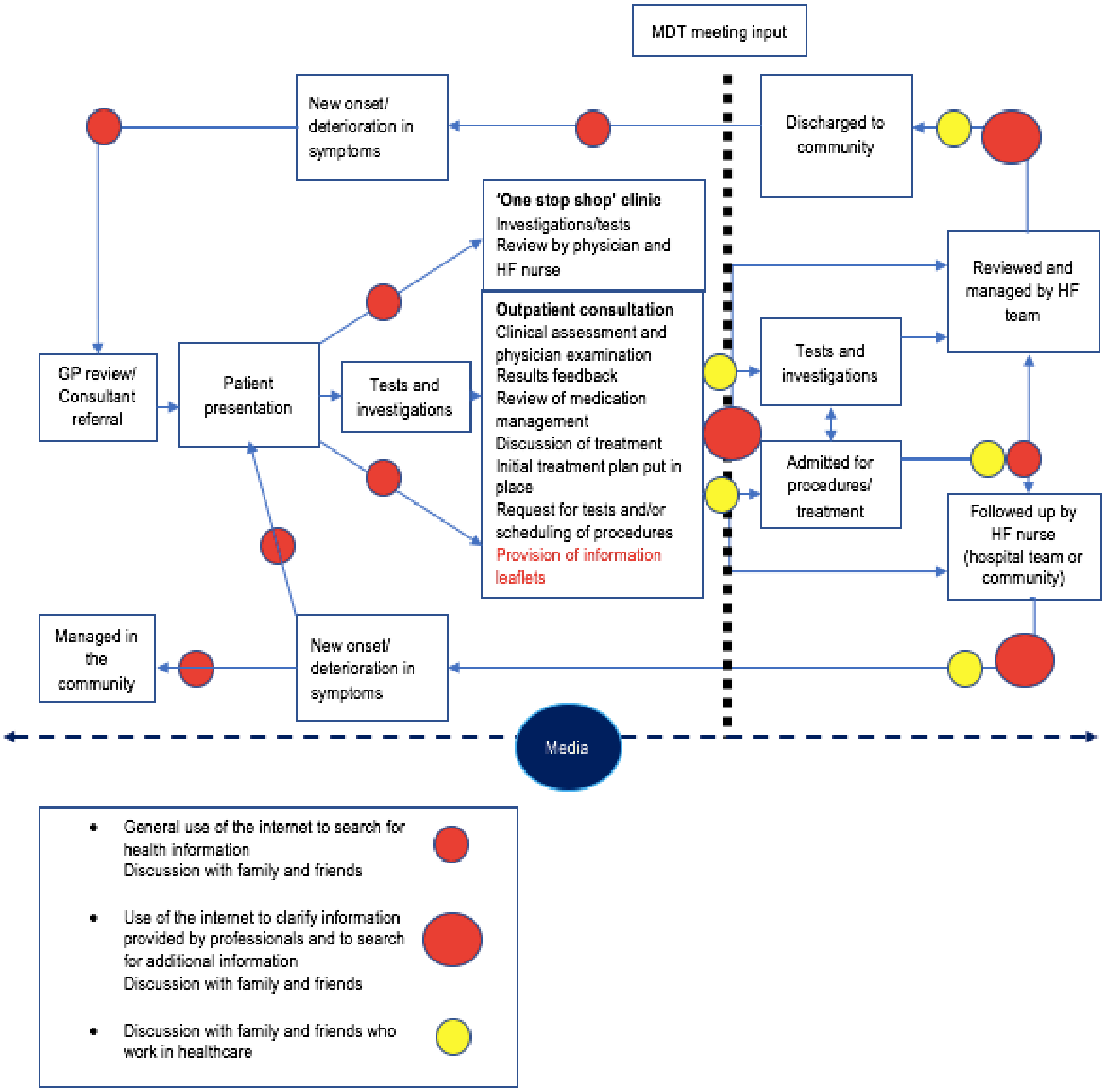
Male patients were more likely to prefer a physician-led approach to decision-making but were more active in discussions about treatments compared to female patients. Male patients viewed the purpose of the clinic consultation to seek expert advice and be provided with a clear treatment plan and management strategy. Male patients focused on their physical health and were confident to ask questions about the practicalities of treatments and different options. Despite this engagement in the treatment discussion, male patients looked to their physician to make the final decision.

Education background

Patients from higher education backgrounds (University educated) were more vocal and engaged in treatment discussions compared to other patients. These patients were confident to challenge the advice of professionals and willing to offer their own ideas for treatment. As reported in the literature, patients with higher education backgrounds frequently searched for additional information online (Tan and Goonawardene, 2017). Patients from higher education backgrounds tended to search for detailed and analytical information on research databases and manufacturer websites. In contrast, patients from low education backgrounds (high school educated) were less likely to engage in treatment discussions. Greater value was given to information provided by their friends and family. Patients from low education backgrounds still searched online for health information, but they were less critical of their findings. This information sourcing behaviour commonly led to misinterpretations and increased confusion over treatment eligibility for both groups of patients.

The sourcing of health information by patients and their relatives was one of the most influential factors on how patients made decisions. Patient behaviour consisted of a cycle of searching, clarifying and verifying information to validate their own beliefs, with the internet and family and friends being primary sources of information. This process of information-sourcing behaviour was continuous and extended beyond the clinical encounter. Importantly, this information informed the value patients attributed to certain treatments and the foundations of their disease beliefs. *Figure 5.1* illustrates when patients source health information along the clinical pathway.

Figure 5. 1 Patients health information sourcing behaviour along the clinical pathway



Identification of these different types of patients extend the findings in current literature. They illustrate the influence of key demographics on patients' approach to decision-making and their preferences for information. Importantly, they demonstrate that communication with health professionals is only one part of a much more complex process of decision-making.

In this study, age and education background were only found to influence patient preferences for involvement in the clinical consultation. A key finding was that patients level of involvement in the discussion of treatment with professionals, was not a true reflection of their broader decision-making process.

5.8 Summary to STRAND I

This qualitative interview study explored the factors that influence patients' decisions about their heart failure management. Thematic analysis of these data identified different types of patients, emphasising the combined influence of multiple factors on patient decisions and health behaviours. Similarities and differences in the views of patients, their family members and health professionals highlighted important barriers and facilitators to decision-making in practice.

All patients and family members supported the development of novel therapies and understood the necessity of clinical research in advancing the treatment and management of heart failure. However, patients and family members had limited understanding of their heart failure aetiology. Consequently, they lacked understanding of personalised medicine and the suitability of treatment to their individual disease needs. This led to misunderstandings and misinterpretations of their treatment and health status. How patients valued treatments was based more on the information sourced from their friends, family and the internet, than the clinical evidence shared by professionals. This is the first in-depth, qualitative exploration of its kind. By taking a holistic approach to better understand this phenomenon these data provide greater insight into the processes involved in how patients make decisions; the factors that influence their views and behaviour; and the barriers and facilitators to delivering SDM in practice.

CHAPTER 6: RESULTS STRAND II: DELPHI

6.1 Introduction to Chapter

A key finding of the qualitative interview study was that health professionals have limited knowledge of patients' information-sourcing behaviour and the extent of its influence on their health beliefs and treatment decisions. Communicating information about treatment is central to a Shared Decision-making (SDM) approach. Patients who base their decisions on misleading or inaccurate information is a major concern, particularly when professionals may misconceive their information needs. Finding the best way to tailor information and ensure it is meaningful is challenging. There is no clear consensus on the best way to do this effectively and little practical guidance exists for professionals.

To support patients in their consideration of information about treatment, further insight in to patient preferences and information needs was required. Strand II of this thesis employed a Delphi survey to test the findings of the interview data and identify ways to improve practice through a collaborative, consensus-driven approach.

The purpose of the Delphi survey was:

1. To explore the views of patients, family members and health professionals towards the provision of health information in heart failure management.
2. To identify the barriers and facilitators to health information provision in heart failure management
3. To gain group consensus on practice recommendations to improve the provision of health information in heart failure.

Using the framework of the mixed methods paradigm (Crewell and Clark, 2011), literature was drawn upon and combined with the findings of the qualitative interview study to design the Delphi survey. The first questionnaire of the Delphi (Round 1) was designed to test and extend the qualitative findings. The second questionnaire (Round 2) was designed to identify and gain consensus on ways to improve how information is provided in practice.

This Chapter reports the results of the Delphi consensus survey. Firstly, the participant characteristics and process of recruitment to the Delphi panel are reported. This is followed by details of the priori level of consensus to be achieved in Round 1 and the results of the first questionnaire. The level of consensus for Round 2 and its results are then reported. Results are presented using descriptive statistics: measures of central tendencies, frequency and percentage. Round 1 tested the differences in views between cohorts. The results are presented in percentage of agreement and frequencies. Round 2 gained consensus on recommendations to improve health information provision in practice.

6.2 Recruitment to the Delphi panel

Round 1

Recruitment to the Delphi panel was conducted between November 2017 and February 2018 at Site 1. The online survey platform 'Surveymonkey®' was used to invite participants to complete the survey. Two collectors were created for data entry: an email invitation with an embedded link to the online survey; and a web link used to input data manually in to the survey using an electronic tablet. Email links to the survey were sent to 21 health professionals, 31 patients and 24 relatives. Seventeen health professionals, 11 patients and 13 family members completed the survey using the email link collector. Eight patients and 5 relatives completed the survey using the electronic tablet provided via the web link collector. Reminder emails were sent at two weekly intervals and the final response rate to Round 1 was 71% (81% of health professional, 61% of patients, 75% of relatives). Two respondents (one who completed the survey using the electronic tablet, the other using the email link), submitted partial responses. These data were excluded from the final analyses and these participants did not enter Round 2 of the survey. The final Delphi panel consisted of fifty-four participants: 19 patients, 18 family members and 17 health professionals.

Round 2

Recruitment to the second questionnaire (Round 2) was undertaken using the email invitation collector. Email invitations with the link to the second questionnaire were sent to all panel members that entered complete responses to Round 1. Twelve patients, 13 family members and 16 health professionals entered Round 2. Response rates of 63%, 72% and 94% respectively. Total response rate of the panel was 76%.

6.2.1 Panel member characteristics

A summary of the panel member characteristics who completed the questionnaires in Round 1 and 2 are presented in *Table 6.1*. Demographic data and characteristics used to purposively select participants for the qualitative interview study were collected for each cohort participating in the Delphi. Health professional role, specialty and number of clinics attended per week was collected. Patients and family members were asked about their ownership of electronic devices to provide context for their health-seeking internet use. The characteristics of panel members from each cohort who completed Round 1 and Round 2 are presented in *Tables 6.2 and 6.3.*

There were some differences between panel members who completed both Round 1 and 2 compared to those who only completed Round 1. Most patients who completed Round 2 lived with their partner or spouse (10 (83%)) and were retired (7 (58%)). All owned three or more electronic devices. Family members who completed Round 2 were younger (9 (69%)) between 40 and 60 years of age. Most were currently employed (54% compared to 39%

in Round 1) and most (12 (92%)) had more than three electronic devices. Only one health professional did not complete Round 2.

Delphi panel members

Table 6. 1 Summary of panel member characteristics

Sub-group	**Round 1 (n=54)**	**Round 2 (n=41)**
Patients:	19	12
Male	15	10
Family members:	18	13
Spouse	11	9
Female	12	8
Health professionals:	17	16
Consultant Cardiologist	3	3
Specialist Registrar	7	7
Clinical Nurse Specialist	6	5
Other	1	1

Table 6. 2 Patient characteristics

Patient demographics	**Round 1 (n=19)**		**Round 2 (n=12)**	
	n	**%**	**n**	**%**
Male	15	(78.9)	9	(75)
Age (years)				
<30	1	(5.2)	1	(8.3)
41-50	3	(15.8)	1	(8.3)
51-60	6	(31.6)	4	(33.3)
71-80	6	(31.6)	4	(33.3)
81-90	3	(15.8)	1	(8.3)
Ethnicity:				
White/Caucasian	16	(84.2)	9	(75)
NYHA Class				
I	3	(15.8)	2	(16.6)
II	12	(63.1)	8	(66.6)
III	4	(21)	2	(16.6)
Lives with:				
Partner/spouse	14	(73.7)	10	(83.3)
Alone	2	(10.5)	2	(16.6)
Other*	4	(21)	0	(0)
Time since HF diagnosis				
<1 year	1	(5.2)	0	(0)
1-3 years	2	(10.5)	2	(16.6)
4-6 years	5	(26.3)	3	(25)
7-9 years	5	(26.3)	4	(33.3)
>10 years	6	(31.6)	3	(25)
Education background:				
High School	5	(26.3)	3	(25)
College	4	(21)	2	(16.6)
Trade/technical/Vocational	1	(5.2)	1	(8.3)
University	8	(42.1)	6	(50)
Other	1	(5.2)	0	(0)
Employment:				
Employed	3	(15.8)	2	(16.6)
Self-employed	5	(26.3)	2	(16.6)
Not employed	2	(10.5)	1	(8.3)
Retired	9	(47.4)	7	(58.3)
Electronic devices owned:				
Mobile phone	17	(89.5)	12	(100)
Tablet e.g. Ipad	11	(57.9)	8	(66.6)
Laptop computer	10	(52.6)	9	(75)
Desktop computer	8	(42.1)	5	(41.6)
None of these	1	(5.2)	0	(0)
>3 devices	10	(52.6)	10	(100)
Total	**19**		**12**	

*All patients were clinically assessed as NYHA II-III as per eligibility criteria. These data represent patient self-report NYHA class.

Three patients lived with children and one in assisted living

Table 6. 3 Family member characteristics

Family member demographics	**Round 1 (n=18)**		**Round 2 (n=13)**	
	n	**%**	**n**	**%**
Male	5	(27.7)	5	(38.4)
Age (years)				
41-50	4	(22.2)	4	(30.7)
51-60	5	(27.7)	5	(38.4)
61-70	4	(22.2)	3	(23)
71-80	4	(22.2)	1	(7.6)
Ethnicity:				
White/Caucasian	16	(88.8)	13	(100)
Relative with HF				
Partner/spouse	11	(61.1)	9	(69.2)
Parent	4	(22.2)	4	(30.7)
Other*	2	(11.1)	0	(0)
Time since relative's diagnosis				
<1 year	1	(5.5)	0	(0)
4-6 years	5	(27.7)	5	(38.4)
7-9 years	6	(33.3)	5	(38.4)
>10 years	5	(27.7)	3	(23)
Education background:				
High School	6	(33.3)	4	(30.7)
College	6	(33.3)	6	(46.1)
Trade/technical/Vocational	1	(5.5)	0	(0)
University	4	(22.2)	3	(23)
Employment:				
Employed	7	(38.8)	7	(53.8)
Self-employed	2	(11.1)	2	(15.3)
Retired	8	(44.4)	4	(30.7)
Electronic devices owned:				
Mobile phone	16	(88.8)	13	(100)
Tablet e.g. Ipad	14	(77.7)	11	(84.6)
Laptop computer	11	(61.1)	10	(76.9)
Desktop computer	8	(44.4)	5	(38.4)
>3 devices	14	(77.7)	12	(92.3)
Total	**17**		**13**	

*1 = Aunt, 1 = daughter

Table 6. 4 Health professional characteristics

Health professional's demographics	**Round 1**		**Round 2**	
	n	**%**	**n**	**%**
Male	7	(41.2)	6	(37.5)
Age (years)				
31-40	7	(41.2)	6	(37.5)
41-50	6	(35.3)	6	(37.5)
51-60	4	(23.5)	4	(25)
Ethnicity:				
White/Caucasian	9	(52.9)	9	(56.2)
Asian/Asian British	5	(29.4)	4	(25)
Mixed/ multiple ethnic groups	2	(11.8)	2	(12.5)
Other ethnic group	1	(5.9)	1	(6.2)
Professional role:				
Consultant	3	(17.6)	3	(18.7)
Specialist Registrar (SpR)	7	(41.2)	6	(37.5)
Clinical Nurse Specialist (CNS)	6	(35.3)	6	(37.5)
Other	1	(5.9)	1	(6.2)
Time working in specialty:				
<1 year	1	(5.9)	1	(6.2)
1-5 years	6	(35.3)	5	(31.2)
6-10 years	5	(29.4)	5	(31.2)
More than 10 years	5	(29.4)	5	(31.2)
Specialist field:				
Heart Failure	10	(58.8)	9	(56.2)
Congenital Heart Disease	2	(11.8)	2	(12.5)
Other	5	(29.4)	5	(31.2)
Average days per week in clinic:				
<1	2	(11.8)	1	(6.2)
1-2	9	(52.9)	9	(56.2)
3-4	3	(17.6)	3	(18.7)
>4	3	(17.6)	3	(18.7)
Total	17		16	

*Post training – Clinical Research Fellow

Includes: Structural Heart Disease, Cardiomyopathy and CMR, Cardiac imaging/Imaging, Heart failure and Transplantation

6.3 Round 1

The purpose of Round 1 was to explore the differences in views between patients, family members and health professionals towards the provision of health information in heart failure management. Three domains of information provision were addressed: Sources of health information; Health information need; and Patient involvement. Each domain included a list of statements whereby patients, family members and health professionals were asked to rate their level of agreement *(Appendix 6.1).* Statements were designed to collect data that represented each participant's views and their perceptions of the views of others. This was important to highlight the differences between cohorts and identify potential misconceptions and knowledge gaps. Statements were phrased so there was no obvious right or wrong answer. Negative statements were added to encourage participant deliberation for each response. Panel members were asked to rate their level of agreement for each of the 41 statements on a 5-point Likert Scale from 'Strongly agree' to 'Strongly disagree.'

The priori consensus threshold for Round 1 was set at:

- >65% of the total panel responding, 'Strongly agree/Agree' or 'Disagree/Strongly disagree'
- <20% difference in agreement/disagreement between cohorts

It was necessary for all key stakeholders in the decision-making process to agree to identify priority areas for practice recommendations. This was important, so recommendations were supported by professionals and service-users which would increase their likelihood of being implemented in routine practice.

Eighteen statements reached group agreement (>65% of the total group responded 'strongly agree/agree). One statement was removed as the wording was found to contraindicate another and led to conflicting data. Three statements had >20% variation in response between cohorts in the categories 'strongly agree/agree' and/or 'disagree/strongly disagree.' A total of 14 of the final 40 statements (35%) met the consensus criteria for Round 1. *See Table 6.5.*

Table 6. 5 Round 1 statements that met consensus criteria

	Round 1 statements	Strongly agree		Agree		Total
		%	n	%	n	n
DOMAIN 1	I am satisfied with the amount of information health professionals provide to patients about treatments	16.67%	9	51.85%	28	54
	Leaflets help patients/relatives increase their knowledge and understanding of heart failure	16.67%	9	57.41%	31	54
	Health professionals themselves are the most valuable source of health information to patients/relatives	37.04%	20	53.70%	29	54
	Patients/relatives will visit a website if it is recommended by health professionals	22.22%	12	66.67%	36	54
	Patients/relatives want to know more about the disease and its cause	46.30%	25	48.15%	26	54
	Patients and relatives use the internet to search for health information to clarify information provided by health professionals	22.22%	12	61.11%	33	54
DOMAIN 2	I am satisfied with the level of health information provided by health professionals to patients about:					
	The cause of the patient's heart failure	14.81%	8	59.26%	32	54
	Investigations and test results e.g. echocardiogram, blood tests	29.63%	16	50.00%	27	54
	Risks and benefits of treatments	24.07%	13	50.00%	27	54
	Lifestyle advice e.g. exercise, diet, quitting smoking	18.52%	10	46.30%	25	54
	Longer clinic appointments are needed for patients to build partnerships and trust with health professionals	25.93%	14	46.30%	25	54
	Health professionals' attitudes towards involving patients in treatment decisions influences how much information they provide to patients	14.81%	8	53.70%	29	54
DOMAIN 3	Patients are more likely to agree to treatments when their opinion is taken into consideration when choosing a treatment	35.19%	19	61.11%	33	54
	All patients should be given the opportunity to be involved in treatment decisions	50.00%	27	48.15%	26	54

6.3.1 Summary of consensus

These results demonstrate collective agreement of the Delphi panel that health professionals are the most valuable source of information to patients and their family members. Patients' treatment decisions are influenced by professionals consideration and attitude toward their personal preferences and level of involvement. The panel were satisfied with the amount of information provided by health professionals. In contrast to the findings of the qualitative interviews, the panel agreed that leaflets were helpful in increasing patient and relatives' knowledge and understanding of heart failure. Information provided by health professionals about the cause of heart failure; investigations and results; and the risks and benefits of treatments; were deemed adequate. Despite these findings patients and relatives used the internet to search for additional information about their heart failure and its cause.

The internet was also used to clarify information provided by professionals. Websites recommended by health professionals were valuable to patients and their family members. There was also group agreement that longer clinic appointments are needed to build trust between patients and professionals. The lowest weighted average score (1.52; 50% strongly agreed) was the panel's response to the statement, 'all patients should be given the opportunity to be involved in treatment decisions.'

6.3.2 Statements with variation in agreement between cohorts

Three statements gained overall group consensus where ≥65% of the total group 'strongly agreed/agreed but had >20% variation in agreement between subgroups *(highlighted in Table 6.6).* These statements did not meet the criteria for consensus in Round 1.

Table 6. 6 Round 1: Statements with >20% variance in group agreement

Round 1 Statement	Cohort	Responses n (% of cohort)		
		Strongly agree/agree	Neutral	Disagree/ strongly disagree
The views and experiences of family are very important to patients when deciding on what treatment to have	Health professionals	15 (88.2)	2 (11.7)	0 (0)
	Patients	16 (84.3)	0 (0)	3 (15.7)
	Family members	11 (64.7)	5 (29.4)	1 (5.8)
Written information available is all at one level and not appropriate for every patient	Health professionals	15 (88.2)	2 (11.7)	0 (0)
	Patients	14 (73.6)	4 (21)	1 (5.2)
	Family members	6 (35.2)	8 (47)	3 (17.6)
The involvement of family members and/or carers is important when making treatment decisions	Health professionals	16 (94.1)	1 (5.8)	0 (0)
	Patients	10 (52.6)	7 (36.8)	2(10.5)
	Family members	16 (94.1)	1 (5.8)	0 (0)

Patients

Sixteen (84.3%) of patients agreed that the views of family members are very important when making treatment decisions. Three (15.7%) disagreed. Patients valued the advice of family members but only 10 (52.6%) valued their involvement in the treatment decision-making process. Two (10.5%) of the remaining patients responded 'neutral' to this statement. This highlights a difference between patient preferences for information from family members and their preferences for family involvement. Fourteen (73.6%) agreed that written information is not appropriate for every patient.

Family members

Only eleven (64.7%) of family members agreed that their views and experiences were very important to patients when making treatment decisions. Five (29.4%) responded ‘neutral’ to this statement. In contrast to the patient cohort, sixteen (94.1%) of family members valued their role and involvement in making treatment decisions. Six (35.2%) agreed written information was not appropriate for each patient and eight (47%) scored ‘neutral.’ This reflects the qualitative interview data where relatives described limited value to the information leaflets they were given by professionals.

Health professionals

The health professional cohort responded with the highest level of agreement that the views of family members are very important to patients’ treatment decisions (15 (88.2%)). Similarly, 16 (94.1%) agreed that family member involvement was important. Analysis of the qualitative data highlighted the high value health professionals placed on written information leaflets as sources of health information. However, fifteen (88%) of health professionals agreed that these leaflets were not written at an appropriate level for every patient.

6.3.3 Similarities and differences between cohorts

Fifteen of the remaining 26 statements that did not reach group consensus, demonstrated marked variance in the responses between cohorts (more than 20% difference in agreement/disagreement). These statements and their percentage breakdown of group responses are illustrated in *Tables 6.7, 6.8 and 6.9*. Key differences in responses are highlighted.

6.3.4 Round 1 statements with variance in responses between groups

Table 6. 7 DOMAIN 1: Sources of health information

Round 1 statements	Cohort	Strongly agree/agree		Disagree/ strongly disagree		Total
		% of cohort	N	% of cohort	N	N
Q4. Patients prefer to ask for additional health information from nurses rather than doctors	Professionals	70.5%	12	5.8%	1	17
	Patients	0.0%	0	68.4%	13	19
	Family	11.7%	2	58.8%	10	18
Q5. I am satisfied with the content of written health information provided by health professionals to patients	Professionals	29.4%	5	29.4%	5	17
	Patients	52.6%	10	10.5%	2	19
	Family	47.0%	8	17.6%	3	18
Q9. The internet is the most valuable source of health information for patients and relatives	Professionals	11.7%	2	58.8%	10	17
	Patients	21.0%	4	26.3%	5	19
	Family	41.1%	7	35.2%	6	18
Q10. Patients use information from the internet to help them make decisions about treatments	Professionals	82.3%	14	17.6%	3	17
	Patients	36.8%	7	42.1%	8	19
	Family	52.9%	9	35.2%	6	18
Q12. The views and experiences of friends are very important to patients when deciding on what treatments to have	Professionals	76.4%	13	11.7%	2	17
	Patients	26.3%	5	26.3%	5	19
	Family	17.6%	3	41.1%	7	18
Patients and relatives use the internet to search for health information because:						
Q17. They prefer to use the internet rather than ask health professionals for more information or further explanation	Professionals	41.1%	7	35.2%	6	17
	Patients	15.7%	3	63.1%	12	19
	Family	17.6%	3	76.4%	13	18
Q18. They feel depressed, anxious or concerned	Professionals	58.8%	10	5.8%	1	17
	Patients	31.5%	6	26.3%	5	19
	Family	47.0%	8	23.5%	4	18

Table 6. 8 DOMAIN 2: Health information need

Round 1 statements	Cohort	Strongly agree/agree		Disagree/ strongly disagree		Total
		% of cohort	N	% of cohort	N	N
I am satisfied with the level of health information provided by health professionals to patients about:						
Q20. The natural course of the disease	Professionals	29.4%	5	29.4%	5	17
	Patients	68.4%	13	10.5%	2	19
	Family	58.8%	10	23.5%	4	18
Q23. Side-effects of medications	Professionals	47.0%	8	23.5%	4	17
	Patients	52.6%	10	26.3%	5	19
	Family	35.2%	6	47.0%	8	18
Q.24 Lifestyle advice e.g. exercise, diet, quitting smoking*	Professionals	52.9%	9	23.5%	4	17
	Patients	68.4%	13	21.0%	4	19
	Family	76.4%	13	11.7%	2	18
Q.27 Written information available is all at one level and not appropriate for every patient	Professionals	88.2%	15	0.0%	0	17
	Patients	73.6%	14	5.2%	1	19
	Family	35.2%	6	17.6%	3	18
Q.29 Patients believe that health professionals do not have the time to adequately address their health information needs*	Professionals	52.9%	9	11.7%	2	17
	Patients	47.3%	9	21.0%	4	19
	Family	52.9%	8	35.2%	6	18
Q.30 Longer clinic appointments are needed for patients to build partnerships and trust with health professionals*	Professionals	94.1%	16	5.8%	1	17
	Patients	57.8%	11	26.3%	5	19
	Family	70.5%	12	17.6%	3	18
Q.32 Health professionals' attitudes towards involving patients in treatment decisions influences how much information they provide to patients*	Professionals	82.3%	14	0.0%	0	17
	Patients	63.1%	12	21.0%	4	19
	Family	58.8%	10	11.7%	2	18

*These statements had the highest % of each cohort responding to one category but with >20% variance in agreement in one or more cohorts.

Table 6. 9 DOMAIN 3: Patient involvement

Round 1 statements	Cohort	Strongly agree/agree		Disagree/ strongly disagree		Total
		% of cohort	N	% of cohort	N	N
Q.33 Health professionals do not ask if patients want to be involved in their treatment decisions	Professionals	17.6%	3	70.5%	12	17
	Patients	21.0%	4	47.3%	9	19
	Family	35.2%	6	58.8%	10	18

Key areas of agreement and disagreement:

Agreement on:

- Health professionals do not have adequate time to address patients' information needs.
- Longer clinic appointments are needed.
- Health professionals do ask patients to be involved in treatment discussions.

Disagreement on:

- Patients preference to ask nurses for health information rather than doctors.
- The value of the internet as a source of health information and patients and relatives' internet
- The influence of friends on patients' treatment decisions
- Reasons why patients and relatives use the internet to search for health information
- The type of information patients and relatives search for on the internet
- The content and literacy level of written information leaflets provided by professionals

6.3.5 Differences between professional disciplines

Twenty statements that did not reach group consensus demonstrated >20% difference in agreement/disagreement between nurses and physicians. These data extend the findings from the qualitative interviews by identifying important differences in views between professionals. These statements and each discipline's corresponding percentage of agreement are presented in *Tables 6.10, 6.11 and 6.12*. Highlighted are the key differences in agreement.

Round 1 Statements with variance in agreement between professional disciplines

Table 6. 10 DOMAIN 1: Sources of health information

Round 1 statements	Professional discipline	Responses *n* (% of professional group)		
		Strongly agree/ agree	**Neutral**	**Disagree/ strongly disagree**
I am satisfied with the amount of information health professionals provide to patients about treatments	Total	8 (47%)	7 (41.1%)	2 (11.7%)
	Nurses	4 (67%)	2 (33%)	0 (0%)
	Physicians	4 (36%)	5 (45%)	2 (18%)
Health professionals regularly discuss with patients where to find additional health information if needed	Total	7 (41.1%)	6 (35.2%)	4 (23.5%)
	Nurses	5 (83%)	1 (17%)	0 (0%)
	Physicians	2 (18%)	5 (45%)	3 (27%)
Patients prefer to ask for additional health information from nurses rather than doctors	Total	12 (70.5%)	4 (23.5%)	1 (5.8%)
	Nurses	5 (83%)	1 (17%)	0 (0%)
	Physicians	7(63%)	3 (27%)	1 (9%)
I am satisfied with the content of written health information provided by health professionals to patients	Total	5 (29.4%)	7 (41.1%)	5 (29.4%)
	Nurses	0 (0%)	4 (67%)	2 (33%)
	Physicians	5(45%)	3 (27%)	3 (27%)
Leaflets provided by health professionals to patients are the most valuable source of health information	Total	6 (35.2%)	6 (35.2%)	5 (29.4%)
	Nurses	1 (17%)	3 (50%)	2 (33%)
	Physicians	5 (45%)	3 (27%)	3 (27%)
The internet is the most valuable source of health information for patients and relatives	Total	2 (11.7%)	5 (29.4%)	10 (58.8%)
	Nurses	0 (0%)	1 (17%)	5 (83%)
	Physicians	2 (18%)	4 (36%)	4 (36%)
Patients use information from the internet to help them make decisions about treatments	Total	14 (82.3%)	0 (0%)	3 (17.6%)
	Nurses	4 (67%)	0 (0%)	2 (33%)
	Physicians	10 (91%)	0 (0%)	1 (9%)
The views and experiences of friends are very important to patients when deciding on what treatments to have	Total	13 (76.4%)	2 (11.7%)	2 (11.7%)
	Nurses	3 (50%)	1 (17%)	2 (33%)
	Physicians	10 (91%)	1 (9%)	0 (0%)
Patients and relatives use the internet to search for health information because:				
They prefer to use the internet rather than ask health professionals for more information or further explanation	Total	7 (41.1%)	4 (23.5%)	6 (35.2%)
	Nurses	2 (33%)	1 (17%)	3 (50%)
	Physicians	5 (45%)	3 (27%)	3 (27%)
They feel depressed, anxious or concerned	Total	10 (58.8%)	6 (35.2%)	1 (5.8%)
	Nurses	2 (33%)	3 (50%)	1 (17%)
	Physicians	8 (73%)	3 (27%)	0 (0%)

Table 6. 11 DOMAIN 1: Sources of health information

Round 1 statements	Professional discipline	Responses *n* (% of professional group)		
		Strongly agree/ agree	Neutral	Disagree/ strongly disagree
I am satisfied with the level of health information provided by health professionals to patients about:				
The natural course of the disease	Total	5 (29.4%)	7 (41.1%)	5 (29.4%)
	Nurses	3 (50%)	1 (17%)	2 (33%)
	Physicians	2 (18%)	6 (54%)	3 (27%)
Whether their disease could be genetically inherited	Total	6 (35.2%)	6 (35.2%)	5 (29.4%)
	Nurses	2 (33%)	4 (67%)	0 (0%)
	Physicians	4 (36%)	2 (18%)	5 (45%)
Please rate your level of agreement for the following statements:				
Health professionals provide information about heart failure and its treatments in language that is difficult for patients to understand	Total	4 (23.5%)	5 (29.4%)	8 (47%)
	Nurses	0 (0%)	2 (33%)	4 (67%)
	Physicians	4 (36%)	3 (27%)	4 (36%)
Patients believe that health professionals do not have the time to adequately address their health information needs	Total	9 (52.9%)	6 (35.2%)	2 (11.7%)
	Nurses	2 (33%)	3 (50%)	1 (17%)
	Physicians	7 (64%)	3 (27%)	1 (9%)
Most patients and family members do not ask for additional information from health professionals	Total	6 (35.2%)	5 (29.4%)	6 (35.2%)
	Nurses	1 (17%)	2 (33%)	3 (50%)
	Physicians	5 (45%)	3 (27%)	3 (27%)
Health professionals' attitudes towards involving patients in treatment decisions influences how much information they provide to patients	Total	14 (82.3%)	3 (17.6%)	0 (0%)
	Nurses	3 (50%)	3 (50%)	0 (0%)
	Physicians	11(100%)	0 (0%)	0 (0%)

Table 6. 12 DOMAIN 3: Patient involvement

Round 1 statements	**Professional discipline**	**Responses** ***n*** **(% of professional group)**		
		Strongly agree/ agree	**Neutral**	**Disagree/ strongly disagree**
Please rate your level of agreement for the following statements:				
Health professionals do not ask if patients want to be involved in their treatment decisions	Total	3 (17.6%)	2 (11.7%)	12 (70.5%)
	Nurses	0 (0%)	1 (17%)	5 (83%)
	Physicians	3 (27%)	1 (9%)	7 (64%)
Health professionals always take in to account the patient's views towards treatment	Total	11 (64.7%)	5 (29.4%)	0 (0%)
	Nurses	5 (83%)	1 (17%)	0 (0%)
	Physicians	6 (55%)	4 (36%)	0 (0%)
Most relatives' opinions are not considered when choosing treatments	Total	7 (41.1%)	7 (41.1%)	3 (17.6%)
	Nurses	1 (17%)	3 (50%)	2 (33%)
	Physicians	6 (55%)	4 (36%)	1 (9%)
Health professionals often lack communication skills necessary to involve patients in treatment discussions	Total	7 (41.1%)	1 (5.8%)	9 (52.9%)
	Nurses	3 (50%)	1 (17%)	2 (33%)
	Physicians	4 (36%)	0 (0%)	7 (64%)

6.3.6 Round 1 Feedback

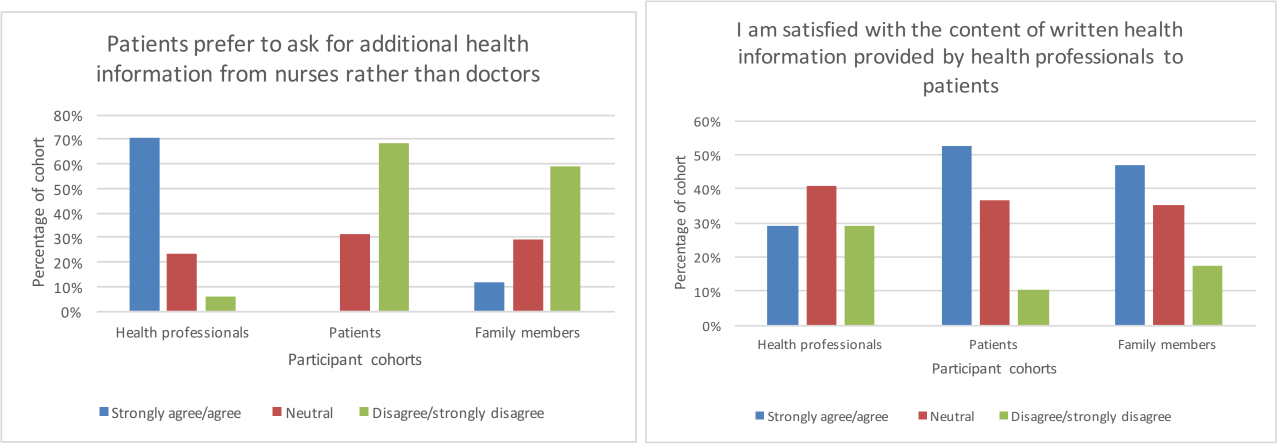
In accordance with the Delphi consensus survey process (Holey et al, 2007), group response and individual responses to statements in Round 1 were fed back to panel members via an individualised feedback form *(see Appendix 6.2).* Each panel member's individualised feedback form illustrated their own response below the graphical representation of each cohort's response (*see Figure 6.1*). This allowed panel members to see how their response compared to that of the group.

A standardised short feedback form was designed to minimise research burden and increase response rates for Round 2. This form used simple and easy to interpret bar charts presenting the breakdown of each cohort's responses. The statements that reached group consensus in Round 1 did not continue to Round 2. The fourteen statements that showed marked variation in group agreement were feedback to participants. This provided important context for the panellists to consider their responses to Round 2, which aimed to gain group consensus on priority areas for recommendations to practice. Each individualised form was sent as an attachment to the email invitation with the embedded link to second online survey.

Figure 6. 2 Example of individualised feedback from Round 1

Domain 1a: Sources of health information

Please rate your level of agreement for the following statements:



Q4. You answered: Strongly disagree

Q5. You answered: Strongly agree

6.4 Round 2

The purpose of Round 2 was to identify priority areas for practice recommendations to improve the communication of treatments in heart failure management. The Round 2 questionnaire was revised to a new format. The results of Round 1 were reviewed together with the qualitative findings to develop a list of items in Round 2, where panel members were asked to rank in order of important or rate their level of importance.

Like Round 1, a priori level of consensus was agreed. The Round 2 questionnaire was divided in to 3 questions with 2 formats (1 rated, 2 ranked). Question 1 used a rating format and required panel members to rate their responses on a five-point Likert scale of importance. The consensus threshold to be reached required:

- 65% of the group to respond to a statement as extremely important/very important (a score ≤ 2) (1=extremely important, 2=very important) and;
- Less than 20% difference between the percent of each cohort choosing that response

Data generated by the electronic survey were exported to SPSS™ v24 for analysis. Descriptive statistics were used to measure consensus and explore the data: Percentage of agreement and measures of central tendencies (mean, median, mode) and standard deviation.

6.4.1 Round 2 questionnaire distribution

Email invitations were sent to all 54 participants that completed the Round 1 questionnaire. Forty-three participants responded, a response rate of 80%. Three questionnaires were partially completed and not included in the overall analyses.

6.4.2 Round 2 results

This section presents the results of the Round 2 questionnaire. The results of Question 1 (scale-rated responses) are presented first, followed by Questions 2 and 3 that used ranking responses. Forty-one participants completed question 1. Twelve of the thirteen items reached group consensus >65%, scored ≤ 2. Only three items met all consensus criteria: Discussion of patient involvement in decision-making; providing information to patients about treatments before clinical consultation; and the need for longer clinic appointments. The remaining 10 items showed >20% difference in agreement between cohorts. It is important to note that >65% of each cohort scored all nine of these statements as ≤3 (all items rated as moderately important or higher). *See Table 6.13.*

Table 6. 13 Round 2 Question 1. The importance of items for treatment discussions

Round 2 statements	**N**	**Score* Mean**	***SD***	**Responses with a score of ≤ 2* N (%)**
Discussion of patient involvement in decision-making	41	1.4146	±0.54	40 (97.6)
Health professionals and patients making a joint decision about treatment	41	1.4390	±0.63	38 (92.7)
Assessment of patient's psychological well-being (depression, anxiety)	41	1.7317	±0.86	34 (82.9)
Patients/relatives preparing a list of questions prior to consultation	41	1.9512	±0.70	32 (78)
List of patient's goals of treatment	41	1.8780	±0.78	31 (75.6)
Training to help professionals involve patients/relatives in treatment decision-making	41	1.9756	±0.85	31 (75.6)
Documentation to record patient involvement in decision-making	41	2.0488	±0.86	31 (75.6)
Health professionals knowing the patient's social circumstances	41	1.9756	±0.87	30 (73.2)
Discussion of the role of patient's relatives in managing their condition at home	41	2.0976	±0.86	30 (73.2)
Providing information to patients about treatments before clinical consultation	41	2.0732	±0.91	29 (70.7)
Assessment of patient's health information needs (e.g. patient's preferences for detail of information, literacy level)	41	2.1707	±1.02	29 (70.7)
Longer clinic appointments	41	2.1951	±1.01	28 (68.3)
Opportunity to integrate technology to increase access to health professionals e.g. Skype consultations	41	2.7561	±1.09	16 (39)

SD – Standard deviation

*Five-point Likert Scale – 1. Extremely important, 2. Very important, 3. Moderately important, 4. Slightly important, 5. Not at all important.

6.4.3 Differences between cohorts

More health professionals rated making a joint decision with patients about treatment as ‘extremely important’ compared to patients and family members [13 (81.3%), 6 (46.2%) and 7 (58.3%) respectively]. This reflects the findings of the qualitative interviews, where patients were found to have different approaches to decision-making and preferences for involvement. Professionals and relatives rated the importance of assessing patient psychological well-being as very/extremely important [14 (87.5%) and 11 (91.6%)]. Fewer patients scored this item as being highly important [9 (69.2%)], with 3 (23.1%) rating this item of moderate importance. The interview data highlighted that patients tailor the information they share with professionals to their disease needs rather than their psycho-social health. This may reflect the responses observed. Professionals and family members raised psychological health as an important issue that influenced patients’ ability to self-manage their condition. More professionals valued the importance of listing patient goals of treatment as ‘extremely important’ compared to patients and their relatives [10 (62.5%), 1 (7.7%), and 4 (33.3%) respectively]. This was an interesting finding as the interview data illustrated that professionals often focus on patient adherence to professional recommendations.

Six patients (46.2%) rated the need for training to help professionals involve patients/relatives in treatment decision-making as 'extremely important'. Three (18.8%) of professionals scored this item as moderately important. These reflect the interview findings where many professionals believed they are already implementing a shared approach to decision-making. Three relatives and six health professionals rated the importance of documentation to record patient involvement in decision-making as extremely important (25% and 37.5%). Only 3 (15.4%) patients scored the same. This documentation is unlikely to impact on patients' experience of treatment discussions but does highlight a professional need for better guidance on patient involvement. For relatives, this documentation may also act as a prompt for professionals to involve them in discussions. The interview data illustrated that few family members feel part of this process. Health professionals knowing patients social circumstances were only considered of moderate importance to 6 (46.2%) patients whereas 6 (50%) of relatives scored this item as 'very important' and 8 (50%) of professionals scored 'extremely important.' This highlights the differences in views on what is considered valuable information to be shared during treatment discussions. This disparity between information shared and what information is needed to support a partnered approach to decision-making, was raised in the interviews. Three patients (23.1%) and six professionals (37.5%) agreed it was extremely important to assess patient health information needs. Yet, patients and relatives valued the importance of providing information about treatments before clinical consultation higher than professionals [extremely important = 4 (30.8%), 6 (50%) and 9 (12.5%) respectively]. Preparing patients and their family members by increasing their understanding of the decision-making process was a key issue raised in the interviews.

6.4.4 Differences between professional disciplines

Seven statements demonstrated >20% difference in responses between physicians and nurses. Three (30%) physicians and 2 (33.3%) nurses rated the need for longer clinic appointments as extremely important. Although nurses tend to spend more time in clinic with patients, these findings highlight agreement among professionals that longer appointments are needed. All nurses considered the discussion of patient involvement in decision-making as extremely important, compared to 7 (70%) physicians. This likely reflects the different approaches of nurses and physicians to treatment discussions. Providing information to patients about treatments in advance of clinic appointments was considered as extremely/very important by 5 (83.4%) nurses, compared to only 5 (50%) physicians. As highlighted in the interview data, nurses tend to have a better understanding of individual patient's knowledge needs through increased continuity and time spent with patients. Providing information to patients prior to clinic consultation make help to prepare patients for upcoming treatment discussions. A similar difference was seen between nurses and physicians' rating of importance of the discussion of relatives in helping to manage patients' heart failure at home. All nurses and only 5 (50%) of physicians scored this item as extremely/very important. As illustrated by the qualitative data, relatives often take on increased roles at home particularly the management of patients' medications. If physicians see limited value in discussing these roles, important issues may be overlooked.

Preparing a list of questions prior to consultation was valued as extremely/very important by all nurses and 7 (70%) physicians. All nurses and 8 (80%) of physicians, rated the assessment of patient psychological well-being as being extremely/very important. The remaining 2 (20%), scored this as moderately important. This reflects the interview data where patients tailored the information they shared with different professionals.

6.4.5 Questions 2 and 3: Ranking responses

Questions 2 and 3 asked panel members to rank a list of items in order of importance (from 1 – most important, through to 10 – least important). The results are presented in *Tables 6.14 and 6.15*. Measures of the median and mode were used to list each item in order of importance.

One family member submitted a partially completed response to question 2, rating only 5 of the 10 items. This response was removed from the final analyses. A total of 40 panellists submitted complete responses.

Table 6. 14 Question 2. The importance of items for treatment discussions

Round 2: Question 2 item list	N	Median	Mode
Availability of health professionals to answer patients/relatives' questions following treatment discussions	40	1.0	1.0
Access and availability of nurse specialists to discuss treatments with patients/relatives	40	2.0	2.0
Family involvement in discussions	40	3.0	2.0*
Access to health information leaflets	40	5.0	4.0*
Details of charities and organisations for patients/relatives to contact for support and lifestyle advice e.g. diet, exercise	40	6.0	6.0
Health professionals recommending websites	40	7.5	8.0
Discussion of information patients/relatives have found on the internet	40	7.0	9.0
Availability of more information leaflets at different literacy levels	40	7.0	9.0*
Discussing patients/relative's use of the internet	40	7.0	10.0
Discussing the views of patient's friends towards treatment	40	8.0	10.0

*Multiple modes exist. The smallest value is shown

6.4.6 Differences between cohorts

Availability and access to health professionals to answer patients/relatives' questions was ranked as the highest item of importance. These results reflect the value patients and relatives place on telephone and email communication with professionals, to clarify information and ask for advice following the clinical encounter. Interestingly, family involvement in treatment discussions was ranked third highest in order of importance. This contrasts with the interview findings where many patients preferred to take the lead in treatment discussions and professionals described family involvement as a common barrier. Similarly, access to health information leaflets was ranked as 4th on the list of importance. The qualitative interview data offered contrasting findings. Alternatively, patients and relatives were found to attribute little value to information leaflets provided by professionals.

Many patients (30.8%) ranked the availability of information leaflets at different literacy levels as 10/10 (least important) and 50% of relatives ranked this item as 9/10. In contrast, 31.3% of professionals ranked its importance as 5th on the list *(see Figure 6.3).* This may reflect the view that most patients and relatives valued alternative sources of information more than information leaflets. More leaflets at different literacy levels would not be viewed as beneficial. A similar difference in rankings between patients/relatives and professionals related to the importance of discussing the views of friends towards treatments. A quarter of professionals ranked this item as 3rd and 4th compared to patients and relatives who ranked it as 9th and 10th (23.1% and 25% respectively). These results mirror the findings of the interview study whereby patients preferred not to discuss the views of their friends during clinical consultations. Interestingly, with a large proportion of patients and relatives accessing health information online, 31% of professionals ranked the importance of discussing patients/relatives' use of the internet as 9/10 (of limited importance). In contrast, 16.7% of relatives ranked this item as 3/10. This reflects family members' knowledge of patients' use of the internet and its influence on their health beliefs, but also relatives' awareness that patients don't often share this information. Relatives may want greater discussion of internet use with professionals. Twenty-three percent of patients ranked details of charities and organisations as 3rd highest compared to most relatives ranking 5th (41.7%) and professionals 6th (37.5%) *(Figure 6.4).* Charities such as the BHF and CMA that were raised in the interviews with patients and relatives, were found to be valuable sources of information.

Figure 6. 3 Availability of more information leaflets at different literacy levels

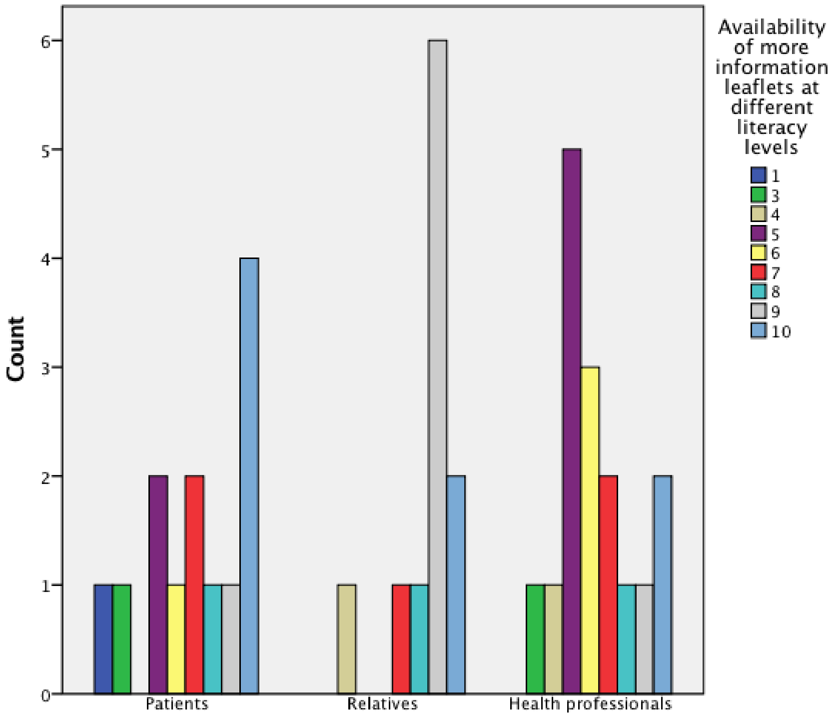
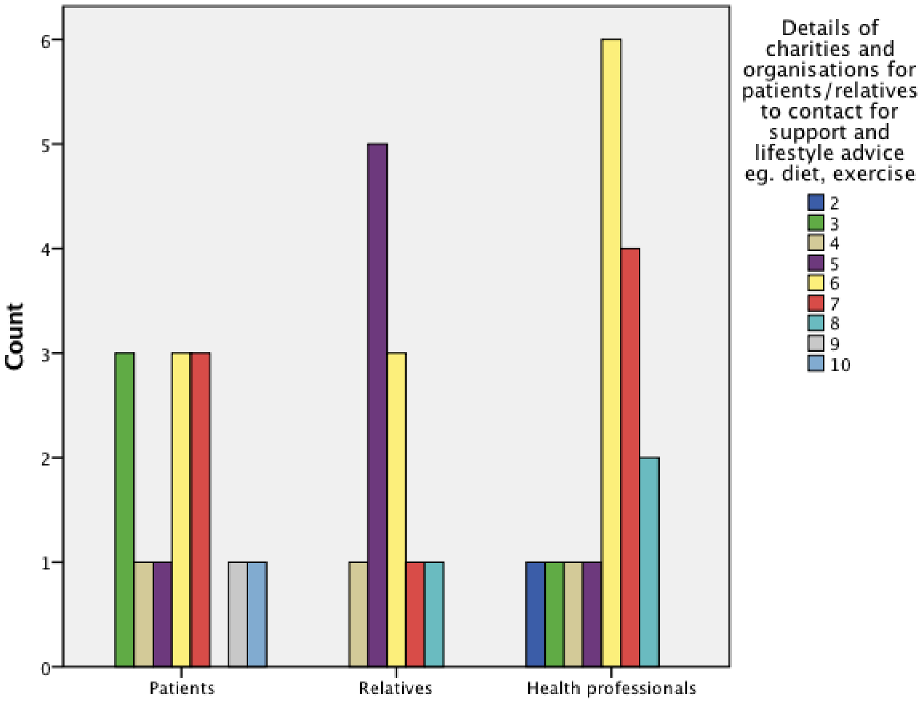


Figure 6. 4 Details of charities and organisations for support and advice



6.4.7 Differences between professional disciplines

Most panel members ranked the item, 'access to health information leaflets' as 4th on the list of importance. Twenty percent of physicians ranked this as 7th on the list compared to 2(33.3%) of nurses who rated the importance as 4th on the list. This was an interesting finding as the interview data highlighted that physicians in particular, highly valued the use of information leaflets to support treatment discussions. When asked to rank the importance of the 'availability of more information leaflets' both physicians and nurses ranked this item as not as important [5(50%) of physicians ranked 5th, 2(33.3%) of nurses ranked 6th and 7th]. Panel members ranked 'family involvement' as 2nd highest on the list of importance. Only 4 (40%) of physicians rated this item as 3rd on the list compared to 3 (50%) of nurses who rated it 2nd highest item of importance. Similar to the rankings of patients and their relatives, 5(50%) of physicians and 3(50%) of nurses agreed that, 'discussing the views of patient's friends towards treatment' was the least important item to address. Nurses had mixed responses to the ranking of importance of providing 'details of charities and organisations' to patients. Whereas 5(50%) of physicians ranked this item as 6th on the list.

6.5 Question 3

Question 3 asked panellists to rank a list of items relating to information about treatments in order of importance. 1 – Extremely important (greatest influence on treatment decision), 10 – not at all important (least influence on treatment decision).

Table 6. 15 Question 3: Order of importance

Round 2 Item list	N	Median	Mode
Cause of the patient's heart failure	40	3.0	1.0
Effect on prognosis	40	5.0	1.0*
Risk of treatment	40	3.0	2.0
Effect on symptoms	40	5.0	2.0
Impact of treatment on quality of life	40	4.0	4.0
How invasive the treatment is (e.g. open heart surgery or key hole)	40	4.5	4.0
Side-effects of medications	40	5.0	5.0
Recovery time	40	8.0	8.0
Length of hospital stay	40	8.0	10.0
Effect on ability to work	40	8.5	10.0

*Multiple modes exist. The smallest value is shown

6.5.1 Differences between cohorts

Patients and relatives ranked information about the cause of heart failure as the most important item (1 = 61.5% and 41.7% respectively), compared to only 18.8% of professionals. Interestingly, most professionals (43.8%)

ranked this item as least important. A similar difference was found between cohorts' views towards information about the risk of treatment. This item was ranked as the 2nd most important item by patients (46.2%) compared to only 12.5% of health professionals. Alternatively, 43.8% of professionals ranked information about the effect of treatment on symptoms as the 2nd most important item (43.8%). Most relatives ranked this item 3rd most important (33.3%) and patients, 6th most important (23.1%).

Thirty-three percent of relatives ranked information about side-effects of medication 2nd most important item compared to less than 8% of patients and professionals (7.7% and 6.3% respectively). This likely reflects the common role of relatives in medication management and the discussion of medications with health professionals. Relatives were also more interested in knowing how invasive procedures were compared to patients (rank 1 = 16.7% relatives, 7.7% patients, 6.3% professionals). Relatives wanted more information about the practicalities and risks of treatment. Length of hospital stay was ranked as less important to most patients [7(53.8%) ranked as 10th] compared to 2 (6.7%) of family members. Six (37.5%) of health professionals ranked this as 9th on the list of importance. This reflects the findings of the interview data where relatives were concerned about the long-term effects of treatment and recovery time.

Surprisingly, patients ranked 'the impact of treatment on quality of life' as only 4th on the list [5 (38.5%)]. This was reflected in the rankings of family members with 3 (27.3%) ranking this item as 4th on the list of importance. In comparison, 5 (31.3%) of professionals ranked the impact on quality of life as having the greatest importance 1st and 2nd on the list. Interestingly, the qualitative data highlighted patients and their relatives' preference for more information on prognosis. Yet the results of Round 2 present mixed findings. Patient results varied in the ranking of 'effect on prognosis' from 1(7.7%) ranking this item 1st and 2(15.4%) ranking it as 9th. Two (16.7%) of relatives ranked this item as 1st (most important) with 3(25%) ranking it as 9th on the list. In contrast, more health professionals 4(25%) ranked 'prognosis' as 2nd highest.

6.5.2 Differences between professional disciplines

In contrast to the rankings of patients, most physicians ranked 'impact of treatment on quality of life' as 3rd important on the list of items (3, 30%). Nurses rankings varied from 1st to 8th. Differences were found between the different disciplines and patients' responses to their rankings of the importance of treatments on the 'effect on prognosis.' Most nurses, 3 (50%) ranked this item as 2nd highest. In contrast, 3(30%) of physicians ranked this as 3rd highest and a further 2(20%) ranked this as only the 8th important item. A further difference was found in ranking the discussion of the cause of the patient's heart failure' in relation to treatment. Two (33.3%) of nurses ranked this item as 10th on the list compared to physicians where there were mixed views [3(30%) ranked 1st and 5(50%) ranked 10th). These results demonstrate the contrasting value attributed by nurses and physicians to different aspects of the treatment discussion. These findings highlight further disparity in the priorities of different stakeholders in the treatment decision-making process.

6.6 Conclusion of Results

This mixed-methods study involved an in-depth exploration of treatment decision-making in heart failure management. The results of this thesis present the process of treatment decision-making in current practice (MDT meeting analyses, Chapter 3); the factors that influence patient decisions about the treatment and management of their heart failure (Strand I); and the views of different stakeholders towards how treatments are communicated in practice (Strand II). The following chapter provides an in-depth discussion of these results in the context of the wider literature and the implications for practice and future research.

CHAPTER 7: DISCUSSION

7.1 Introduction to Chapter:

This thesis used a mixed-methods design to explore how patients make decisions about their heart failure management. The current practice of making treatment decisions was explored through analyses of MDT meetings. The views of patients, family members and health professionals were explored to identify the similarities and differences in approaches to decision-making and preferences for communication about treatment. Together these data were used to identify the key barriers and facilitators to a shared approach to decision-making (SDM) in practice.

These findings add to the literature by illustrating a disparity between decision-making policy, practice and patient need. The three studies reported in this thesis demonstrate considerable variation in: the practice of decision-making; the views and approaches to decision-making of patients, family members and health professionals; what is considered valuable information; and the priorities for improving current practice.

The findings reported are relevant to policymakers, health professionals and researchers. Policymakers need increased understanding of patients' preferences, so health policy can reflect patient need and is deliverable. Health professionals need increased understanding of how patients make decisions, so they can tailor communication about treatments. These findings highlight an important gap in the evidence-base which can inform the purpose and design of future research through consideration of the patient perspective.

The following Chapter discusses these findings in the context of the literature and the wider healthcare perspective. It starts by presenting the key findings. This is followed by discussion of the key barriers to SDM in practice. Barriers are discussed under three subheadings that reflect the SDM model: patient involvement; health information provision; and delivering SDM in practice. The limitations of this thesis are then presented. The factors found to facilitate a SDM approach are discussed in support of key recommendations for practice. Together these findings inform the next steps for future research in this field.

7.2 Key findings

The results of the Multidisciplinary team (MDT) meeting analyses emphasise the gap between decision-making policy and practice. Meetings were predominantly physician-led with few to no specialist nurses and allied health professionals in attendance. No patients, relatives or carers were invited to attend the meetings and not every patient was informed of their case being discussed. The lack of involvement of patients in this process (for many, their lack of awareness) is concerning, particularly as MDT meetings form a core process of decision-making. Policy on decision-making advocates partnership between patients and professionals and joint decision-making.

The results of these analyses demonstrate a strong degree of isolation. Making decisions without giving patients the opportunity to share their views conflicts directly with a SDM approach.

It is important that these results are interpreted in the context of the study design and sample analysed. The response rate was low (35%) with a small sample size of nine MDT meetings. These results cannot be generalised, but they do offer insight in to the variation in practice within and across NHS Trusts. The MDTs included experts in sub-specialties of cardiology and cardiothoracic. The patients being managed by these teams were complex cardiac patients requiring specialist care. This is reflected in the high number of different consultant specialists in attendance. MDT meetings conducted at smaller, district general hospitals may follow different structures. Nevertheless, in specialist hospitals with established cardiac services and clinical research portfolios, it is surprising to find meetings with no nurse presence and rarely attended by allied health professionals and researchers.

The qualitative interview study reported in this thesis explored patients' views and experiences of their heart failure management. How patients formed their beliefs about treatments emerged through their descriptions of past experiences and their knowledge and understanding of their heart failure. Age, gender and educational background were found to influence patients approach to decision-making and their treatment preferences. Yet the greatest influence on how patients valued treatments was the patient-professional relationship. Having a trusting relationship with professionals meant patients were more likely to value their advice.

A key finding of the interview study was that patients and family members had limited understanding of their heart failure aetiology and the concept of personalised medicine. Patient understanding of their heart failure was influenced by information sourced from the internet, their family and friends and the media. All patients regardless of age, gender and educational background had accessed online health information. Importantly, it was the process of independently searching for information that patients and family members valued. The influence of that information on patient behaviour depended on how they perceived the information to align with their own beliefs. Patients' information-sourcing behaviour directly influenced whether they chose to take their medications or not or whether they agreed to a specific treatment.

One of the key barriers to the assessment of patient information needs was that patients frequently tailored the information they shared to different professionals. Information was limited to their disease needs when communicating with physicians. Alternatively, patients were more likely to share information about their psychological health or social circumstance with nurses. This may in part explain professionals' assumptions about patient preferences and behaviour. Those patients that appeared 'passive' in consultations were perceived to want less information and more likely to agree to treatment recommendations. This was not found to be the case in this study. The result of these assumptions meant that only patients who asked for additional information were given information. This was limited to written information leaflets which patients and family members did not value.

It is important to note that this was not a representative sample. Patients who participated in interviews were recruited from two tertiary centres. Patients were referred with complex cardiac conditions, some of whom had self-referred. All patients interviewed were supportive of novel treatments (including gene therapy and stem cell therapy) regardless of their age, gender, symptom severity or education background. This reflects a bias sample which is important when considering their health beliefs and behaviours. Individual one-to-one interviews encouraged participants to give their private views opposed to the public view (as reported in Creswell and Clark, 2011). These findings cannot be generalised statistically to a clinic representative patient population. Yet the key themes that emerged from the interview data can be generalised theoretically.

The Delphi survey built upon these findings and explored the views of each cohort towards the communication of treatments in practice. Thirty-five percent (14/40) statements in Round 1 met the consensus criteria. Considerable variation in the views between cohorts and professional disciplines was reported. There was group consensus that all patients should be given the opportunity to be involved in treatment decisions. The discussion of patient involvement in decision-making was ranked as the highest item of importance when discussing treatments. Yet more health professionals rated making a joint decision with patients about treatment as 'extremely important' compared to patients and family members [13/16 (81.3%), 6/12 (50%) and 7/12 (58.3%) respectively].

Patients and relatives wanted more information about the cause of their heart failure and the risks of treatments. Relatives wanted more information about the side-effects of medications and how invasive procedures were. In contrast, professionals valued sharing information about the effects of treatments on patient symptoms and their quality of life. Patients and relatives attributed less value to this information. The Delphi results illustrate limited consensus on the priorities for improving treatment communication in practice. These findings emphasise the variation in views and the limited agreement in what constitutes the best approach.

The Delphi design followed a new format unlike previous studies. This is important to consider when interpreting the study results. The panel consisted of a mixed cohort: patients, family members and health professionals all responding to the same set of questions. Few studies have adopted a mixed panel format with no previous studies recruiting patients, family members and health professionals. Recruiting a mixed panel was important as the purpose of the study was to extend and test the qualitative data. Similar sample cohorts were purposively recruited (using the same eligibility criteria) to the interview study. Patients and family members owned multiple electronic devices, and this reflects individuals who are likely to be technology literate and use the internet as part of their everyday lives.

Further Rounds may have encouraged a greater level of consensus. Yet due to time constraints and the burden on participants, a third Round was not feasible in the remits of this thesis. The sample size for each cohort recruited to the Delphi panel was small. The purpose was not to find statistically significant differences in levels of agreement but to reach consensus on priorities for recommendations to improve practice. For this reason, further statistical analysis of the data was not conducted. A larger sample would be required to identify any associations between participant characteristics and their responses, and between-group differences.

7.3 Barriers to a SDM approach

7.3.1 Patient preferences for involvement

Encouraging patient involvement in decision-making is a core component of the SDM model. Yet it appears that patients and professionals have different interpretations of what involvement means. Health professionals' perceptions of patient involvement aligned with the literature. Little consideration was given to the influences on patient preferences for involvement beyond demographics. Health professionals viewed patient involvement in decision-making as their level of engagement in the clinic consultation. Engagement was perceived to be the extent of interaction patients had with professionals. Patients who did not ask questions were viewed as not wanting to be involved in decisions. Conversely, patients who voiced their views and asked for more information were viewed as wanting more involvement. Consequently, professionals tailored their approach to decision-making primarily based on this observed behaviour. In contrast, patients viewed involvement as a measure of responsibility for making the final treatment decision. Greater involvement meant greater responsibility. This likely explains why so many patients demonstrated limited engagement in consultations. Patients preferred the professional, '*the experts,'* to make recommendations and a treatment plan. Patients would then decide on the value of that advice based on information they collected from other sources and whether it validated their own beliefs.

Patients approach to decision-making was influenced by their age, gender and education background. Yet the extent of influence of these factors varied between individuals. Patient behaviour in the clinic consultation was not found to reflect their wider decision-making processes. When explored in the Delphi, 81% (13/16) of professionals rated making a joint decision with patients as 'extremely important,' compared to only 50% (6/12) of patients. Making a collaborative decision about treatment was not considered an expectation of the consultation. An agreed understanding of patient involvement in making decisions is needed so patients can see the value in sharing their views and goals.

The literature reports patient preferences for involvement are influenced by their culture and ethnicity, particularly in end-of-life care. Shrank et al (2005) conducted a focus group study and reported differences between non-Hispanic White participants and African-American patient preferences for information and family participation in discussions. In contrast, a cross-sectional survey in the US (n=974) used assessed the association between patient ethnicity and preferences for SDM (Peek et al, 2011). The authors reported no significant differences in preferences for a shared role (response rate = 67%). In the UK, results of the national cancer patient experience survey (n=41411) reported that patients from ethnic minorities had substantially fewer positive experiences of involvement compared to white patients ($p<0.001$) (El Turabi et al, 2013). Further evidence comes from a literature review conducted by Mead et al, (2013). The researchers reviewed decision-making in cancer care among ethnic minority patients. Of the 23 studies, most were undertaken in the US (n=19) comparing African Americans, Latinas and Asian patient groups. Differences were noted between and within the subgroups of patients in terms of preferences. The sample populations in this thesis were predominantly White British. Further research is required to assess the influence of ethnicity, culture and religion on patient preferences and approach to decision-making.

These differences in perceptions had substantial impact on patient-professional interactions. Patients needed to be *'pushy'* to feel their views were acknowledged and *'taken seriously.'* This may be explained by health professionals' perception of their role as primary decision-makers. Professionals viewed patient agreement with their recommendations as the primary outcome of treatment discussions. If at first patients did not show support for their treatment advice, professionals would revisit the discussion at a later date. Professionals' preference to lead decision-making was influenced by external pressures such as time constraints. Many believed this prevented adequate adoption of a shared approach. Due to the lack of clinical guidance and variability in the literature, it is understandable why professionals are yet to envision the benefits of SDM.

Situational factors such as the type of treatment being considered were also important factors influencing patient preferences for involvement. The literature suggests that patients facing invasive procedure decisions demonstrate higher rates of preference for involvement (Chewning et al, 2011). This was a study of cancer patients and did not reflect the preferences of the heart failure patients in this study. In contrast, there was tendency for patients to pass the responsibility for decision-making to professionals for complex treatments such as device therapy and surgery. Increased involvement in decisions about their medication management was what patients wanted. Alternatively, physicians placed greater importance on involving patients in decisions about device therapy and invasive procedures. More time was spent in clinic trying to explain the rationale for these treatments. This is likely due to the nature of these treatments, often carrying higher risks and irreversible outcomes compared to medication changes.

The limited time in consultations puts pressure on professionals to be able to effectively communicate all the information to patients about treatments and the different options. This need is evidenced in the literature where focus is on strategies to improve risk communication and develop new Decision Aids. However, what is useful for one patient may not be to another. Research suggests that patients often do not read all the information they are given (Manta et al, 2018). Professionals are bound by the law and their duty of care to gain informed consent prior to any procedure, investigation or treatment (NMC 2015; GMC, 2019). What started as an important process to ensure the ethical care and safety of patients, is becoming more challenging. Consent forms and patient information sheets frequently contain pages of information, a lot which is considered irrelevant by patients. In practice, this information is the basis of patients making 'an informed' decision. Arguably the current process is not fit for purpose.

Patients and their relatives want to know about the effects of treatment on their prognosis, the risks involved and the impact on recovery. Their views towards treatments were influenced by multiple factors, not just their level of health literacy. Patients in this study demonstrated unrealistic expectations of treatment regardless of their education background. Better tailoring of information to individual needs may help to translate scientific information more effectively.

Family members play an important role in the management of patients' heart failure. They take on increased responsibilities at home, often as primary carers and are affected physically and psychologically by the burden of heart failure. Patient preferences for family involvement in treatment discussions were influenced by their age and gender, but mostly by individual relationships. Older patients and male patients described their family members as *'fussing'*. In contrast, professionals believed older patients valued the advice of their relatives, so they were more likely to include these family members in treatment discussions. This inclusion may act to harm the patient-professional relationship by focusing on 'unwanted' family involvement. Male patients preferred to take the lead in discussions, yet their spouse/partner was often heavily involved in their care at home. Younger patients were more likely to act on the advice of family members and female patients were more likely to talk to their children about their heart failure, rather than their spouse. The individual dynamics between patients and their family members are an important influence on patient decisions and behaviour. It is important that professionals consider the involvement of family on an individual basis.

The findings of this thesis illustrate that family members want to be involved in the clinic consultation. Particularly in decisions relating to their relative's medications. Discussing the role of family in the patient's care may provide important insight in to how patients are coping and managing at home. However, finding the right balance of patient/relative involvement is challenging. Nurses viewed involvement of family members as key to getting the complete picture of the patient. Family were viewed as an important resource to retain information and encourage treatment adherence. Conversely, physicians were often challenged by family involvement in treatment discussions. With relatives having differing agendas and views towards treatment, it was difficult for physicians to focus on the needs and preferences of the patient.

7.3.2 Health information provision

How patients form their disease beliefs starts far earlier and extends beyond the end of the clinic consultation. Patient preferences for involvement in the consultation depends largely on how they view their role in decision-making. The sourcing of information before and after clinic consultations was found to be a key influence on how patients made their decisions. The deliberation of this information and formation of opinions about treatment was an integral part of this process. Patients combined their past experiences of healthcare with information they received from friends, family and the internet to decide on the value of professionals' advice and ultimately, whether to follow it or not.

Education is essential to supporting patients with chronic disease to adhere to their clinical follow-up (Kamat et al, 2018) and to improve adherence to treatment (Vanhaecke Collard et al, 2017; Zhao et al, 2015). A key finding of this study was that patients and their relatives had limited understanding of their heart failure aetiology and the suitability of different treatments. Patients were knowledgeable of their medications and need for titration. But many considered the number of medications they were taking as a reflection of their health status. More medications meant worsening health. Patients viewed their heart failure as a series of investigations or procedures they had undergone. This meant that treatments and their effects were often considered in isolation. Importantly, how professionals described treatments influenced how patients valued them. This information and the style in which it is communicated was a key driving force of patients' health information seeking-behaviour. Patients and relatives want more information about the cause of their heart failure and prognosis. But physicians in particular, preferred a positive approach to communication, favouring discussion of treatment that extends life rather than discussing mortality. Although professionals discuss the rationale of treatments in detail, their explanations do not appear to be translating to accurate patient knowledge and understanding.

The findings of this thesis highlighted physicians' views that health education and information provision is the role of the nurse. This was explored further in the Delphi (Round 1). Eighty-three percent (5/6) of nurses agreed that professionals regularly signpost patients to additional sources of information. Only 18% (2/11) of physicians agreed. Eighty-three percent (5/6) of nurses and 63% (7/11) of physicians believed patients prefer to ask nurses rather than doctors for more information. In contrast, 68% (13/19) of patients and 56% (10/18) of relatives disagreed. These findings highlight that patients and relatives view both nurses and doctors as important sources of information. Physicians who refer patients to nurses for all their health information needs, are missing important opportunity to educate patients. There is a need to break down the idea that only biological information is valued by physicians.

Professionals frequent use of medical terminology is arguably leading to further confusion and misinterpretation of information. Patients and relatives use this information to measure their health status, compare their health to others and evaluate the effectiveness of treatments. Terminology that was valued included measures of: Ejection Fraction (EF), valve function (mild to moderate, moderate to severe) and blood results (Brain Natriuetic Peptide, BNP; Creatinine and Urea; Glomerular Filtration Rate, GFR). There was a tendency for patients and relatives to focus on the quantification of disease. This is a concern when most patients demonstrate limited understanding of its context. Accuracy of patient knowledge was not found to be influenced by education background. Patients from higher education backgrounds wanted more analytical information. But this commonly led to further fixation on quantifiable measurements of health and less consideration of treatment suitability. These findings suggest that professionals need to address patient understanding of their heart failure and be mindful of the language they use to communicate health information.

Patient preferences for more complex information was demonstrated by their use of the internet. This information may be evidence-based and useful but was also found to be inaccurate and misleading. Today patients can undertake virtual consultations with doctors, order DNA sequencing online and use ‘symptom checker’ websites to establish provisional diagnoses. The internet has become a part of peoples’ everyday lives, with most people having access to at least one internet-enabled device (commonly a smartphone). It provides an easy, quick way to access information both on the go for ‘real-time information’ and when people want to search freely and gather additional information on a specific topic. Recent advances in mobile technology have seen a rapid increase in the number of applications designed to assess and monitor patient health. From mobile phone enabled electrocardiograms (ECG) and Fitbit® devices that measure heart rate and sleep patterns. To health applications designed to remind patients when to take their medications and advice for healthy lifestyle choices. In many ways, this is a positive move encouraging patients to take ownership of their health. The challenge for patients and professionals is knowing which technology to choose and the sensitivity and reliability of the data provided. Many of these applications are designed by technology experts but lack guidance from clinicians.

A positive finding was that patients were aware of validated websites (CMA and BHF most commonly referenced), but few patients described using these sites. Common use of ‘Google’ as the starting point of online searches suggests that patients are wanting further information but have limited knowledge of where to access it. There was limited use of internet healthcare platforms such as hospital websites, online booking systems and repeat prescription services. To combat concerns of patients accessing inaccurate information online, healthcare providers need to become more internet literate.

Despite the internet not being viewed as a replacement for health professionals it is a source of information frequently used by patients and their relatives. Since its inception in 1991 there have been studies reporting association between internet use and non-compliance. A recent web-based public survey conducted in China (n=336) reported that the quality of health information sourced online impacted on patient compliance with their physician’s advice, despite its source (Lu et al, 2018).

Patients and relatives value the internet as an important source of information. Over half of the patients interviewed searched for health information online. Those patients who did not search online gained access to online information from their friends and family. The Delphi reported 39% (7/18) of family members as viewing the internet as the most valuable source of health information compared to only 26% (5/19) of patients. This reflects the interview data where family members frequently sourced information and shared it with patients. Patients and relatives formed their own beliefs about the trustworthiness of information. This was based on their perceived value of the internet and how the information they found aligned with their views. Importantly, value was given to independently searching the internet rather than being confined to a few sites deemed acceptable by professionals.

The process of searching for online health information varied widely. In support of these findings, McMullan et al (2006) reported that most patients use the internet to search for health information after speaking to health professionals. The Delphi study reported 82% (14/17) of health professionals believed that patients use the internet to help make decisions about treatments. Yet only 21% (4/19) of patients agreed. Sixty-three percent of patients (12/19) and 72% (13/18) of relatives stated that they preferred to ask professionals for further explanations rather than use the internet. There is preference for patients and their relatives to gain further information from professionals however, unmet need is triggering patients and their relatives to use the internet.

Health professionals currently underestimate patient access to online information. Few health professionals raised the issue of health-seeking internet use in their consultations. The findings of the Delphi emphasise professionals' misconceptions. Fifty-nine percent (10/17) of professionals believed patients use the internet because they feel depressed, anxious or concerned. Of these 73% (8/11) were physicians. In contrast, only 32% (6/19) of patients agreed. Depression has been associated with internet use with patients reporting high levels of depressive symptoms following extended use of the internet ($p<0.001$) (Morrison and Gore, 2010). This has not been demonstrated in a heart failure population. The ease of access to health information was viewed by some physicians as taking away their sense of control. When explored in the Delphi, there was group agreement that patients and relatives would visit a website recommended by health professionals. If professionals clearly sign post patients to validated websites it may well help to minimise decisions based on poor quality information.

Whether patients and relatives chose to share the information they had sourced online with each other or not, few discussed their findings with professionals. A survey conducted by the Health on the Net Foundation (n= 2621) reported that only a third of patients would ask their physician if they did not understand the information they had sourced from the internet (Boyer et al, 2002). The main reasons for not discussing information was not wanting to *'waste their time.'* When patients did share information, this was commonly with the nurse rather than the physician. There was consensus among patients that professionals do not value information sourced from the internet. Patients and their relatives were aware it may not be the best or most accurate source, so they chose not to share their behaviour with professionals. This 'hiding' of information provides further argument for professionals to raise internet use in their discussions with patients.

Alternatively, patients were more likely to ask health professionals questions about information they had seen or read in the media. The media continues to play an important role in publicising public opinion particularly when it comes to healthcare. In the past national media campaigns have publicised negative views through stories of funding crises, negative outcomes of research and more recently MRC contracts for doctors. The way the media portrays these events can lead to public concern and negative opinion toward the national health service. This behaviour may reflect professionals' observations where the media was viewed as a strong influence on patients' views.

Friends played an important role in patients accessing the internet and discussion of information sourced online. Professionals viewed the experience and views of patients' friends as a key influence on their decisions. This was confirmed in the Delphi where 76% (13/17) of professionals agreed that friends played a very important role in influencing patients' decisions. In contrast, only 26% (5/19) of patients and 16% (3/18) of family members agreed. Information sourced by family and friends activated patients to ask questions in the clinic consultation. Patients valued this information when it validated their own views or the advice of a 'trusted' health professional. How this information influences patient adherence to treatment requires further exploration.

All patients valued information sourced from friends and family who worked in healthcare. Relatives sought information from these friends/family members prior to the medical encounter (information about the cause of symptoms and advice on whether to seek medical review). Following the medical encounter for reassurance, to check medication regime and views on new treatment plans. The Delphi reported that 82% (14/17) of professionals agreed that the views and experiences of family members were important to patients when deciding on treatment. Only 61% (11/18) of family members agreed. This reflects family member preference to be more involved in treatment discussions with 88% (16/18) agreeing that their role in decision-making was important. Nearly all professionals agreed that family member involvement was important (94% (17/18), compared to only 53% (10/19) of patients. Not all patients wanted their family members to be involved therefore, professionals need to assess patient preferences on an individual basis.

Professionals tended to take a reactionary approach to information provision, with a philosophy that 'those that don't ask don't get.' Professionally written information leaflets were professionals primary choice of information provision. This reflects the findings of the Picker Institute that reported limited signposting of patients to reliable information by health professionals (Swain et al, 2007). The interview data illustrated the high value professionals attribute to use of leaflets. But few patients and no relatives attributed the same value. Interestingly, the Delphi reported that 45% (5/11) of physicians compared to 17% (1/6) of nurses, believed leaflets to be the most valuable source of information. When tested in Round 2 of the Delphi, 33% (4/12) of patients ranked the availability of more information leaflets at different literacy levels as the least important item of what to include in clinic consultations. This reflects clinical practice where the provision of information leaflets is often favoured by physicians. Further research in to patients' views toward information leaflets and their effects on patient behaviour is required to properly assess their value.

The differences in views between patients, family members and professionals towards decision-making, involvement and preferences for information provision, were key barriers to the adoption of a SDM approach. To tackle current problems of medication adherence, improve access to services and support patients to self-care, professionals need to review their assumptions and perceptions of patients' information needs.

7.3.3 Adopting SDM in practice

The findings of this thesis illustrate the extent to which health professionals are challenged when making treatment decisions and managing patients with heart failure. To assess the application of health policy in clinical practice, the wider context of healthcare service delivery was considered.

The identification of new disease taxonomies and the emergence of new sub-specialties means that professionals are adopting a more tailored approach to heart failure management. This is reflected in the evidence-based guidelines that support professionals in making treatment decisions (ESC, 2016; NICE, 2018). The development of treatments to target therapeutic benefit to smaller sub-populations is an important advance in heart failure. A move to target treatments at the genetic level is advancing medical science. But a consequence of this is that professionals may be losing site of the complete patient picture. This narrowing focus may put professionals at risk of treating only the disease and not the person. The tailoring of therapies to more specific disease needs means that professionals are having to communicate increasingly detailed and technical information to patients. The pressures and resource constraints placed on today's services means there is less time for professionals to convey this information.

The discussion of the patient in dedicated MDT meetings is one of the key processes in this pathway. Discussion is primarily about current hospital inpatients, but complex patients that are managed as outpatients are also reviewed. As discussed in Chapter 3, the MDT meeting evolved from an increase in the complexity of patients disease and management needs. The collaboration of different disciplines was agreed to be the best method to allow expert consideration of the whole patient (Koshman et al, 2008; NHS, 2014).

A MDT approach to heart failure management is widely advocated and its effects have demonstrated positive patient outcomes (ESC, 2016). Today the practice of MDT meetings is largely based on the preferences of the clinical leads. There is little formalisation or standardisation of meetings. The findings of the MDT meeting analyses demonstrate marked variation in the processes, functions and structures of MDT meetings both within specialties and across London NHS Trusts. Only a short time is afforded to the discussion of each patient. It is difficult to comprehend that in short time a holistic review of the patient can be made.

It was concerning, yet maybe not surprising, that many health professionals continue to approach treatment decision-making from the biological perspective. The medical model was apparent in most MDT meetings with senior physicians dominating discussion. With limited presence and input from nurses and other allied health professionals, a truly collaborative approach is yet to be achieved. As a core process of treatment decision-making in heart failure it was interesting to find that many patients were unaware of its existence. There was no patient involvement in any of the MDT meetings examined. These findings highlight potential missed opportunity to integrate the patient voice in to the MDT meeting. Isolation of this process has resulted in patients and their families having limited understanding of how treatment recommendations are made.

Benefits of involving patients in MDT meetings have been reported in the literature. Choy and colleagues (2007) reported that involvement of breast cancer patients in MDT meetings (n=30) led to agreement by clinicians of patients having increased understanding of their disease and treatment, without increasing anxiety. Yet patient satisfaction with treatment decisions were not significantly different compared to those patients that did not attend meetings. Choy et al (2007) reported education level being a key influential factor on whether patients chose to attend the MDT meetings or not. It cannot therefore be assumed that involvement of patients and relatives is the right approach for everyone. Yet facilitating involvement for those who want it is important.

The patients in this study were managed as outpatients. Traditionally, treatment recommendations are made by the physician. This usually occurs after seeing the patient and listening to their symptoms and assessing for any objective physical signs. Today with developments in diagnostics and subspecialties patients are often being sent for a series of tests (bloods, x-rays, scans and non-invasive investigations) before seeing their physician. These results are then reviewed by the patient’s heart failure team and treatment recommendations are fed back to patients and their relatives in clinic.

This process of treatment decision-making has been advanced by the introduction of new technology. There is a focus on increasing the speed of diagnostics, so patients can commence treatment quickly. Point-of-care testing is one of the recent advances that have been introduced (King et al, 2016). These devices give near immediate results including: NT-proBNP, troponin and INR. Their use allows professionals to identify actual and potential problems early so patients can initiate treatment as soon as possible. In practice, this means that decisions about treatments are being approached much earlier in the patient pathway. Patients are being asked to make decisions soon after they have undergone tests and investigations. As a result, patients and their relatives are having less time to reflect on this information and consider different options. The delivery of services in this way has arguably resulted in a fragmented system of care.

Patients and relatives want greater access to professionals when they are at home. To ask questions and get advice about their heart failure management. Heart failure nurses currently provide this service with telephone support and email communication with patients and their relatives. The focus of this support is usually on patients who have recently been discharged from hospital, currently titrating their medications and those at later stages of the disease trajectory. Nurses argue that this service is not being efficiently used. Some patients are still missing the opportunity to have nurse support. The findings of this thesis showed nurses concern for patients that chose not to contact them for advice. For a SDM approach to work, patients need to be able to access health professionals to share information and decide on the best approach to management. A partnered approach to decision-making extends beyond the clinic consultation of treatment. To be fully integrated it needs to be adopted in to the entire patient pathway.

The findings of this study demonstrate that professionals are trying to tailor the time they spend with patients to individual needs. Organising their clinic lists dependent on patient need and using different styles of communication for different patients. Yet there remains widespread agreement that the short time spent with patients does impact on patient care and safety. The patient pathway consists of a series of visits to the hospital culminating in a single discussion in clinic. Only at this point do patients and their relatives have opportunity to question, challenge and share their own views with professionals. This limited time means that patients and relatives often feel unable to ask the questions they want.

Services have tried to overcome some of these barriers with some heart failure teams offering a ‘one stop shop’ clinic. This involves patients attending a whole day or half day in clinic (day case). During this time patients undergo investigations and tests and are then reviewed by their physician and often by the heart failure nurse specialist. These ‘all in one’ clinics are valued by professionals as an efficient and effective means of overcoming limited resources. These clinics were introduced to streamline heart failure care and based on professionals’ assumption that patients do not want to attend multiple hospital appointments. However, limited evidence exists evaluating the benefits and cost impact of these services. The focus in the literature and policy is on cancer diagnostic day case services (Dey et al, 2002; NHS, 2018). Empirical evidence demonstrating benefit in heart failure populations is lacking.

Patients who attend these clinics are not necessarily gaining their proposed benefits. Patients, family members and professionals all agreed that time constraints were one of the greatest barriers to a collaborative approach to decision-making. Taking time off work, managing childcare and arranging transportation were all shown to be obstacles to patient attendance. A day or morning dedicated to seeing patients and sending them for tests which can then be reviewed, and a treatment plan made, may appear to be an effective use of professionals’ time. But there are concerns about the benefits of this service. Physicians raised the complexity of setting up these services and the challenge to arrange all the investigations required at one time. Nurses demonstrated concern that patients may find the process overwhelming and the challenges of being able to tailor support to patients’ needs. A busy day of rushing around having multiple investigations ending in review with the physician and often the specialist nurse, was exhausting for patients and their relatives. This makes the effective communication of treatments even more challenging.

Konrad et al (2010) conducted a survey study of physician perceptions of time constraints in primary care. The study compared perceptions across the UK, Germany and the US. On average, British physicians reported having <11minutes to see new referrals and <10 minutes to review follow-up patients. The US physicians had the longest duration of time followed by UK physicians (Konrad et al, 2010). The clinics at each recruitment site involved the consultant and a cardiology specialist registrar (SpR) reviewing patients independently. The new referrals were often seen by the consultant and follow-up patients reviewed by the SpR or junior doctors. The growing numbers of patients and the regular turnover of junior doctors has led to a lack of continuity. Patients found this to be a significant barrier to building a trusting relationship with professionals. Patients described less confidence in young doctors with some requesting to be seen by their consultant. This often led to clinics overrunning with each patient having less time to be seen. Physicians tended to focus on patient assessment, result feedback and treatment risk due to this limited timeframe. This practice reflects the focus in the medical literature on the use of Decision Aids as a tool to support professionals in their communication of risk (Stacey et al, 2017; O'Conner et al, 2009).

Greater continuity of care is often afforded by heart failure nurses working in hospitals and community settings. Heart failure nurses traditionally have more time to spend with patients with more frequent scheduled clinic appointments. Often heart failure nurses would communicate with patients by phone and/or by email correspondence. They would provide advice about symptom management, medications and monitoring and support patient and family well-being.

Physicians and nurses frequently accompanied their verbal explanation of treatment with written literature. Little evidence exists regarding the most effective way or content of written information to be provided to patients. As reflected in the MDT meeting analyses, choice of literature was often based on physician preference. The primary 'go-to' source of information is professionally-derived information leaflets. These leaflets contain information about the anatomy and physiology of heart failure, individual treatments, advice on self-management. They are easily accessible in most clinic environments and favoured by professionals as they provide validated and reliable information. The increased demand on clinics means that professionals highly value literature that patients can take away and read after the treatment discussion. Research has shown that patients often do not take in all the information during clinic consultations (Kessels et al, 2003). Patient leaflets have been reported as an important part of information provision to support patients' recall (Sustersic et al, 2013; Raynor et al, 2007). There is also evidence that patients continue to ask for more written information (Gaston and Mitchell, 2005). However, there is no literature to date evaluating the impact of information leaflets on recall and decision-making in heart failure populations.

There is a strong interest in the development of technology to assist patient care due to the mounting pressures on services. Current technologies used to assist professionals in managing patients remotely include information technology (IT) based systems that collect and transfer data from patients to professionals. These include the monitoring of vital signs (Blood pressure (BP) devices, INR testing, weigh scales) and device therapy downloads. How patients value these technologies has been studied. Research reports mixed views and levels of patient satisfaction (Seto et al, 2010). Some studies have reported up to 95% of patients have high levels of satisfaction with ICD remote monitoring devices (Raatikainen et al, 2008) and are satisfied with their usability (Marzegalli et al, 2008).

In this study, physicians were supportive of more remote monitoring of patients and the use of technology such as 'skype consultations' as an adjunct to their clinic service. Heart failure nurses tended to value in-person consultations, so they could see the full patient picture. The differences in roles between physicians and nurses are likely to explain these contrasting views. Nurses were the key staff involved in managing and reviewing tele-monitoring of patients. They were concerned about the quality of data being collected and patients' misinterpreting the data. This was likely fuelled by nurses having to deal with increased telephone communication to reassure patients. Physicians may arguably not be aware of the impact of remote monitoring on nurses workload. Patients and their relatives valued in-person consultation. Many were supportive of remote monitoring, but most wanted to maintain their regular appointments with their physician and nurse.

Faced with growing pressures on services, the use of technologies and the remote management of patients will likely grow. It is important to understand why patients value in-person consultation so future changes to services can be tailored to better suit their needs. What patients and their relatives valued was regular contact with professionals whether it be in-person, by telephone or email correspondence. Having access to professionals for advice and reassurance helps patients to manage their condition and feel 'looked after.' This contact is essential to encourage patients to access services and support the smooth transition of care from the hospital to the community.

The current delivery of heart failure services is leaving many patients and their relatives overloaded with technical information and with limited time to absorb and consider different treatment options. The challenge is how best to support patients to make quality decisions.

7.4 Facilitators of SDM in practice

The key facilitator to a shared approach was the building of trust between patients and professionals. A trusting relationship influenced the level of patient engagement in the clinic consultation and the likelihood of patients following professionals' advice. Trust was developed through positive experience of past treatments and professionals getting to know their patients, their experience of symptoms and their social circumstances. In Round 2 of the Delphi, 50% (8/16) of health professionals rated 'knowing patient's social circumstances' as extremely important. Professionals valued this information and its importance in providing a holistic picture of the patient. The private view of how they are coping, opposed to the public view they display in clinic (Creswell and Clark, 2011). The assessment of patients' psychological well-being was rated 'very/extremely important' by each cohort. Professionals that encourage the discussion of psychological health and its impact on patients and their families are likely to gain greater insight in to patient needs, as well as facilitate openness and trust.

The importance of Trust between patients and professionals is widely reported. Croker et al (2013) conducted a secondary analysis of national GP survey data in England and reported 'being taken seriously' as the strongest predictor of patient trust in professionals. Developing trust and rapport is a skill and can be challenging. In the UK, nurses are trained to diploma or degree level. An important part of the programme syllabus is the development of strong communication skills. Only in the last decade have medics seen integration of communication skills training in to their curriculum (BMA, 2018). This may reflect the different styles of professionals in practice. Good communication skills, honesty, a caring bedside manner and clear explanations of treatment helped to build trust. Style of communication was not found to be influenced by professionals' years of experience, their gender or discipline. Patients were found to be more receptive to a style that was tailored to their communication approach. If they showed preference for facts and a direct style of communication, or they were very anxious and required a more reassuring approach. This was a factor found to influence their level of trust in professionals.

Continuity of the health professional who was reviewing the patient was a significant facilitator of trust. Knowing patients disease needs and personal circumstance was important. A trusting relationship meant that patients and relatives were more likely to seek the advice of professionals before altering their disease management. Patients described occasions when they had gone against the advice of professionals, regardless of their demographics and disease characteristics. Professionals need to encourage patients to raise their concerns, whether that be in clinic or contact a professional when they are at home. The development of a trusting relationship is paramount.

Heart failure nurses often spend more time with patients and their families both in-person and remotely through telephone conversations and email correspondence. This time enables nurses to gain a better understanding of the patient, their social circumstances, disease needs and health behaviours. In today's healthcare, it is unlikely that physicians will be afforded more time with patients or allow for greater continuity. Nurses are arguably getting a more holistic view of patients. This unique understanding needs to be acknowledged by physicians. Knowing the factors that are likely to influence patient views toward treatment recommendations is important to support decision implementation. Nurses knowledge is a vital resource to the heart failure MDT and physician support is needed to ensure nurses are more actively involved in this decision-making process.

Knowing how to tailor communication is extremely important. A 'good' bedside manner means going beyond a pleasant demeanour and politeness. Honesty, providing clear explanations, reassurance and listening to patients concerns were all important attributes. In practice, this requires continuity of professional and more in-person communication. This view was supported by the results of the Delphi (Round 1). Seventy-two percent (39/54) of the panel agreed that longer clinic appointments were needed to develop trust. The clinic consultation is the focus of communication between patients and professionals in practice. Professionals and policy makers may need to accept that longer appointments might be necessary to support the tailoring of communication about treatments.

As discussed in chapter 2, a shared approach to decision-making has potential to help patients make decisions about treatment that they are more likely to adhere to and be satisfied with (Coulter and Collins, 2011). Current health policy is already evaluating health services on their ability to implement this approach with financial implications being placed on Trusts who fail to adopt SDM in practice (NHS England, 2017). Different types of patients emerged from this thesis, but not every old or young patient, whether they have high or low educational backgrounds have the same needs or behave in the same way. The similarities and differences in views and behaviours of patients, family members and professionals illustrate that current service delivery is not yet equipped to deliver SDM in practice.

7.5 Study limitations

The qualitative study reported in this thesis (Strand I) used the process of constant comparison and thematic analysis to collect and analyse the interview data. This involved purposive selection of participants to generate a maximum variation sample with the aim to reach data saturation, where no new themes emerge. The interview data from health professionals was considered to reach data saturation, but the patient and family member interview data did not.

The mean age of patients interviewed was young (62 years, 34 to 91). These patients had complex conditions and had been referred/self-referred to a tertiary centre for specialist management. The patients tended to be younger, educated and from higher socio-economic backgrounds. This reduced the mean age and increased the level of education of the study sample. To address this bias, purposive selection of older patients and those from lower educational backgrounds was conducted. Seven patients were identified as eligible for the study but not approached due to increased frailty. Increased frailty is an important risk factor for morbidity and mortality. These patients were older with multiple morbidities and may have had different views towards treatment and their heart failure management. The small sample size of family members was a result of primary recruitment of patients followed by recruitment of their relatives. Forty-five percent (5/11) of relatives declined to participate due to time commitments.

Most patients and family members seen in clinic were White British, with fewer ethnic minority patients compared to local District hospital populations. Attempts were made at both sites to recruit patients from different ethnic minority backgrounds, but few patients attended the clinics during the recruitment window. Those patients that did meet the study criteria were approached, but five did not speak English well enough to participate in an interview. The decision not to use an interpreter was based on cost and the barrier it may cause when exploring patients' private views. The raw data is the patient's own words and translation may not reflect their true views. Patients and relatives from minority ethnic backgrounds may have cultural and religious influences on their views towards treatments and their approach to decision-making. The influence of culture and ethnicity could not be explored.

There is no target size for the panel used in Delphi consensus surveys. Few studies exist where multiple stakeholder views have been sort. The decision to recruit a mixed panel was based on the need for stakeholder agreement to develop practice recommendations that were reactive and realistic. The threshold for consensus was a lower cut-off compared to Delphi studies using single expert panels. However, the response rate for each round was >75% which supports methodological quality. Yet the consensus threshold used needs testing in further mixed cohort panels to determine its suitability. The Delphi consisted of two Rounds of questionnaires. A third Round may have been useful in achieving greater levels of consensus. The numbers were too small to demonstrate statistical significance in relationships between variables and participant responses.

7.5 Recommendations for practice

The output of this thesis is the provision of guidance for professionals to support patient involvement in decision-making and tailor communication about treatments. In the literature, the SDM model has been designed to be used to make preference-sensitive decisions. However, its application in all treatment and management decisions is viable as the sharing of information is what has shown to be the pivotal influence on patient decisions. The combined findings of these studies have demonstrated considerable variation in patient preferences, information needs and decision-making processes. Different types of patients emerged from these data, but the level of influence of demographics and contextual factors varied within groups. A prescriptive tool for professionals would not be an effective way to tailor discussions. Its use would fail to account for the wider context of different patients decision-making processes and seen as a tick box exercise.

As it stands, it is difficult for the SDM model presented in current policy to be effectively adopted today. These recommendations are intended to be used as a guide for health professionals to improve the process of treatment decision-making in heart failure management.

7.5.1 Heart failure MDT meetings

All patients should be informed of their case being discussed prior to the MDT meeting. This discussion should address the purpose of the MDT meeting, the process of how decisions are made, staff attendance and how recommendations are fed back to patients. Patients should be asked their views towards treatment, their goals, preferences and concerns. Following the meeting patients should receive verbal and written feedback about the outcomes by a member of their clinical team.

The structure, function and process of MDT meetings should be formally agreed and documented in a Terms of Reference (ToR). This should include its purpose, objectives, goals, frequency, information to be presented on each patient, recording and documentation of decisions, and an evaluation process on how and when to review the process. Time for teaching and discussion of research and trial recruitment should be formally integrated in to the meeting structure.

The core group of professionals attending each MDT meeting should be decided in advance and outlined in the ToR. This core group should include named physicians and clinical nurse specialists. Additional professionals whose expertise could be drawn upon should be agreed by the team. This should include allied health professionals (physiotherapist, occupational therapist, psychologist, pharmacist) and members of other teams for collaborative decisions requiring cross specialty expertise (e.g. oncology, surgical, respiratory). All members should be notified of the patients to be discussed in each meeting and requests for additional members to attend can be made.

An allocated chairperson should be assigned to each meeting and their role agreed by the team. This should include processes to facilitate multidisciplinary involvement with allocated time for collaborative input from nurses and allied professionals. Psychosocial considerations and patient preferences should be considered at each meeting.

Every meeting should have physicians, nurses and researchers in attendance. If cases are considered by the Chair as not requiring input from additional allied professionals then written correspondence prior to the meeting can raise their optional attendance. This needs to be formally documented and agreed by the staff choosing not to attend.

A national framework for heart failure MDT meetings should be established to reduce variation and support a structured, efficient and measurable process. The development of the framework should include key stakeholders including health professionals, patients and their family members. Discussion of the role and involvement of patients and their relatives/carers needs to be agreed.

7.5.2 Communicating information about treatments

The SDM model is described in health policy as an approach to be used when deciding on preference-sensitive treatments. Yet for some patients there may only be one treatment option that is indicated. The key concept of SDM is the sharing of information between patients and professionals. It is this process that needs to be integrated in to communication with patients, so professionals can better understand the complex nature of how patients make decisions.

Health professionals' perceptions of patient information needs, preferences for involvement and information sourcing behaviour have shown to be inaccurate. To increase understanding of individual patient needs the sharing of information should be encouraged in all discussions about treatment. Patients may want professionals to lead decision-making and make recommendations based on what they feel is best. But for treatment plans to have patient support and be followed, professionals also need to hear from the patient. Focus needs to be on the assessment of patient understanding, knowledge needs and information sourcing behaviour.

Patients and family members want more information about the cause of their heart failure, the risks of treatments, the impact on recovery, symptom burden and the side-effects of medications. Patients look to physicians and nurses for this information. Professionals should be open to discuss patients' health-information sourcing behaviour (and that of their relatives) to better assess their information needs. Professionals should consider the role of family members in heart failure management. Professionals can then sign-post patients and their relatives to validated sources tailored to their individual preferences.

Finding the balance between patients perceived information need (assessed by professionals) and their information preferences (whether they want information or not) requires a flexible and fine-tuned approach. To address patient behaviours of comparing treatments to their friends, family and information online, patients need a better understanding of why treatments are recommended. Professionals must normalise internet use and accept it as part of patients' decision-making process. This may help patients to feel comfortable and confident to share the information they have sourced. Only then will professionals be able to assess its accuracy, explain its relevance and provide advice on future use of the internet.

Professionals should promote openness about use of the internet when discussing treatments with patients. This is important to encourage patients and family members to discuss their health-seeking internet use and explain the relevance of the information. Written information leaflets are a key source of validated information available to professionals. These should be offered to patients following discussion of their information preferences and needs.

Documentation of discussion of treatments and the views/preferences of patients and their relatives should be recorded in the patient medical notes. This will help to support continuity of care by having readily available access to treatment communication by different professionals interacting with the patient.

7.6 Recommendations for future research

The focus of current research is on interventions aimed at delivering SDM and changes to the practice of the clinic consultation. This is not surprising with current health policy driving the integration of patient-focused models of care and the financial implications facing services. The findings of this thesis demonstrate that interactions in the clinic consultation are not a true reflection of the wider contextual influences on patients' decisions and behaviour. Before working to establish the best approach to adopting SDM, researchers should address the question, is the SDM framework advocated in health policy fit for purpose? Knowing what patients want and why, is the first step to delivering a service that reflects the needs of patients. The key barriers and facilitators identified in this thesis require further in-depth exploration in a larger representative sample of patients.

Patients and professionals have different understandings of what patient involvement in decision-making means. This is not helped by multiple terminologies that are used in the literature, patient 'participation, engagement, involvement.' These make comparisons of interventions and measures of effect difficult. To assist the process of a shared decision-making approach and the quality of future research, a standardised definition needs to be sought. One that both patients and professionals agree on and understand. Use of consensus techniques with a mixed cohort group may help to determine agreement on a definition.

Age, gender, education background and symptom severity were all found to influence patients' approach to decision-making and their information preferences. The sample populations in this thesis were predominantly White British. Further research is required to assess the influence of ethnicity, culture and religion on patient preferences and approach to decision-making.

The degree of influence of patient demographics and disease characteristics requires further investigation. Similarly, the influence of the patient-professional relationship on patient interactions with professionals and their adherence to treatment plans requires further exploration. Future research needs to explore these variables in greater depth in a larger heart failure population.

Research is needed in to how professionals can provide information to patients in a way that they understand and value. Whether this be in written form, use of visual aids or interactive approaches via the internet and use of technology. Further examination of patients and their relatives use of the internet is required so professionals can better understand patient behaviour. Further research in to information leaflets and their effects on patient knowledge and understanding of their heart failure and health behaviour is needed to properly assess their value.

Exploration of how services can better meet the needs of patients to support their decision-making pathway are required. Assessment of the value of a 'one stop shop' clinic in a larger representative study sample and use of skype consultations as an adjunct to in-person consultations, may help to identify the best use of resources. The literature reports that patient and carer involvement in MDT meetings can lead to positive outcomes: collaborative team work, reduced decisional conflict and increased rates of patient and clinician satisfaction. However, the evidence-base predominantly arises from cancer care models based on observational studies and lacks large-scale RCTs determining the effects on clinical outcomes. To date no research has been conducted investigating the effects of patient involvement in heart failure MDT meetings. Further research is needed to investigate the involvement of patients in the MDT meetings and evaluate effect on patient satisfaction, decision implementation, adherence to treatment and clinical outcomes.

7.7 Conclusion to chapter

The findings of this thesis illustrate the multifactorial process of how patients make decisions about their treatments and heart failure management. These findings have identified key factors shown to influence patients' approach to decision-making and their preferences for involvement and additional information. However, the individual effect of these contextual factors on patient disease beliefs and behaviours requires further exploration. Clinical practice must reflect the patient perspective and future research should be informed by stakeholder consensus on the priorities to improve how treatment decisions are made.

CHAPTER 8: CONCLUSION

Today a shared approach to decision-making (SDM) is advocated in national and international health policy. This patient-focussed model of care is driven by demands for greater involvement of patients in decisions about their care. The concept of SDM was introduced over a decade ago, but since then it has been slow to integrate in to routine clinical practice. In the UK, SDM is on the national policy agenda with the NHS Constitution emphasising patients' rights to be involved in decisions. Today financial implications face health services who fail to demonstrate its adoption. The evidence-base for a SDM approach is mixed. It is confounded by multiple outcome measures, definitions and underpowered studies. There is limited research demonstrating positive clinical outcomes and cost-effectiveness. Consequently, little clinical guidance exists to support professionals on how to adopt a SDM approach in practice.

In recent years, the treatment and management of patients with heart failure has taken on a more personalised approach. Advances in biomedical science and genetics has led to treatments focussed on smaller and more defined patient populations. New treatments and advanced management strategies means that patients are living longer, often with multiple comorbidities and increased frailty. This makes treatment decision-making more complex and challenging for professionals. Knowing the treatment that might have the best therapeutic effect, does not necessarily mean it is the right treatment for that patient. To date no other research has explored the preferences of heart failure patients for involvement in decision-making. No research has explored the contextual influences on these patients' decision-making process.

The findings of this thesis demonstrate extensive variability in the views, preferences and approaches to decision-making of patients, their family members and health professionals in heart failure management. This limited concordance has highlighted assumptions and misconceptions which are a key barrier to a SDM approach. Many patients are developing their disease beliefs and views towards treatments based on inaccurate information. This is strongly influencing their decisions about treatments and their subsequent health behaviours.

The processes involved in how patients make decisions is not known or misunderstood by health professionals. Professionals need to do more than simply provide written information leaflets and signpost patients to validated websites. The approach to communication about treatments needs critical evaluation. Factors shown to influence patient decisions needs to be considered individually for each patient. Professionals need to adapt their approach to treatment discussions and address patients (and their relatives) information needs and health information sourcing behaviour. The internet is an important source of information for many patients and openness about online information needs to be encouraged. Information sourced online and use of the internet should be discussed with every patient.

For patients to be fully involved in decision-making, health professionals and organisations need to integrate the patient voice in to the clinical decision-making pathway. MDT meetings provide an established framework to do this yet further research is needed to determine the best way to do this in heart failure.

This thesis highlights major barriers to the adoption of SDM in heart failure management. Current healthcare ideology about decision-making and organisational culture means that services are not equipped to implement SDM. The priority of policymakers, professionals and researchers needs to change. Focus needs to be redirected back to the patient and value given to the importance of human behaviour and behavioural change. What is missing, is the patient voice.

CHAPTER 9: NEXT STEPS

Policymakers and researchers are focused on driving the integration of SDM in to practice. The findings of this thesis challenge this focus. The priority needs to be redirected back to what patients want and need. Patients and health professionals have mixed views towards a SDM approach and different perceptions of what it means to be involved in decision-making. An agreed understanding of patient involvement is needed so patients can see the value in sharing their views and goals.

A collaborative approach using research methodologies that facilitate open discussion and the sharing of views may help to establish an agreed definition. Knowing what patients want from professionals will help them to better understand and tailor their communication and services to patient needs. A Delphi approach was useful in this study in terms of bringing together a mixed cohort of stakeholders. In–person discussion using focus group methods or consensus techniques such as the Nominal Group Technique, may facilitate collaborative problem-solving and the identification of research priorities. Encouraging buy-in from clinicians and nurse specialists is important and therefore, involving professionals in the setting of research agendas may help to gain further support.

Review of current practice is necessary to identify unmet patient need. The ‘one stop shop’ clinic has amassed support from health professionals across the Country, but only some patients found this service useful. Limited evidence exists evaluating the benefits and cost impact of these services. Further research evaluating the effects on patient satisfaction and decision implementation should be conducted. These data can be used to inform changes to service delivery and streamline the patient pathway.

There is considerable variation in the preferences of patients for health information provision. Professionals may consider themselves to be meeting the information needs of patients, but it is clear there is still much to do. Written information leaflets may be useful to some patients but for many, they have limited value. For professionals to tailor communication about treatments to individual patients there needs to be access to more resources. The internet has shown to be an important source of health information used by many patients and their families. A focus in research on developing new internet-enabled technologies and online sources of validated information would better equip professionals to tailor their communication. For new information sources to be meaningful and useful, researchers, health professionals, technology experts and patients need to be involved in their study design and development.

A SDM approach that can be effectively integrated in to heart failure management will not be envisioned overnight. Professionals, researchers and patients need time to better understand the process, to determine the best ways to share information and break down the ideologies in current healthcare.

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Appendix 1: Abstract Poster Presentations and Awards

Poster presentations:

1. SP Welch, AR Lyon, JP Riley (2017) Ask Dr Google: how heart failure patients source health information. Poster Presentation at the National Heart & Lung Institute Post Graduate Research Day, Imperial College London, 2017.

2. SP Welch, AR Lyon, JP Riley (2016) Supporting patients decision-making: Putting patients in the driving seat. Accepted Abstract submission to HFA Congress, May 2016, Florence.

3. SP Welch, AR Lyon, JP Riley (2016) Do patients value personalised medicine. Accepted Abstract submission to EuroHeartCare, April 2016, Athens.

4. SP Welch, AR Lyon, JP Riley (2016) Treatment decision-making in heart failure management. Accepted abstract. North West London Annual Research Symposium for Health Professionals

5. SP Welch, AR Lyon, JP Riley (2016) Treatment decision-making in heart failure management: a personalised approach. AHP, HCS and Nurses Poster Day. Royal Brompton & Harefield NHS Foundation Trust.

Awards:

- First prize for best talk by a student in the clinical category for the presentation, ‘Ask Dr Google: How heart failure patients source health information.’ Poster Presentation at the National Heart & Lung Institute Post Graduate Research Day, Imperial College London, 2017

- The Council for Cardiovascular Nursing and Allied Professionals (CCNAP) travel grant to attend EuroHeartCare Congress, Athens 2016

- The Heart Failure Association (HFA) Nurse Training Fellowship, awarded 24,000 Euros 12/2013

National Heart & Lung Institute Post Graduate Research Day, Imperial College London 2017

Ask Dr Google: how heart failure patients source health information

Welch SP, Lyon AR, Riley, JP

Background:

Traditionally professionals have been the main providers of health information to patients. With increased access to information online, more patients are turning to the internet. Many patients want to be fully informed and more involved in health decisions. To support a shared approach to decision-making (SDM) professionals need increased understanding of how patients source health information. Knowing what sources patients value is important so professionals can tailor information provision to individual patient's disease need and personal preference. By adopting a more personalised approach patients may be better supported to self-care.

Purpose

To explore how patients make decisions about their heart failure (HF) management.

Method:

Phase I of a mixed methods study. Qualitative semi-structured interviews of patients, family members and health professionals from 2 UK specialist hospitals. Data analysed by thematic analysis.

Results:

Forty-one participants were interviewed. 22 patients with a mean age of 62 years (34 to 91), 79% male (n=19), 16% lived alone (n=4) and 50% experiencing symptoms on mild exertion (n=12). 6 family members, 66% female (n=4) all spouses. 13 health professionals: 4 Cardiologists, 4 Cardiology Registrars, 5 HF nurses. Here we report on the emerging theme, 'Information provision versus information preference.' Patients and relatives valued the internet as a primary source of health information. 50% of patients described information sourced from the internet (n=12). Only 16% (n=2) used validated websites (CMA, BHF). We found no influence of age, gender, education level or disease severity on access to online health information. Alternatively, professionals highly valued information leaflets. No relative described reading a leaflet and patients valued information from family and friends more than professionals. We found no influence of age, gender or disease severity.

Next steps:

These data highlight a disconnect between current practice of information provision in HF management and patient preference. Further analysis of the emerging themes is required and the identification of different patient typologies. Interview data will be used to generate hypotheses that will be tested by a Delphi consensus survey to identify the barriers and facilitators to a SDM approach in HF management.

Heart Failure (2016). 3RD World Congress on Acute heart failure. Florence, Italy.

Supporting patient's decision making: putting patients in the driving seat

SP Welch, AR Lyon, JP Riley

Background:

Developments in biomedical science and advanced heart failure treatments have resulted in patients facing complex healthcare decisions at different stages in the disease trajectory. Shared decision-making, with its emphasis on patient-centred care, has emerged as a major driver in healthcare policy. Its aim is to empower patients to enable them to be involved in decision-making. This approach requires a partnership between patients and professionals, and the sharing of information. To provide effective support, professionals need an increased understanding of the influences on how patients' make healthcare decisions.

Purpose:

To explore patients' decision-making in their HF management.

Method:

A qualitative study using semi-structured interviews with patients recruited from a specialist hospital in the UK who were taking part in a study of gene therapy in advanced HF. These data were analysed using thematic analysis.

Results:

Nine patients with a mean age of 57 years (34 to 74 years), 7 (78%) male, 3 (33%) lived alone, and 5 (55%) symptomatic on mild exertion (NYHA III). Here we report on 3 major themes: symptom relief, "burden" of treatment and information sourcing. Patients' experience of symptom relief influenced their beliefs about their HF management. Patients (5 (55%)) who experienced immediate symptom relief from a 'one off' invasive intervention (such as PCI) described a value to these treatments. However, they did not describe the same value to 'ongoing' treatments (such as medication) and where they did not experience an immediate improvement in their functional ability. Patients' decisions were influenced by information from friends, more than professionals and by information that validated their own views. No patient demonstrated understanding of treatment based on heart failure aetiology or LVEF. We noted no difference with age, gender and disease trajectory, but the major limitation was small numbers.

Conclusion:

Factors that influence patients' health decisions differ according to the impact of the treatment and its ongoing monitoring on their daily life. Patients' decision-making was influenced by friends, symptom relief and treatment burden. These findings have important implications for the way in which professionals provide information about different treatment options and work with patients to support their decision-making. Further exploration in a larger sample and at different stages in the disease progression are required to confirm these provisional findings.

EuroHeartCare Congress, April 2016, Athens.

Do patients value personalised medicine: results of a pilot study

SP Welch, AR Lyon, JP Riley

Background:

Recent developments in healthcare biogenetics are changing the way professionals make decisions about the best treatment for each patient. Advances in pharmacogenetics and the discovery of target biomarkers in myocardial dysfunction have strengthened this potential for a more personalised approach to heart failure management. Heart failure patients present with similar clinical signs and symptoms, yet treatment now depends on the underlying cause. Patient involvement in this decision-making process is the cornerstone of health policy. Novel therapies may offer benefit for different heart failure aetiologies. However, supporting informed patients to make treatment decisions based on therapeutic response is clinically challenging. There is limited knowledge about how patients view personalised medicine and shared decision-making and the extent to which it may influence their treatment decisions.

Purpose:

This study explores patients' decision-making processes in their heart failure management.

Method:

A qualitative study using semi-structured interviews. These data were analysed using thematic analysis.

Results:

6 patients with a mean age of 73 years, 2 (33%) male and 5 (83%) symptomatic on mild exertion (NYHA III). Three key themes were identified: Information sourcing; patient demographics; understanding of treatment. Patients' treatment decisions were not influenced by the advice of professionals. Decisions about their heart failure management were influenced by the effect of treatment on the quality of life of their friends. 67% (n=4) perceived older age to be a discriminate factor in the treatments offered by professionals. We report no influence of gender. 67% (n=4) described the cause of their heart failure yet no patient described how their heart failure management was influenced by its aetiology.

Conclusion:

This small pilot study shows that patients have limited understanding of personalised medicine. Their expectations of specific heart failure treatments are influenced by the knowledge and understanding they gain from friends. To improve patient outcomes professionals should tailor patient education to their individual disease and treatment needs. More time is needed for professionals to develop their knowledge and understanding of the patient. In today's health service government targets, financial restrictions and staff shortages already overburden professionals. Clinical pathways should be adapted to provide decision-support. A larger cohort is required to confirm these provisional findings.

APPENDIX 3.1 MDT meeting proforma V1: Pilot data

Pilot proforma Trust MDT meeting data:

Title of meeting			
Chairperson	Yes/No/other	Discipline:	Formal training: yes/no
Meeting terms of reference	Yes/No/other	Who agrees/reviews terms of reference	Frequency of review:
Allocated MDT coordinator	Yes/no/other		
Frequency of meeting	weekly	monthly	other
Length of meeting			
Number of patients discussed per meeting	Number:	All new patients discussed: yes/no	other
Registry of staff attendance	Yes/no/other	Includes discipline: yes/no/other	Available for review
Number of professionals that attend	Approximate total	Per discipline: Consultants (speciality) SpRs SHOs Clinical Nurse Specialists Palliative care professional Allied health professionals: OTs Physios pharmacist Research fellows Research nurses Other	
Minutes taken: Reviewed by: Circulated:	Yes/no/other		
Where are meeting outcomes documented?	Electronic/patient medical notes/other Feedback to patients: When/where/by who		
Meeting environment- Formal/informal Lecture format/Table discussion Power point/other			
Who presents patients: Summary of issues discussed ie clinical presentation, PMH, diagnostic procedures, comorbidities, psycho-social needs, other			
Are patients informed prior to MDT discussion	If no, reasons why:		
Patient preferences discussed: By whom (discipline)		Staff member/discipline:	

APPENDIX 3.2 MDT meeting profoma V2

Survey of Cardiology and Cardiothoracic MDT Meetings

Instructions:

- Please provide details of one MDT meeting per survey.
- Please circle or highlight the answer/s that best describe the MDT meeting
- If you select 'Other' please specify in the comments section.
- To add additional information please use the section provided.

Name: **Job title:** **Email:**	**Department:** **Trust:**
Title of MDT meeting:	
Patient population:	

Q.	**Structure of MDT meeting**	**Please indicate the answer/s that best describe the MDT meeting**				
1	Which patients are discussed in the meeting?	Inpatients	Outpatients	New referrals		
2	How frequent is the meeting?	Weekly	Fortnightly	Monthly	Quarterly	Other
3	What is the average duration of the meeting?	<1 hour	1 hour	2 hours	>2 hours	
4	Approximately how many patients are discussed per meeting?	1	2-5	6-9	>10	
5	Does the meeting have a 'Terms of Reference? *A document that details the purpose and scope of the meeting	Yes Formally documented	Yes Not formally documented	No	Don't know	
6	Does the meeting have a chairperson?	Yes	No	Don't know		
7	Is the meeting also used for teaching purposes?	Yes	No	Don't know		
	Additional comments					
	Attendance					
8	Is there a register of attendance?	Yes	No	Don't know		
9	On average, how many people attend the meeting?	<5	6-10	11-15	16-20	
10	Are patients invited to attend?	Yes	No			
11	Are family members and/or carers invited to attend?	Yes	No			

12	On average how many Consultants attend?	1-3	4-6	>7		
13	On average how many specialist registrars attend?	1-3	4-6	>7		
14	On average how many junior doctors attend? Eg. House Officers and Senior House Officers	1-3	4-6	>7		
15	On average how many nurse specialists attend?	1-3	4-6	>7		
16	Do other allied health professionals attend? Eg. Pharmacists, Physios, occupational therapists	Always	Sometimes	Rarely	Never	Don't know
17	Do researchers attend? Eg. Research nurses, fellows	Always	Sometimes	Rarely	Never	Don't know
	Additional comments:					
	Processes of MDT meeting					
18	Are formal minutes taken of the meeting?	Yes	No	Don't know		
19	Are the meeting outcomes documented?	Yes	No	Don't know		
20	Where are the outcomes documented?	Patient medical notes	Electronic patient records	MDT meeting file	Other	
21	Are patients informed prior to MDT discussion?	Always	Sometimes	Rarely	Never	Don't know
22	How do treatment recommendations get fed back to patients?	In-person	By telephone	By post	Other	
23	Who feeds back this information?	Doctor	Nurse	Other		
24	What sources of additional information are provided to patients at the time of feedback?	Information leaflets	Internet website	Other	None	
	Additional comments:					

Thank you for your time and support in completing this survey.

APPENDIX 3.3 MDT meeting profoma V3

Survey of Cardiology and Cardiothoracic MDT Meetings

Aim:
To increase our understanding of treatment decision-making in current practice by collecting data on the structure and processes of cardiology and cardiothoracic MDT meetings.

Instructions:

- You may complete this survey electronically or print a paper copy
- Please provide details of **one** MDT meeting per survey.
- Please circle or highlight the answer/s that best describe the MDT meeting
- If you select 'Other' please specify in the comments section.
- To add additional information please use the section provided.

Name: **Job title:** **Email:**	**Department:** **Trust:**
Title of MDT meeting:	
Patient population:	

Q.	**Structure of MDT meeting**	**Please indicate the answer or answers that best describe the MDT meeting**				
1	Which patients are discussed in the meeting?	Inpatients	Outpatients	Community	New referrals	
2	How frequent is the meeting?	Weekly	Fortnightly	Monthly	Quarterly	Other
3	What is the average duration of the meeting?	<1 hour	1 hour	2 hours	>2 hours	
4	Approximately how many patients are discussed per meeting?	1	2-5	6-9	≥10	
5	Does the meeting have a 'Terms of Reference? *A document that details the purpose and scope of the meeting	Yes Formally documented	Yes Not formally documented	No		
6	Does the meeting have a chairperson?	Yes	No			
7	Is the meeting also used for teaching purposes?	Yes	No			
	Attendance					
8	Is there a register of attendance?	Yes	No			
9	On average how many people attend the meeting?	<5	6-10	11-15	16-20	
10	Are patients invited to attend?	Yes	No			
11	Are family members and/or carers invited to attend?	Yes	No			
12	On average how many Consultants attend?	0	1-3	4-6	≥7	

13	On average how many specialist registrars attend?	0	1-3	4-6	≥7
14	On average how many junior doctors attend? Eg. House Officers, Senior House Officers. Medical students	0	1-3	4-6	≥7
15	On average how many nurse specialists attend?	0	1-3	4-6	≥7
16	Do other allied health professionals attend? Eg. Pharmacists, Physios, occupational therapists	Always	Sometimes	Rarely	Never
17	Do researchers attend? Eg. Research nurses, research fellows	Always	Sometimes	Rarely	Never
	Processes of MDT meeting				
18	Are formal minutes taken of the meeting?	Yes		No	
19	Are the meeting outcomes documented?	Yes		No	
20	Where are the outcomes documented?	Patient medical notes	Electronic patient records	MDT meeting file	Other
21	Are patients informed of the purpose of the MDT discussion prior to the meeting?	Always	Sometimes	Rarely	Never
22	How do treatment recommendations get fed back to patients?	In-person	By telephone	By post	Other
23	Who discusses the treatment recommendations with the patient?	Doctor	Nurse	Other	
24	Are additional sources of information provided to patients at the time of treatment discussions?	Yes		No	
25	What sources of additional information are provided to patients?	Information leaflets	Internet websites	Other	None
	Additional comments:				

Thank you for completing this survey.

APPENDIX 6.1 Delphi consensus survey: Round 1 questionnaire

Delphi Consensus Survey: Round 1

Aims of the survey:

1. To explore the views of patients, family members and health professionals towards the provision of health information in heart failure management.
2. To identify the barriers and facilitators to health information provision in heart failure management
3. To gain group consensus on practice recommendations to improve the provision of health information in heart failure management.

For the purpose of this survey we have defined 'health information' as:

All information related to heart failure and its management in verbal, paper or electronic form. This includes for example, information about heart failure diagnosis; prognosis; treatments; investigations; lifestyle advice; monitoring; identification of symptoms; self-management techniques.

Instructions:

Please rate your level of agreement for each statement by putting an X in the box

We use a 5-point Likert scale for rating the statements from 'strongly agree' through to 'strongly disagree'

Please choose only one score on the scale for each statement

There are no right or wrong answers

Domain 1: Sources of health information		**Strongly agree**	**Agree**	**Neutral**	**Disagree**	**Strongly disagree**
Please rate your level of agreement for the following statements:		**1**	**2**	**3**	**4**	**5**
1	I am satisfied with the amount of information health professionals provide to patients about treatments					
2	Health professionals regularly discuss with patients where to find additional health information if needed					
3	Patients prefer to ask for additional health information from nurses rather than doctors					
4	I am satisfied with the content of written health information provided by health professionals to patients					
5	Leaflets provided by health professionals to patients are the most valuable source of health information					
6	Leaflets help patients/relatives increase their knowledge and understanding of heart failure					
7	Health professionals themselves are the most valuable source of health information to patients/relatives					
8	The internet is the most valuable source of health information for patients and relatives					
9	Patients use information from the internet to help them make decisions about treatments					
10	The views and experiences of family are very important to patients when deciding on what treatment to have					
11	The views and experiences of friends are very important to patients when deciding on what treatments to have					
12	Patients/relatives will visit a website if it is recommended by health professionals					

		Strongly agree	Agree	Neutral	Disagree	Strongly disagree
Patients and relatives use the internet to search for health information because:		1	2	3	4	5
13	They want to know more about the disease and its cause					
14	They have not received enough support or information from health professionals					
15	To clarify information provided by health professionals					
16	They prefer to use the internet rather than ask health professionals for more information or further explanation					
17	They feel depressed, anxious or concerned					

Domain 2: Health information need		Strongly agree	Agree	Neutral	Disagree	Strongly disagree
I am satisfied with the level of health information provided by health professionals to patients about:		1	2	3	4	5
18	The cause of the patient's heart failure					
29	The natural course of the disease					
20	Investigations and test results eg echocardiogram, blood tests					
21	Risks and benefits of treatments					
22	Side-effects of medications					
23	Lifestyle advice eg exercise, diet, quitting smoking					
24	Ways to manage their condition at home eg daily weight, signs of deterioration					
25	Whether their disease could be genetically inherited					

Please rate your level of agreement for the following statements:		1	2	3	4	5
26	Written information available is all at one level and not appropriate for every patient					
27	Health professionals provide information about heart failure and its treatments in language that is difficult for patients to understand					
28	Patients believe that health professionals do not have the time to adequately address their health information needs					
29	Longer clinic appointments are needed for patients to build partnerships and trust with health professionals					
30	Most patients and family members do not ask for additional information from health professionals					
31	Health professionals' attitudes towards involving patients in treatment decisions influences how much information they provide to patients					

Domain 3: Patient involvement		Strongly agree	Agree	Neutral	Disagree	Strongly disagree
Please rate your level of agreement for the following statements:		1	2	3	4	5
32	Health professionals do not ask if patients want to be involved in their treatment decisions					
33	Health professionals always take in to account the patient's views towards treatment					
34	Patients are more likely to agree to treatments when their opinion is taken into consideration when choosing a treatment					
35	Most relatives' opinions are not considered when choosing treatments					

36	All patients should be given the opportunity to be involved in treatment decisions					
37	The involvement of family members and/or carers is important when making treatment decisions					
38	Health professionals often lack communication skills necessary to involve patients in treatment discussions					
39	Training is needed for health professionals on how to involve patients in treatment discussions					

APPENDIX 6.2 Standardised feedback of Round 1 results

Delphi survey Round 1: Results feedback

Participant ID:

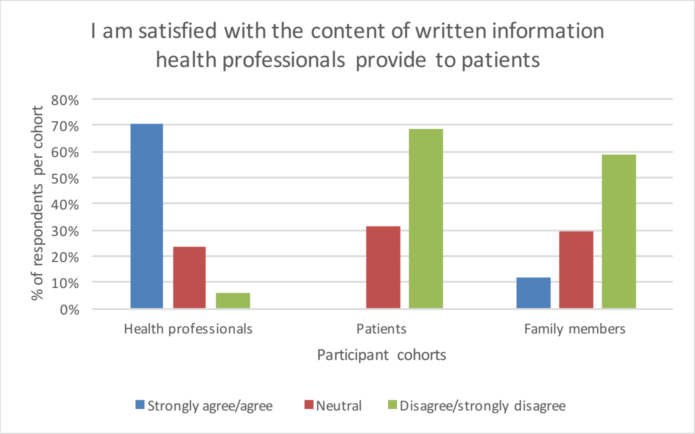
Patients, family members and health professionals agreed on 14 of the 40 statements in the first questionnaire (Round 1). Of the remaining 26 statements, 12 showed marked variation in responses between the groups (more than 20% difference in agreement/disagreement). Your responses and those of the group to the remaining 26 statements were used to develop a second questionnaire (Round 2).

Purpose:
The second questionnaire aims to identify key components to be included in health professional's approach to information provision in heart failure.

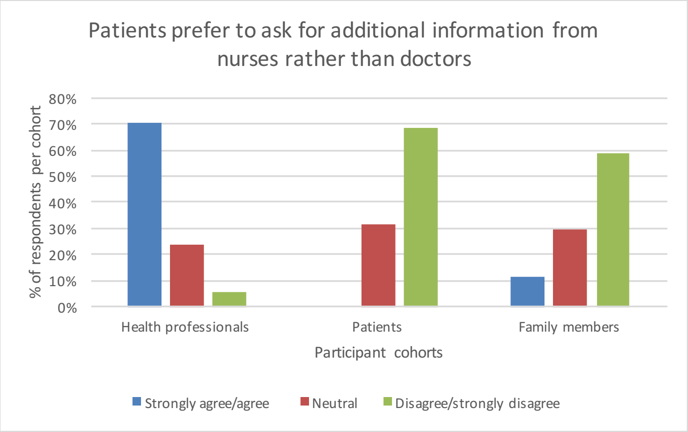
To help you decide on your ratings we have displayed the results of 12 statements below which showed the greatest variation in responses between groups. We have marked your previous response to each statement as a black dot on each bar chart. This is so you can see where your answer sits within the group. Each participant has received an individualised feedback form and only you can see your answers.

Domain 1a: Sources of health information

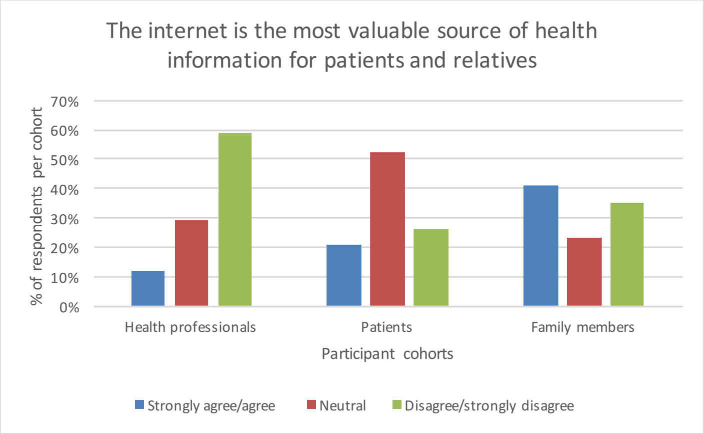
Please rate your level of agreement for the following statements:


I am satisfied with the content of written information health professionals provide to patients

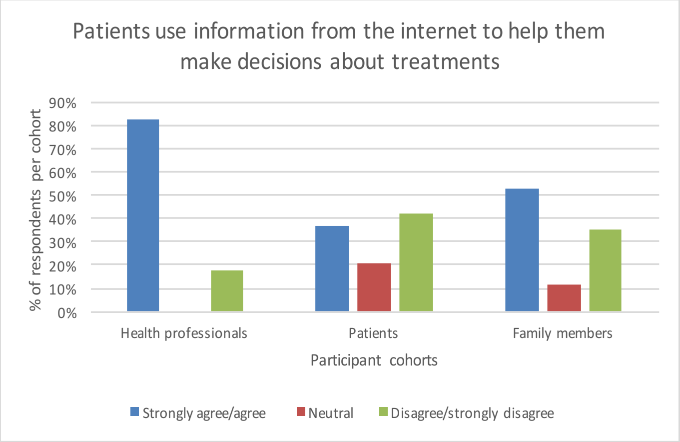
Q6. You answered:


Patients prefer to ask for additional information from nurses rather than doctors

Q4. You answered:


The internet is the most valuable source of health information for patients and relatives

Q14. You answered:


Patients use information from the internet to help them make decisions about treatments

Q15. You answered: