

**The self management of heart failure:  
a place in practice?**

***Jonathan Silcock***

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***School of Healthcare***

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The candidate confirms that the work submitted is his own and that appropriate credit has been given where reference has been made to the work of others.

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## **Abstract**

### ***Background***

Self management of heart failure has been suggested as a way to prevent hospital admissions. Understanding influences on self management could help to achieve targets for clinical outcomes and patient engagement. The implementation of self management in heart failure appears to be limited compared with other long term conditions. We know little about why this is the case.

### ***Aim***

To identify patients' and healthcare professionals' knowledge of and attitudes towards self management of chronic heart failure.

### ***Setting and Participants***

Twenty-one patients (14 women and 7 men with a mean age of 74) recruited from a general medical practice in an urban area of Leeds, West Yorkshire. Professionals (six doctors, five nurses, five pharmacists and three others) recruited from the local health economy.

### ***Methods***

Semi-structured interviews were recorded with patients meeting defined inclusion criteria and professionals who cared for them or developed local services. Tapes were transcribed verbatim and thematically coded. Relationships between themes were explored qualitatively using 'Framework' analysis as a guide.

### ***Results***

Patients' activities were restricted in similar ways by symptoms, but only nine had good understanding of their diagnosis. Patients trusted their doctors, but were given few opportunities to learn about their condition and engage with its management. Patients' need for explanations, capacity to understand and potential for clinical improvement were probably underestimated. If it was proposed, all patients would monitor and record signs or symptoms to guide variable diuretic dosing. Few patients wished to self adjust doses by protocol, preferring instead to follow direct professional instructions. Few patients felt they could learn from group work with peers: a regular part of self management training. Patients' attitudes towards disease management were informed by their interpretation of symptoms, care and daily living. Their greatest priority was continuity of care not having more choice or responsibility. Professionals' conceptions of patient self management varied considerably. Specialists tended to support full disclosure and possible self management for a wide variety of patients; whereas generalists were more cautious.

### ***Conclusions***

Patients who could potentially benefit from self management were not aware of it or given enough opportunities to participate. Patients and professionals should work towards more open discussions about diagnosis, expectations and care.

## Dissemination

Aspects of this research have been presented at these conferences and meetings:

- Silcock J. Do providers have the attitudes, knowledge and resources to support self-management? ERSC Seminar Series on Self Management, University of Salford, March 2007.
- Silcock J, Raynor DK, Atkin K. Patients' views about self-management of heart failure, ERSC Seminar Series on Self Management, University of Salford, January 2007.
- Silcock J, Raynor DK, Atkin K. Self-management of heart failure: a place in practice? *International Journal of Pharmacy Practice* 2005, 13, R12. (Pharmacy Practice Research Supplement, BPC Abstracts)
- Silcock J. Do patients with heart failure want to self-manage? *Medicine taking: learning from patient perspectives*, Royal Society of Medicine, London, September 2005.
- Silcock J. Heart failure: patients' experience of treatment and attitudes towards self-management. Pharmacy Practice Research Trust Awards Seminar, Royal Pharmaceutical Society of Great Britain, London, April 2004.
- Silcock J, Raynor DK, Atkin K. Self-management, well-being and learning. Health Service Research and Pharmacy Practice Conference, King's College London, March 2004. Volume of Abstracts: ISBN 0 9544961 3 2.
- Silcock J, Raynor DK, Atkin K. Heart failure: patients' experience of treatment and attitudes towards self-management. Second International Shared Decision Making Conference, University of Wales, Swansea, September 2003.

This research has informed the writing of the following professional publications:

- Silcock J, Standage C. Exploring adherence to cardiovascular medicines. *British Journal of Cardiac Nursing* 2007, 2, 223-228.
- Silcock J, Standage C. Getting patients into medicines. *Chemist and Druggist*, 6 May 2006, 21-24. (Pharmacy Update: C+D Clinical CPD Article)
- Silcock J. Developing partnerships in medicines taking (Chapter 7) in *Getting the Best Out of Medicines*, DK Raynor et al (writers). NHS Education for Scotland (Pharmacy), Glasgow, 2005.
- Silcock J. Ask me! I'm a pharmacist. *Pharmaceutical Journal* 2003, 271, 515. (Article in special issue on concordance)

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## Abbreviations

AHCPR	Agency for Health Care Policy and Research, an American government agency now called the Agency for Healthcare Research and Quality.
ACEI	Angiotensin converting enzyme inhibitor, a class of drugs shown to reduce mortality in LVSD.
ARB	Angiotensin receptor blocker, a newer class of drugs related to ACEIs and also shown to reduce mortality in LVSD.
A&E	Accident and emergency, non-elective admissions area for a hospital. Emergency Room (ER) in American usage.
AF	Atrial fibrillation, common disorder of heart beat.
BDCS	Beliefs about Dietary Compliance Scale (Bennett et al., 2001).
BMCS	Beliefs about Medication Compliance Scale (Bennett et al., 2001).
BMI	Body mass index, standardised measure of obesity, weight in kilograms divided by square of height in metres.
CABG	Coronary artery bypass graft, surgical treatment for CHD, also known as 'bypass'. Pronounced 'cabbage'.
CCF	Congestive cardiac failure, term used for heart failure causing congestive symptoms (shortness of breath, oedema).
CDSMP	Chronic Disease Self-management Programme, generic self management training developed in US and on which UK EPP is based.
CHD	Coronary heart disease, group of conditions caused by dysfunction of blood supply to the cardiac muscle.
CKD	Chronic kidney disease, group of conditions causing long term decline in kidney function.
COPD	Chronic obstructive pulmonary disease, also known as COAD.
CPAP	Continuous positive airways pressure, a form of mechanical respiratory support.
DH	Department of Health, UK Central Government department with responsibility for health policy in England.
DGH	District general hospital, provider of secondary care for patients with general medical or surgical conditions.
EBM	Evidence based medicine, method and philosophy of medical practice based on proven interventions.
ECG	Electrocardiograph, electrical monitoring of the heart.
Echo	Echocardiograph, ultrasonic visualisation of heart function.
EHFScBS	European Heart Failure Self Care Behaviour Scale (Jaarsma, Strömberg, Mirtensson, & Dracup, 2003).
EPP	Expert Patient Programme, the UK's main generic self management training programme. Sponsored by the Department of Health.

ESC	European Society for Cardiology, a European professional association.
GP	Medical general practitioner, a family doctor.
GPP	Good practice point, term used in guidelines for care believed to be good practice but not supported by strong objective evidence.
GRIP	Getting research into practice, methods used to encourage the take up of proven healthcare interventions.
GTN	Glyceryl trinitrate, emergency treatment for angina, usually self administered as sub-lingual spray (and formally as a tablet).
HFKT	Heart Failure Knowledge Test (Artinian et al., 2002).
IPA	Interpretive phenomenological analysis, a method of qualitative data analysis used mainly in the psychology research community.
KP	Kaiser Permanente, large US healthcare system.
NHS	National Health Service, the UK's publicly funded healthcare system, in which most care is provided free at the point of need.
NICE	National Institute for Health and Clinical Excellence, independent body that advises the NHS in England on standards of care.
NSF	National Service Framework, a series of guides outlining expected care standards for various patient groups and clinical conditions.
NYHA	New York Heart Association, an American professional body that now forms part of the American Heart Association's Founders Affiliate.
LTHT	Leeds Teaching Hospitals NHS Trust, a local provider of general and specialist secondary medical and surgical care (an 'Acute Trust').
LSOA	Lower layer super output area, smallest area for which aggregate National Statistics are made widely available (minimum population 1000).
LVSD	Left ventricular systolic dysfunction, a common type of chronic heart failure.
LVF	Left ventricular failure, usually used as less specific synonym for LVSD.
MCA	Multi-compartment compliance aid, a device (segmented box marked with days and times) to support medicines adherence.
MDC	Metropolitan district council, unitary local authority providing public services (including personal social care) in urban areas of England.
MDT	Multi-disciplinary team, team of professionals focused on the provision of care for a group of patients with a similar profile or clinical condition.
MI	Myocardial infarction, a 'heart attack'
LREC	Local research ethics committee, now known simply as REC.
PCT	Primary Care Trust, local NHS organisation that holds contracts for primary care professionals and commissions secondary care services.
PDG	Patient group direction, prescribing guideline for patients in a similar clinical situation used by (non-medical) supplementary prescribers.
PIL	Patient information leaflet, consumer information provided by law in each pack of a medicine.

OTC	Over the counter, method of medicine sale or advice provision from retail premises, often but not always a community pharmacy.
QOF	Quality and Outcomes Framework, financial incentive scheme for achieving clinical targets in the GP contract. Pronounced ‘quaff’.
RCT	Randomised controlled trial, robust experimental method for comparing the effectiveness of healthcare interventions.
R&D	Research and development
RHFScBS	Revised Heart Failure Self Care Behaviour Scale (Artinian et al., 2002).
SCHFI	Self Care of Heart Failure Index (Riegel et al., 2004)
SMHFI	Self Management of Heart Failure Instrument (Riegel, Carlson, & Glaser, 2000)
SHA	Strategic Health Authority, organisation that monitors NHS Trust activity in an area coterminous with UK Central Government regional office.
SHO	Senior house officer, trainee doctor, now known as FY1 or FY2 (FY=foundation year).
SIGN	Scottish Intercollegiate Guidelines Network, independent body that advises the NHS in Scotland on standards of care.
SOB(E)	Shortness of breath (on exertion), classic symptom of heart failure.
U&E	Urea and electrolytes, routine blood monitoring results.
WHO	World Health Organisation, directing and coordinating authority for health within the United Nations system.
WYMAS	West Yorkshire Medical Ambulance Service, now merged into a larger NHS Ambulance Trust for the whole of Yorkshire and the Humber.

## Style notes

1. Single inverted commas or italics are used for emphasis; double inverted commas are used for short direct quotes; longer quotes are indented.
2. Reference style is APA 5th, the closest to the University of Leeds style (British Standard version of Harvard) that was supported by Endnote X.0.2
3. The British Approved Name (BAN) of the drug frusemide (a commonly used diuretic) was officially changed to furosemide in December 2003. Depending on context (for example, in direct quotes) both synonyms are used.
4. I have purposefully tried to adopt a direct writing style, which includes use of the personal pronoun.

# 1 Heart failure and its management

An intention to investigate aspects of heart failure and its management was founded on two key local observations:

- the repeated hospital admission of some people with unstable (decompensated) heart failure; and
- the inability of the formal healthcare system to find an effective way to prevent such admissions.

In this chapter the background to these problems and their potential solutions is explained. In **Section 1.1** a statement of focus is made and brief definitions of key terms (*italicised* in the focus statement) are provided. The rationale for empirical investigation is explained fully in **Section 1.2**. A clinical overview of heart failure and its management is given in **Section 1.3**; and an organisational overview of National Health Service (NHS) structure and policy is given in **Section 1.4**. These overviews expand on the rationale and place local issues in their national (and international) context. They are supported by relevant official guidance on good practice, respectively, heart failure management guidelines (from a variety of sources) and general healthcare policy (from UK Central Government). A chapter summary is provided in **Section 1.5** and the structure of the whole thesis is briefly summarised in **Section 1.6**. Many of the issues identified in this chapter will be explored in more detail in **Chapter 2** (literature review).

## 1.1 Focus of the investigation

The focus of this investigation became the *self management* of chronic *heart failure* by patients living in their *own homes* and routinely cared for in a *primary healthcare setting*. Focus development is described in the rationale below, however, a ‘clinical’ and an ‘organisational’ aspect are immediately apparent. These aspects recognise that clinical care is provided in an organisational context not a vacuum. Therefore, to improve care requires attention to the nature of any clinical interventions (for example: medicines, surgery and diagnostic tests), *and* the manner in which those interventions will be implemented (for example: by whom, where and when). This thesis seeks to provide an example of such integration.

It will be seen in **Chapter 2** that clinical and organisational guidance share a concern for self management in some form. This concern has been enhanced rather than diminished during the period of the investigation (2001-2009). The originality of this investigation relies on the subject matter, the context and the means of inquiry:

- the self management of heart failure has benefited from relatively few investigations compared to other conditions with a similar prevalence;
- reported patient views on self management most commonly come from volunteers who have completed organised development courses; and
- few attempts have been made to place competing views of self management in the context of a defined setting and an existing network of relationships.

The completed investigation may be unique in its comprehensive analysis of the potential for heart failure self management in a particular location and the use of self management as a case study about the variable implementation of healthcare policy.

Definition of the key terms in the focus statement is required here to clarify language as used in this document. They are starting points not finishing points; and sometimes related terms (or disputed meanings) must be introduced at this stage so that the concepts can be clearly understood. Conventionally, I use 'patient' to refer to a person who suffers from any minor ailment or serious disease, in relation to which they have sought (or been given) advice or treatment from a recognised healthcare professional. The word patient is not meant to imply any particular type of relationship with a healthcare professional. Occasionally, I use 'customer' for the general situation of a person seeking, or being provided with, some good or service.

'Heart failure' is a broad term for a number of related pathologies. The National Institute for Health and Clinical Excellence's (NICE) guideline on management defines it as (National Collaborating Centre for Chronic Conditions, 2003):

A complex syndrome that can result from any structural or functional cardiac disorder that impairs the ability of the heart to function as a pump to support a physiological circulation. The syndrome of heart failure is characterised by symptoms such as breathlessness and fatigue, and signs such as fluid retention.

Heart failure is a 'long term condition', for which a general definition supported by the Long Term Conditions Alliance ([www.ltca.org.uk](http://www.ltca.org.uk)) is (Wilson, 1999):

A condition of prolonged duration that may affect any aspect of the person's life. Symptoms may come and go. Usually there is no cure, but there are often things that can be done to maintain and improve quality of life.

It should be noted that both of the above definitions lack clarity and defy easy use of their associated terms as labels. In the context of long term conditions (chronic disease), it is important to distinguish between two forms of self management, which are called here 'clinical' and 'generic' (cf. **Sections 2.1** and **2.5**).

As I define it, clinical self management of heart failure involves the patient in some or all of the following tasks within a framework established by a healthcare professional:

- monitoring signs and symptoms, for example, weight gain;
- recording chronologically any changes in signs or symptoms; and
- taking diuretics to normalise these signs and symptoms.

Whereas, generic self management of long term conditions, including heart failure, involves patients setting themselves functional (and other) targets, which they meet in incremental steps with the possible encouragement of a facilitator. Clinical and generic self management of long term conditions are specific forms of 'self care'. Self care can also include treatment of minor ailments and activities to prevent disease. Broadly, I consider self care as any action taken by an individual to improve, maintain or decelerate a decline in their own (health-related) quality of life.

Self care is a broad term and its precise manifestations vary considerably (Department of Health, 2007) (Alliance for Self Care Research, 2009). However, for most people an idea that those who are relatively well (and have appropriate capacity) should 'self care' in some way is probably not contentious. Self management of long term conditions is increasingly seen as an effective way to improve health and reduce the use of healthcare resources. The utility of this form of self care is somewhat disputed as we shall see in **Chapter 2**, however, the English Department of Health's Expert Patients Task Force (2001) state that:

Research and practical experience in North America and Britain are showing that today's patients with chronic diseases need not be mere recipients of care. They can become key decision-makers in the treatment process. By ensuring that knowledge of their condition is developed to a point where they are empowered to take some responsibility for its management and work in partnership with their health and social care providers, patients can be given greater control over their lives. Self management programmes can be specifically designed to reduce the severity of symptoms and improve confidence, resourcefulness and self-efficacy.

It seems obvious, therefore, that if self management is successfully promoted, then it will have a profound impact on the way that both primary and secondary care are organised. The primary healthcare setting in the UK is characterised by a first point of consultation with general medical practitioners (GPs, family doctors), practice nurses and community pharmacists. These generalists provide most routine formal healthcare and refer patients to specialists when necessary. Traditionally, specialists are trained and based in secondary care settings (that is, hospitals). However, the provision of specialist care in primary care settings is increasingly common. I focus on patients whose current needs are mainly for primary healthcare because I do not want their responses to be unduly influenced by acute need. In addition, patients in their own homes (whether owned or rented) retain responsibility for their everyday healthcare, which patients in care homes (nursing and residential) and hospitals do not.

## ***1.2 Rationale for the investigation***

The rationale presented here represents my first thoughts on the need for this project and is intended to be atheoretical. In subsequent chapters the motivations, evidence and concepts described will be clarified, explored and refined. The project began in 2001 when I was employed jointly by the University of Leeds and the Leeds Teaching Hospitals Trust (LTHT) as a research practitioner (50% researcher/teacher, 50% pharmacy research manager). In 2004, I became Lecturer in Pharmacy at the University of Leeds, but the field work and analysis for this project continued. In fact I changed roles partly to create the time to complete the project, which was nevertheless a slow process.

In the course of my role as pharmacy research manager at the LTHT (2000-2004), I was provided with some internal data about heart failure admissions. Review of the relevant clinical case notes revealed that for some patients re-admissions were common, for example, repeated episodes of acute shortness of breath resulting in several calls for emergency help (999) over a period of 12 months. Clearly, from the LTHT's point of view (and that of the Ambulance Service) any intervention that could reduce such admissions would be considered valuable. The nationally recognised need to improve the management of heart failure is illustrated by:

- the inclusion of a heart failure chapter in the National Service Framework for Coronary Heart Disease (CHD) (National Health Service, 2000a);
- publication of NICE and SIGN guidelines for heart failure (National Collaborating Centre for Chronic Conditions, 2003) (Guideline Development Group, 2007); and
- service review by the Healthcare Commission in 2005/06 (Healthcare Commission, 2007).

In **Section 1.3.3** below there is some discussion about the detailed contents of each of these documents.

Clinical self management appeared to be a promising intervention, versions of which were supported by a growing evidence base for a number of long term conditions and attracting the interest of clinicians specialising in heart failure (Broadley & Marshall, 1999) (Cowie & Zaphiriou, 2002). At its most basic level, clinical self management of heart failure would involve patients taking additional doses of diuretic ('water') tablets when they notice the short term weight gain (caused by increased fluid retention) that often precedes shortness of breath. That is, if the 'sign' is spotted early enough, then action can be taken to avoid the 'symptom' and reduce consequent use of healthcare resources. Self management may also have a positive psychological impact on patients (Patient Liaison Group and General Practitioners Committee, 2007). The need to engage more patients in self management and self care activities is a major conclusion of two HM Treasury reports in the past decade (Wanless, 2002) (Wanless, 2004).

Self management is used extensively in the treatment of asthma and diabetes, often from the point of diagnosis and initial treatment (Gibson et al., 2002) (Goodall & Halford, 1991). However, my observation of practice suggested that the development of self management for heart failure was relatively slow, but perhaps more prevalent in the later stages of the disease. I thought that an investigation of the barriers to uptake and the steps that could be taken to promote self management would provide valuable information for those participating in service development (patients, frontline professionals and service managers).

There are many approaches that could be taken to such an investigation and I decided to undertake a qualitative inquiry (rather than conduct an experiment or carry out a survey) for two main reasons:

- whatever the barriers to uptake were it seemed clear that they would involve the complex interaction of healthcare systems, professionals and patients that only ‘thick description’ could hope to capture; and
- I wanted my investigation of these issues to be founded on patients’ perceptions of their problems and treatment. Qualitative inquiry seemed to offer the most appropriate starting point.

A ‘thick description’ of behaviour provides an explanation in context (Geertz, 1994). Its purpose is to make description more meaningful and explain the specific factors that influence behaviour at a point in time. A conventional experimental study was considered, which would have involved the development of a procedure for self management of heart failure, followed by the testing of that procedure in a randomised controlled trial (RCT). However, it soon became apparent that valid experimentally tested procedures already existed (cf. **Section 2.4.1**). Survey methods did not seem to offer enough opportunities to explore the thoughts and actions of patients (and others) in context. They are useful for determining the extent and strength of preference in a representative sample, however, they are less effective at determining the reasons why people think as they do and the external forces acting on them (Bowling, 2002). I saw my role as a concerned healthcare professional wondering about why the evidence base was not being applied in practice and what could be done to encourage uptake. In

addition to this primary motivation I was interested to learn about methods of qualitative inquiry for two reasons.

Firstly, part of my role was encouraging and supporting practice based research. However, pharmacists' research into the practice of pharmacy often seemed to overlook the viewpoint of patients and other customers (Bond, 2000). For example, services would be audited against professional standards but the value of the service to the end user would not be questioned. Encouraging more qualitative work seemed to be a useful way to correct this problem, by exploring how people make sense of aspects of their lives in a social context. Pharmacists are employed to be concerned about the way medicines are used but, in my opinion, often fail to recognise that their customers (patients and professionals) attach somewhat less importance to issues that they think should be vital.

Secondly, I have been trained in health economics, which has a decision maker focus in the UK. That is, health economists typically see themselves as providing information for decision makers that forms only part of the decision making criteria; the decision maker then weighs 'objective' clinical and economic data alongside other factors (which may be intangible). However, my experience was that in day-to-day practice (patient level) economic criteria were given little weight, and for strategic decision making (population level) economic criteria were given too much weight. This caused me to think about how subjective information could best be utilised, to provide balanced decision making at all levels. A more recent systematic review reports that there are many obstacles to decision makers' use of economic evaluations at the local level (Eddama & Coast, 2008).

This rationale provides a foundation for what follows; represents the justification provided to my managers and supervisors; and allows the reader to judge the impact of my motivation on the investigation.

### **1.3 Clinical overview of heart failure and its management**

This section describes the classification, epidemiology, aetiology, treatment and prognosis of heart failure. These details are important for a number of reasons:

- to support the need for research into this common condition, which has significant clinical and economic impact;
- so that evidence based guidelines for the management (including social aspects) of this complex syndrome can be understood;
- so that the patients' described experiences of heart failure can be understood in relation to the progression of their underlying condition;
- so that the professionals' experiences of disease management can be understood in relation to the apparent complexities and uncertainties;
- so that those described experiences that are likely to be common can be distinguished from those likely to be more unique or distinctive; and
- to appreciate the value (and limitations) of interventions that can reduce the incidence and/or severity of heart failure symptoms.

#### **1.3.1 Epidemiology and classification of functional capacity**

Heart failure is a common long term condition, accounting for 5% of all medical and geriatric admissions and 2% of all healthcare spending. The age-adjusted incidence of heart failure is stable but its prevalence is thought to be rising in the developed world as populations age. Age at admission and death due to heart failure may be increasing because of successful prevention activities (McMurray & Pfeffer, 2005). Readmission rates for heart failure are relatively high and many admissions may be preventable (Cowie et al., 1997). Estimates for the population burden of heart failure in the UK are given in **Table 1.1**. Typically, heart failure has a poor prognosis: 30-40% of patients die within a year of diagnosis and 60-70% die within five years (McMurray & Pfeffer, 2005). However, prognosis varies with grade of disease and is difficult to assess for individuals: in particular sudden death is common.

Physicians may use the terms mild, moderate and severe to distinguish grades of disease and monitor progression. These terms have no precise meaning but often refer to functional capacities II, III and IV respectively of the New York Heart Association (NYHA) classification of patients with cardiac disease. Full NYHA classification includes both ‘functional capacity’ and ‘objective assessment’, this is reproduced in **Table 1.2** (Criteria Committee of the New York Heart Association, 1994). Those classified with functional capacities I, II and III will have few symptoms of heart failure at rest.

Functional capacity is based on subjective symptoms and objective assessment is based on measurements such as electrocardiograms, stress tests, X-rays, echocardiograms and radiological images. Two-dimensional echocardiography (“an echo”) is the standard imaging technique (National Collaborating Centre for Chronic Conditions, 2003). This uses ultrasound to visualise a cross-section of the heart, which allows assessment of blood flow patterns, rate of blood flow, valve function (for example, regurgitation) and the general physical state of the heart (for example, wall thickening). Functional capacities I-IV do not correspond to objective assessments A-D (**Table 1.2**). Instead they are ‘mixed and matched’ to give an overall classification for the individual patient. A patient’s experience of heart failure does not necessarily correspond to its objective severity. Psychosocial function is also impaired in heart failure with over a third of sufferers experiencing severe and prolonged depressive illness (Sharp & Doughty, 1999) (Lynn, Harrell, Cohn, Wagner, & Connors, 1997).

Local data supported some national findings about the impact of heart failure. Leeds General Infirmary and Chapel Allerton Hospital (the former “United Leeds Teaching Hospitals”) reported 686 heart failure admissions in 1999/2000 by 586 patients. Patients’ average age was 74 and the sexes were equally represented. 90% of the admissions were acute and 25% of patients died during the year. Multiple admissions (most commonly following ‘shortness of breath’) were reported for 17% of patients.\*

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\* Routinely collected admissions data was supplied to me by Yorkshire Heart Centre administrators.

**Table 1.1:** Population burden of heart failure

<i>Characteristic</i>	<i>Measurement</i>
Incidence	1 new case per 1000 population per year
Rate of incidence increase	10% per year
Incidence (age 85 or older)	10 new cases per 1000 population per year
Median age of presentation	75 years
Male: female ratio	2:1
Prevalence	3-20 people per 1000 population
Prevalence (age 75 and older)	80 people per 1000 population

*Source:* (National Health Service, 2000a)

**Table 1.2:** NYHA classification for cardiac disease

<i>Functional capacity</i>	<i>Objective assessment</i>
<p><b>Class I.</b> No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dyspnea or anginal pain.</p>	A. No objective evidence of cardiovascular disease.
<p><b>Class II.</b> Slight limitation of physical activity. Comfortable at rest. Ordinary physical activity causes fatigue, palpitation, dyspnea or anginal pain.</p>	B. Objective evidence of minimal cardiovascular disease.
<p><b>Class III.</b> Marked limitation of physical activity. Comfortable at rest. Less than ordinary physical activity causes fatigue, palpitation, dyspnea or anginal pain.</p>	C. Objective evidence of moderately severe cardiovascular disease.
<p><b>Class IV.</b> Unable to carry on any physical activity without discomfort. Symptoms of heart failure or the anginal syndrome may be present even at rest. If any physical activity is undertaken, discomfort is increased.</p>	D. Objective evidence of severe cardiovascular disease.

*Source:* (Criteria Committee of the New York Heart Association, 1994)

### 1.3.2 Aetiology and acute presentation

The heart is divided into four chambers with the following basic functions:

- 1 Right atrium – receives deoxygenated blood from the general (venous) circulation.
- 2 Right ventricle – pumps deoxygenated blood to the lungs.
- 3 Left atrium - receives oxygenated blood from the lungs.
- 4 Left ventricle – pumps oxygenated blood to the general (arterial) circulation.

Arterial blood pressure is usually measured in the arm when the left ventricle pumps (systolic) and relaxes (diastolic). Most frequently, the proximal cause of heart failure is left ventricular systolic dysfunction (LVSD) secondary to poor blood supply to the cardiac muscles, which is in turn caused by CHD including myocardial infarction (MI). One third of heart failure is associated with hypertensive heart disease (National Health Service, 2000a), which can be related to both systolic and diastolic dysfunction (McMurray & Pfeffer, 2005). Heart failure may also be caused by heart valve diseases (since valves separate the heart chambers) and a number of less common conditions.

Several biological mechanisms (which are only well understood in relation to LVSD) contribute to worsening cardiac dysfunction and the retention of fluid by the body. In the natural world, this fluid conservation mechanism might be considered a beneficial adaptive response that minimises the chance of death following acute bleeding or dehydration (Nesse & Williams, 1996). However, in heart failure of old age it is maladaptive and causes increasing problems for healthcare systems in the developed world. When the patient with heart failure is nevertheless stable they are said to be in a 'compensated' condition. That is, despite their condition, biological mechanisms maintain an adequate level of normal functional capacity. Acute exacerbations or episodes of 'decompensation' leave patients with unmanageable shortness of breath at rest and/or on exertion (Felker, Adams, Konstam, O'Connor, & Gheorghiade, 2003).

Patients discharged from hospital with heart failure fall into three main groups (McMurray & Pfeffer, 2005):

- patients with new heart failure following another acute cardiac event, for example, MI;
- patients presenting for the first time with decompensation of previously unrecognised dysfunction; and
- patients with worsening of established heart failure.

Prevention of admission is not always possible but up to 50% of admissions may be preventable (National Health Service, 2000a). To the extent that it is possible, avoidance of admission relies on early recognition and swift corrective action. It is worth noting at this point that the main symptom of heart failure (breathlessness) is not obviously related to the heart. This presents professionals with difficulty, especially when first diagnosing the condition, and provides a challenge when providing patients with education to understand their condition. For those symptomatic heart failure patients with *reduced* systolic left ventricular function (about 50% have *preserved* function) evidence suggests careful management may slow natural disease progression and reduce the need for emergency medical care (McMurray & Pfeffer, 2005).

### **1.3.3 Heart failure management protocols and guidelines**

Heart failure is a complex syndrome occurring as a consequence of other cardiac morbidity and in conjunction with other age-related disorders (National Health Service, 2000a). It cannot be treated in isolation or without risking side-effects. When it occurs, shortness of breath can limit all normal activity. Solving the problem of heart failure symptoms and admissions implies effort in both primary and secondary prevention. For all these reasons the treatment protocols (for individual medicines and their combination) and management guidelines (for comprehensive care packages) produced by various organisations are an invaluable resource for evidence based practice. The most comprehensive management guidelines for general use are:

- Chapter 6 (Heart Failure) of the National Service Framework for CHD, henceforth “NSF Chapter 6” (National Health Service, 2000a);

- Chronic Heart Failure (NICE Clinical Guideline 5), henceforth “NICE CG5” (National Collaborating Centre for Chronic Conditions, 2003); and
- Management of Chronic Heart Failure (Scottish National Clinical Guideline 95), henceforth “SIGN 95” (Guideline Development Group, 2007).

NSF Chapter 6 provides standards of care, brief management guidelines and milestones for NHS organisations. NICE CG5 and SIGN 95 provide detailed management guidelines. Each recommendation made by NICE or SIGN is labelled with a clear grade (A-C, highest-lowest), which has been determined by the strength of evidence found in systematic review of relevant literature. In addition, the guideline developers highlight what they consider to be Good Practice Points (GPPs). NSF Chapter 6 states the broad standard of care that the NHS aims to provide (National Health Service, 2000a):

Doctors (*sic*) should arrange for people with suspected heart failure to be offered appropriate investigations (e.g. electrocardiography, echocardiography) that will confirm or refute the diagnosis. For those in whom heart failure is confirmed, its cause should be identified – the treatments most likely to both relieve symptoms and reduce their risk of death should be offered.

This thesis is mainly concerned with treatment (pharmacological and lifestyle) and monitoring after diagnosis has been made. However, it is worthwhile to note that diagnosis may be difficult, take time to confirm and be confused with other long term conditions. There are people with unrecognised heart failure and those being treated with an unfounded diagnosis (National Health Service, 2000a). As stated above, evidence based treatments are mainly for patients with confirmed LVSD, which is the most common underlying cardiac abnormality in the UK (Guideline Development Group, 2007).

NICE CG5 and SIGN 95 broadly agreed about the nature of interventions suitable for most patients and the strength of evidence supporting them. I ignore medicines, medical devices and surgical techniques that are suitable only for certain sub-groups of patients. The major common interventions in rough order of evidence strength (NB: this is not necessarily the order of intervention) are:

- 1 Care (especially follow up) provided by a multi-disciplinary team (MDT), which may be nurse-led and home-based (Grade A).
- 2 Prescription of an angiotensin converting enzyme inhibitor (ACEI) for all patients with LVSD (Grade A).
- 3 Prescription of angiotensin II receptor blockers (ARB) as an alternative to ACEI if intolerant (Grade A) or in addition to ACEI for some (Grade B).<sup>†</sup>
- 4 Prescription of a beta-blocker for all patients with LVSD to be initiated when they are in a stable condition (unless contraindicated Grade A).
- 5 Prescription of digoxin for patients who still have symptoms despite optimised treatment with ACEI, beta-blocker and diuretics (Grade A).
- 6 Prescription of spironolactone, unless contraindicated, for patients with moderate to severe LVSD (Grade A in NICE CG5, Grade B in SIGN 95).
- 7 Promote adherence: keep the medicine regimen as simple as possible (Grade B in NICE CG5); involve pharmacists in care (Grade A in SIGN 95).
- 8 Take regular exercise, which may require a formal programme or motivational support (Grade B).
- 9 Stop smoking (Grade B in SIGN 95, GPP in NICE CG5).
- 10 Prescription of diuretics for patients with fluid retention and congestive symptoms such as ankle oedema and shortness of breath (Grade B in SIGN 95, Grade C in NICE CG5).
- 11 Limit alcohol consumption (Grade C).
- 12 Tailor communication to the patient (Grade C in NICE CG5).<sup>‡</sup>
- 13 Individualise diuretic doses (up and down titration to maintain appropriate fluid balance) (Grade C in NICE CG5, GPP in SIGN 95).

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<sup>†</sup> ARB's role has been clarified between the publication of NICE CG5 and SIGN 95, but is subject to uncertainty. Strength of recommendation for addition of ARB to ACEI relates to SIGN 95 only.

<sup>‡</sup> Both interventions 12 and 18 require consideration of health literacy, which will be discussed later.

- 14 Encourage and educate patients to take part in monitoring, for example, daily weight measurement (GPP).
- 15 Be aware of and provide information about local support networks (GPP).
- 16 Be ready to openly discuss prognosis (GPP).
- 17 Adopt a low salt diet avoiding potassium substitutes (GPP in SIGN 95).
- 18 Tailor self-management to the patient (GPP in SIGN 95).

In the context of this investigation, some key points to be taken from this long list of routine interventions include:

- the role of traditional therapies (digoxin and diuretics) is diminished by high quality evidence supporting the use of ACEI and beta-blockers;
- diuretics retain the most important role in the day-to-day control of troublesome symptoms;
- taking more exercise and smoking cessation are the most important elements of lifestyle modification;
- there is strong support for a multi-disciplinary approach to care for heart failure patients;
- patients can play an important role in their own care if they wish to, but evidence for the clinical significance of this is limited; and
- clear open communication (especially regarding prognosis) involves consideration of both professional willingness and patient capacity.

The production of clinical evidence is not value neutral and is partly a result of commercial decision making (Tunis, Stryer, & Clancy, 2003). Thus, one reason why good evidence exists for the use of medicines is that it is required by well resourced pharmaceutical companies to obtain marketing authorisations (licences) and support commercial activity generally. Although the grade of evidence (from highly selected research samples) supporting social or behavioural interventions is generally lower, it may be highly significant in everyday practice. It is unusual to have high grade evidence for interventions such as home visits and the involvement of specific non-medical professionals (nurses and pharmacists) in care.

In addition, guidelines that say what should be done are one thing but actually carrying through the specified tasks is quite another. Clinical guidelines themselves are neither necessary nor sufficient for the adoption of good practice. If clinical practice was already good then arguably there would be no need for guidelines in the first place. There are likely to be barriers to good practice that the publication of guidelines is not sufficient to overcome (Grol & Grimshaw, 2003).

NSF Chapter 6 lists these reasons for heart failure readmission: uncontrolled symptoms, non-concordance (sic) with medication, non-concordance (sic) with diet, over-consumption of alcohol, intercurrent infection, failed social support and psychological problems. By “concordance” what is meant by NSF Chapter 6 is compliance (cf. **Sections 2.1.2 and 2.1.3**), that is, how closely instructions to take medicines are followed. So the recognised general barriers to best practice involve both the provision of good care by professionals (supported by guidelines) and engagement of patients with that care package (influenced by many clinical and social factors). Thus, it is possible to conclude that understanding and over-coming barriers is a socially constructed process.

In support of NSF for CHD implementation, the Healthcare Commission undertook a general review of cardiac services in 2003/04 and a specific review of heart failure services in 2005/06, which used NICE CG5 as a benchmark. They concluded that service development was significant but patchy, which supports the influence of the specific local context (Healthcare Commission, 2007). Specifically, in 2005/06:

- most areas had a specialist nurse-led heart failure service, but not widely available to all patients, and some services were financially unstable;
- national recorded prevalence of heart failure was lower than expected and prevalence by Primary Care Trust (PCT) varied widely;
- the percentage of patients with a confirmed diagnosis (by PCT) varied from 69.4% to 100%;
- waiting times for echocardiography continued to improve;

- 82.5% of patients with confirmed heart failure were prescribed an ACEI, but again there was variation (0% to 100%);
- improvement was required in beta-blocker prescribing, for which there was no Quality and Outcomes Framework (QOF) target (GP bonus payments);
- the “vast majority” of organisations had guidelines consistent with NSF Chapter 6 and NICE CG5 (SIGN 95 has official standing in Scotland);
- fewer than 20% of organisations were able to meet all the audit criteria in NSF Chapter 6 and NICE CG5;
- 90% of communities provided education and support packages, which help patients to understand and monitor their condition;
- only 52% of organisations had evaluated patient satisfaction with specialist heart failure services; and
- only 35.6% of organisations had carried out systematic evaluations of heart failure patients’ quality of life.

Therefore, quite wide variation in practice and significant barriers prevented all patients from accessing effective care packages tailored to their needs.

This clinical overview was intended to provide a broad understanding of heart failure and its management, particularly in relation to the most common manifestation of the syndrome, which is LVSD. The Healthcare Commission’s report indicates that although progress has been made improving the management of heart failure, performance variation between PCTs is wide. They speculate that “this may reflect the capacity and differing levels of maturity of specialist services in different localities” (Healthcare Commission, 2007). Their analysis is limited to say the least and one of the Healthcare Commission’s recommendations is simply for more “assertive” application of NICE CG5, whatever that may mean in practice.

## **1.4 Organisational overview of NHS structure and policy**

This organisational overview is provided both to help the reader unfamiliar with the NHS understand the context in which services develop and also to provide familiarity with the culture of the local healthcare economy. This information will aid understanding and analysis of the empirical accounts provided later by patients and professionals. It is necessary if specific recommendations for service development are to be made. A brief overview of general healthcare policy is provided, so that both the treatment of heart failure and local healthcare services can be compared to broader developments and the ‘direction of travel’ of public services. Continuous structural reorganisation has been an occupational hazard in the NHS, so this overview also explains some of the particular difficulties of working in and researching in the service.

### **1.4.1 The local healthcare economy**

The management of heart failure, like most long term conditions, requires input from all parts of the healthcare system which are drawn on from time-to-time (Department of Health, 2005a). Basic healthcare revolves around individual patient registration with a GP who normally works as part of a group medical practice. Traditionally, GPs are business partners (or their associates) who provide services to the NHS as independent contractors, but GPs may be directly employed in some (usually relatively deprived) areas. Medical practices typically employ staff such as receptionists and practice nurses. They have not been directly involved in commissioning (purchasing) healthcare services since the demise of fund-holding under first New Labour administration (1997-2001). However, more recently Practice Based Commissioning has been developed to encourage local decision making (Peckham, 2007). District nurses, midwives and health visitors may be attached to medical practices but are employed by NHS Trusts. GPs are now rewarded for meeting specific clinical targets listed in the QOF, some of these targets relate to the management of chronic disease (The Information Centre, 2007).

Primary Care Trusts (PCTs) can both commission and provide services, although they are now encouraged not to provide services directly unless absolutely necessary (Department of Health, 2005b) and these two aspects of their work are managed separately. PCTs hold GPs’ NHS contracts and those of other independent contractors,

for example, general dental practitioners and community pharmacists. At the time this study started (2001) PCTs were relatively small organisations (5 covered the Leeds Metropolitan District Council (MDC) area), but mergers created one PCT for the MDC area (with 5 localities) in 2006.

At times of serious or acute illness, responsibility for patient care is handed over from GPs to hospital based specialist consultants in medicine and surgery. So-called “Acute Trusts” (often managed as a group) are typically district general hospitals (DGHs) or large teaching hospitals. Admission to hospital can be classified as emergency/unplanned or elective/planned. Unplanned admissions are frequently disruptive and potentially avoidable (Halfon, Eggli, van Melle, Chevalier et al, 2002). They tend to occur via Acute Trust Accident and Emergency (A&E) departments, who transfer patients who need to stay in hospital to appropriate wards. As well as consultants (and more junior doctors) Acute Trusts also employ a wide range of nurses (often with specialist care responsibilities), scientific staff (pharmacists, laboratory workers) and therapists.

Psychiatric services are often provided by Mental Health Trusts that have tended to shut old style hospitals and provide local treatment in smaller units (Leff, 2001). Some areas have Care Trusts that provide both psychiatric services and personal social services. Leeds has two major teaching hospitals, which are parts of a single Acute Trust (formed by the merger of two previously separate groups), and a Mental Health Trust (now Leeds Partnerships NHS Foundation Trust).

Ambulance services are provided by another type of NHS Trust, which at the time this study started included WYMAS (West Yorkshire Medical Ambulance Service), but a merger in 2006 created one Trust (the Yorkshire Ambulance Service) for the Yorkshire and the Humber Strategic Health Authority (SHA) Area.

### 1.4.2 Healthcare policy and monitoring

The Yorkshire and the Humber SHA area is coterminous with the area covered by the UK Central Government office for the region (GOYH). SHAs monitor the care provided by all types of NHS Trusts (NHS Yorkshire and the Humber, 2009). Mergers created one large SHA (by 2006) from smaller authorities, which included the West Yorkshire SHA. The Healthcare Commission, whose report on heart failure services is discussed above, provided central monitoring of clinical care and NHS administration. The Care Quality Commission recently replaced (from 1 April 2009) the Healthcare Commission as the body responsible for assessing how well a Trust has met Department of Health (DH) core standards and national targets for NHS healthcare providers. This new body also regulates social care provision (Care Quality Commission, 2009). A separate organisation also monitors the performance of Foundation Trusts, which have more autonomy from central control (Monitor, 2009). The Audit Commission contributes its assessment of Trust and SHA financial performance (Audit Commission, 2009). Guidance on standards of care flows from both the DH (which has overall responsibility for the NHS) and the independent body NICE (National Institute for Health and Clinical Excellence, 2009).

NICE guidance in relation to heart failure is discussed above, their website also now includes a guide to commissioning heart failure services, which links the achievement of clinical standards with more general healthcare policy (National Institute for Health and Clinical Excellence, 2008). DH policy is outlined in 'White Papers', six major White Papers have been published during the course of this investigation. Most White Papers are supported by formal consultation documents ('Green Papers'), public consultation exercises and research reports. The DH also publishes guides on the implementation of specific aspects of White Papers and progress reports at regular intervals. The years 1999 to 2008 saw the publication of at least 48 major official documents relevant to the management of heart failure as a long term condition in England (cf. **Section 7.4**).

Self care is a significant aspect of general healthcare policy and is presented publically both as an underpinning philosophy (or matter of public preference) and as an evidence-

based care strategy (Department of Health, 2009a). The NHS Plan envisages that the NHS will “become a resource which people routinely use every day to help look after themselves” and a return to self care is the ultimate goal of most episodes of treatment (Department of Health, 2000). The NHS Plan reaffirms and extends the policy to establish an Expert Patients Programme (EPP), first announced in *Saving Lives* (Department of Health, 1999). The Expert Patients Task Force set up in 1999, under the leadership of the DH’s Chief Medical Officer, published its report in 2001 (Expert Patients Task Force, 2001), which included a key recommendation to provide self management training for patients with long term conditions. This recommendation is supported by an explicit evidence base, the strength of which is disputed (cf. **Section 2.5.3**).

The centrality of self care and self management in healthcare policy sits slightly at odds to its more peripheral role in condition specific guidelines. Whereas the self care agenda is strongly linked to the provision of better information (“to empower patients”) in the NHS Plan, the EPP report goes further stating:

Patient self management programmes, or Expert Patients Programmes, are not simply about educating or instructing patients about their condition and then measuring success on the basis of patient compliance. They are based on developing the confidence and motivation of patients to use their own skills and knowledge to take effective control over life with a chronic illness.

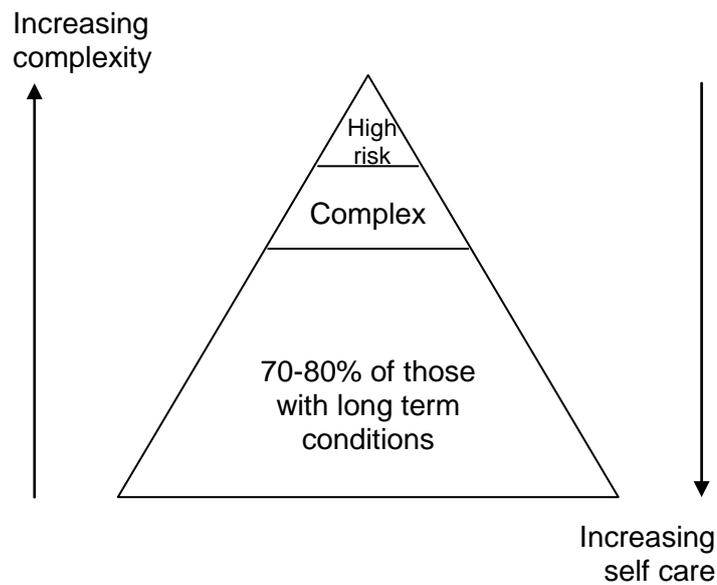
It is hoped that this level of patient engagement will reduce the variability in patient experience of the NHS that was apparent in the 2005/06 review (Healthcare Commission, 2007). The question of whether patients generally want or will accept “effective control” in relation to long term conditions is central to the success of self care policy. The NHS draws its notion of generic self management (EPP) from the work of Lorig and others at Stanford University in the USA, who established the importance of self-efficacy in self care development (Shoor & Lorig, 2002). Such concepts as control, empowerment and self-efficacy are presented uncritically in DH documents as if there is no current or historical debate about their utility (Department of Health, 2004a) (Department of Health, 2006), indeed the concepts are rarely even given the benefit of a clear consistent definition.

In DH documents focusing on long term condition management, self management appears as part of a disease management triangle (Department of Health, 2004b) (Department of Health, 2005a), which has been borrowed from Kaiser Permanente one of the USA's largest integrated healthcare organisations. Integrated care organisations bring together the needs and functions of insurers and providers, this system has parallels with our own NHS, and the two systems share a concern to provide good care at reasonable cost. The Kaiser Permanente Triangle (**Figure 1.1**) has three levels:

- Level 1 - self care supported by knowledgeable and confident patients;
- Level 2 - disease management such as that described in the NSF for CHD and NICE CG5; and
- Level 3 - case management of “high intensity users” of unplanned hospital care, sometimes termed “frequent flyers” by ambulance crews.

In the UK, Level 3 care may be managed by ‘community matrons’, who are skilled experienced nurses given the responsibility to coordinate packages of home-based care (Department of Health, 2005c). Different documents present a confusing view about whether the top of the triangle should be defined chiefly by high risk (Department of Health, 2006) or high complexity (Department of Health, 2004b) (Department of Health, 2005a). I consider that it may be better to conceptualise need as a variable combination of risk and complexity, which draws increasingly intensive professional support.

The Government makes a link between this model of care and the “public’s growing desire” to make healthier choices, including choices by people in disadvantaged groups and areas (Department of Health, 2005a). Choice has two faces: selecting a preferred provider; and exercising personal control over health. The former is emphasised in initiatives like “Choose and Book” for the location of out-patient appointments (Department of Health, 2006); the latter is emphasised in the context of behaviours to support health promotion and disease prevention (Department of Health, 2004a). There are elements of each in the management of long term conditions, the emphasis in this thesis is on behavioural choice not provider choice.



**Figure 1.1:** Kaiser Permanente Triangle/NHS and Social Care Model

Adapted from (Department of Health, 2005a) and (Department of Health, 2006)

## 1.5 Chapter summary

There are standards for the treatment of heart failure, management of long term conditions and CHD prevention, for example, those found in NSF Chapter 6 (National Health Service, 2000a), NICE CG5 (National Collaborating Centre for Chronic Conditions, 2003), Supporting People with Long Term Conditions (Department of Health, 2005a) and Choosing Health (Department of Health, 2004a). Local hospital re-admission statistics indicated (in 1999/2000) that the management of chronic heart failure could be improved and this was supported by the Healthcare Commission's more recent national audit (Healthcare Commission, 2007).

Proximal causes of poor outcomes relate to professional behaviour (for example, inadequate diagnosis and prescribing), patient behaviour (for example, low adherence, unhealthy lifestyle) and institutional support (for example, lack of audit) (Healthcare Commission, 2007). I believe fundamental causes are harder to elucidate, but may include communication (inter-personal and across care boundaries) and access to

resources. Self management (clinical and generic) is offered as part of the solution to bad practice, working mainly via encouragement of:

- personal responsibility for health; and
- more effective engagement between patients and professionals.

Healthcare policy tends to assume that the solutions offered (for example, self care in long term conditions) are appropriate always and everywhere (Expert Patients Task Force, 2001). However, implementation problems associated with particular diseases, locations and people are not explored. The purpose of the thesis is not only to describe a set of general issues but also to provide a detailed contextualised exploration of what policy actually means for the people it affects.

## **1.6 *Brief outline of thesis***

In **Chapter 2**, a literature review, the evidence supporting self management as part of long term condition management is evaluated and the concepts underpinning self management are elucidated. In **Chapter 3** the aim and objectives of my empirical investigation are stated. It continues with an explanation of methodology and underpinning assumptions, then goes on to describe the methods of qualitative inquiry used. **Chapter 4** describes the recruitment of participants and their characteristics. **Chapter 5** is an evaluation of current care for heart failure as described by patients and professionals. **Chapter 6** evaluates participants' thoughts and feelings about greater clinical self management of heart failure. **Chapter 7** summarises the empirical findings, and provides conclusions for healthcare policy, practice and research.

## 2 Literature review

**Chapter 1** described the context for the management of heart failure as a long term condition, and explains my interest in the potential for its self management. This **Chapter 2** identifies and supports objectives for an empirical investigation. Its objectives are to: identify good practice for self management; describe specific models for heart failure self management; refine issues for further exploration; and inform topics to be discussed with research participants. The literature review also provides a bank of studies for comparative evaluation, once the results of the empirical investigation are known.

This review is relatively complex because it was the intention to explore known issues in their context. **Sections 2.1 to 2.4** concern heart failure specifically, firstly with a consideration of what clinical self management involves, then continuing with related issues of importance to patients and professionals. **Section 2.5** considers how clinical self management of heart failure relates more broadly to generic self management of long term conditions, and as such complements **Section 2.1**. In **Section 2.6** both types of self management are related to broad matters of economic policy, this process is influenced by sociological considerations. Finally, **Section 2.7** provides a chapter summary, a platform for **Chapter 3** (aims and methodology) and an assessment of the value of narrative literature review.

The normal ‘systematic review’ process of identifying key words, searching, scanning titles, screening abstracts, applying inclusion/exclusion criteria and standardised evaluation of papers would probably be unproductive here for several reasons:

- there are few studies that focus only on heart failure self management;
- self management and self care terminology are used inconsistently;
- self management issues are frequently embedded in other work;
- titles do not always reflect self management content;
- this study is concerned with both the effectiveness of self management *and* factors that influence its implementation; and

- since implementation is contextual its systematic evaluation is problematic.

It was also known that some reviews of heart failure management programmes and (general) self management initiatives already existed. Therefore, a more narrative review was conducted in which the major issues have been scoped out and key literature identified. The approach was structured and has the benefit (over systematic review) of describing issues for investigation in their broader context.

An initial keyword search in Medline and Embase (using the MeSH term “heart failure” and free text “self management”) identified some literature and authors with programmes of work in this area. The Cochrane Library was scanned for relevant systematic reviews. References were also taken from the policy documents and guidelines discussed in **Chapter 1**. Reference lists in relevant papers were then scanned for further articles of interest. When key articles in major journals were identified, then citation alerts were set up to provide notification of new papers citing that work. Tables of contents from key journals were scanned throughout the period of the study. More focused keyword searches (on particular aspects of self management) were conducted near the end of the study period to check for recently published papers. Grey literature was monitored on key websites for example the: British Medical Association, DH, King’s Fund and Long Term Conditions Alliance. Personal contact was made with a small number of key authors, for example, Riegel (self care assessment), Pignone (health literacy) and Barlow (review of effectiveness).

## **2.1 Clinical self management**

A definition of clinical self management was provided in **Section 1.1** and is justified here. If the engagement of heart failure patients in disease management is to be enhanced at all, then this is likely to be one of the first things suggested after general improvement of patient knowledge. To an extent it is obvious that all patients self manage in some sense, so it is important to clarify what any changes to existing practice would mean and also how existing practices are likely to influence implementation.

### **2.1.1 What is clinical self management?**

It has been suggested that patients with heart failure could safely alter diuretic doses according to a pre-determined scheme (Broadley & Marshall, 1999) (Cowie & Zaphiriou, 2002). This level of self management provides one of the simplest solutions (prompt reduction in excess fluid) to the proximal cause of re-admission to hospital with decompensated congestive heart failure. However, people taking diuretics also run the risk of dehydration in the short term, and dangerous metabolic or electrolyte disturbances especially potassium loss. It is necessary to determine the minimum requirements for clinical self management that would ensure both safety and efficacy. For example, those taking diuretics daily should have regular electrolyte monitoring (Joint Formulary Committee, 2008a) and monitor weight daily (Ross, Hershberger, & Ellison, 2006).

Traditionally, large fluctuations in daily weight or adverse changes in electrolytes would be reported to the patient's physician (by the patient themselves, a nurse or the laboratory as appropriate) who would then make a decision about any action required. It is also possible for pacemakers to give advance warning of weight gain (up to two weeks) based on impedance measurement in the chest (Yu et al., 2005), however, relatively few patients require pacemakers and this function (if present on the implanted device) is usually disabled. There is good evidence for the effectiveness of nurses or multidisciplinary teams in the role of volume control by diuretic dose adjustment, but patient self adjustment is less well studied (Ross et al., 2006).

In the absence of any definitive trial data, some practical questions about self adjustment remain largely unresolved (Macfadyen & Struthers, 2000):

- What characteristics define patients who can cope with adjusting doses?
- What magnitude of weight gain is clinically important?
- Can shortness of breath caused by heart failure be distinguished from other complications or conditions?
- Which additional diuretic should be used, at what dose and for how long?

Meanwhile efforts continue to identify methods of volume control that do not rely on diuretics or would allow dose reduction. This is considered important not least because there is little high quality evidence (RCTs rather than opinion and experience) regarding the general safety and effectiveness of diuretics in heart failure (Hill, Yancy & Abraham, 2006). Better quality evidence for the use of diuretics in heart failure is unlikely to emerge because (a) clinical experience is unequivocal (b) withholding diuretics from those with congestive symptoms would probably be considered unethical and (c) there is no commercial interest in organising trials for patent expired medicines.

The diuretic side effect profile is such that dose reductions that don't cause decompensation are desirable, and any doses increases (to reduce weight gain) should be reversed as soon as it is clinically appropriate. If suitable patients can be selected and appropriate dosing schedules devised, then the minimum requirements for safe self adjustment appear to be:

- daily monitoring of weight and, potentially, other symptoms;
- recording these weights so that trends can be observed.

Recording would be important so that the effectiveness of additional diuretic doses could be confirmed and to avoid adverse consequences from becoming too dehydrated. It is important to start (additional) diuretics in a timely fashion and equally important to reduce doses to normal (or nil) as soon as possible. These conditions and minimum requirements correspond to conclusions reached in a systematic review of asthma self management that all adults should be offered a written action plan, self monitoring and regular medical review (Gibson et al., 2002). No particular type of monitoring was favoured, but expiratory peak flow measurement is common in the context of asthma Interventions without a written action plan were considered less efficacious. In addition to weight, heart failure patients could monitor shortness of breath, ankle oedema (swelling) and blood pressure. Weight and blood pressure measurement ideally require the use of validated equipment, which is routinely checked or maintained. The conjunction of related symptoms may help to distinguish heart failure decompensation from the effects of other conditions.

Weight monitoring and diuretic self adjustment are cornerstones of patient involvement in their own medical care, but will only help to control short term exacerbations. Congestion relief alone is inadequate (Cohn, 1996) and these interventions fall short of what might be considered clinical self management capable of preventing exacerbations and improving longer term health outcomes. From a medical viewpoint, full clinical self management should also involve the patient in maintaining high levels of adherence to other prescribed medication (especially ACEIs and beta-blockers) and adopting a healthy lifestyle (for example, smoking cessation, moderate exercise and dietary control). Regular electrolyte monitoring (U&Es) seems likely to remain a professional responsibility but could be prompted by patient request.

### **2.1.2 Adherence to self management behaviours**

An obvious professional concern is that self managing patients will misunderstand advice, follow instructions incorrectly or adopt their own unsafe practices. The best available evidence on medication adherence suggests that at least 30% of medicines for chronic diseases are not taken as the prescribers' intended (Sabate, 2003). Studies suggest that in cardiovascular disease medication adherence is an important indicator of outcomes including mortality (Silcock & Standage, 2007). Specific heart failure studies also identify low adherence as an indicator of poor outcomes, in particular hospital admission (Bennett, Hays, Embree, & Arnould, 2000). It is important to understand the philosophy behind the terms 'adherence' and 'concordance', which are both used (sometimes inappropriately, cf. (National Health Service, 2000) in **Section 1.3.3**) as synonyms for the more widely understood 'compliance'.

Compliance is the traditional term used to describe the relationship between patients' behaviour and their physicians' intentions. In relation to medicines taking, it can be defined as the extent to which the patient's behaviour matches the prescriber's recommendations (Horne, Weinman, Barber, Elliott, & Morgan, 2005). This is usually expressed as a percentage indicating the proportion of prescribed doses taken:

- accurately (for example, right number of tablets);
- effectively (for example, by the right route or with regard to cautions); and
- on time (for example, within one hour of the appointed time).

Compliance may be measured by: tablet counting; electronic recording; direct measurement of a drug or marker in the body; or measurement of the intended pharmacological effect (Aronson & Hardman, 1992). Compliance and adherence are close synonyms, however, the latter term is considered less paternalistic. For careful users adherence is defined as extent to which the patient's behaviour matches *agreed* recommendations from the prescriber (Horne et al, 2005).

In 22 older heart failure patients recently discharged from hospital, Cline et al (1999) found adherence to prescribed medicines as high as 73%, which is similar to the 74% level found in 113 new out-patients by Ni et al (Ni et al., 1999). The level found by Cline et al was considered sub-optimal especially as 83% took medicines that weren't prescribed at discharge (Cline, Björck-Linné, Israelsson, Willenheimer, & Erhardt, 1999). Reviews focused on heart failure patients find low adherence related to both medicines taking and other self management behaviours (Evangelista & Shinnick, 2008) (van der Wal & Jaarsma, 2008). Reported adherence rates in heart failure patients for various components of clinical self management are (van der Wal & Jaarsma, 2008):

- medication adherence 10%-99%;
- sodium restricted diet 13%-75%;
- fluid restriction 23%-70%;
- daily weighing 12%-79%.

Absolute adherence levels and reasons for their variation require explanation, noting that medication adherence has both the highest level and the greatest variation. However, some variation is likely to be an artefact of inconsistent definition, measurement and analysis, rather than a consequence of patients' actual behaviour (Silcock, Knapp, Raynor, & Jackson, 2006). Low levels of adherence to diet and medication are most frequently associated with hospital admission (van der Wal & Jaarsma, 2008).

Adherence behaviour is complex (Horne et al, 2005). To improve levels of adherence physical and cognitive barriers (leading to *unintentionally* lower levels of adherence) first need to be lowered or removed. This may include the provision of physical aids

and written materials designed for easy reading. *Intentionally* low adherence relates chiefly to the experience (or fear) of side-effects and the perceived need for interventions (Horne et al, 2005). The cost of care (except in relation to transport) is not a major factor explaining adherence to heart failure interventions in the UK where the NHS provides care free at the point of need and free medicines for older people. Strategies to improve medication adherence in long term conditions are mostly complex and not very effective (Haynes, Ackloo, Sahota, McDonald, & Yao, 2008).

### **2.1.3 Concordance or shared decision making**

More recently professionals have begun to consider how best to involve patients in clinical decision making, rather than just expecting them to follow instructions. Concordance is a broader term that describes an *ideal* relationship between patient and professional. The essential elements of concordance are explicit agreement, respect for mutual beliefs and the patient's right to self determination (a casting vote on treatment options) (Concordance Coordinating Group, 1998). For the professional, concordance requires increased understanding and acceptance of the patient's beliefs about medicines and illness. They must also help the patient to overcome any practical problems that they face. It is proposed that, patients should then adhere more closely to agreed proposals for care and achieve better long term health (and psychological) outcomes.

The knowledge and expertise offered by patients may include: experience of illness, social circumstances, attitude to risk, values and preferences. Professionals meanwhile contribute: diagnosis, disease aetiology, prognosis, treatment options and outcome probabilities (Coulter, 2001 cited by (Expert Patients Task Force, 2001)). The concept of concordance was developed in the context of medicines taking but I think it applies equally to other aspects of the doctor-patient relationship. Synonyms might be partnership, therapeutic alliance or shared decision making; the latter term is common in the medical profession (Charles, Gafni & Whelan, 1997).

Regardless of semantics (Makoul & Clayman, 2006), there is a general trend away from viewing the passive respectful patient as normative and towards more equal power relationships, which imply greater patient involvement in clinical decision making

including self management of long term conditions. The range of possible doctor (sic) patient relationships can be described as (Charles, Gafni, & Whelan, 1999) (Charles, Gafni, & Whelan, 2000):

- Paternalistic
- Shared
- Informed

In these different ‘modes’ the ill person is seen respectively as patient, client and consumer. Charles et al (1999) (2000) express a preference for shared decision making: patient as client. Self management of long term conditions tends to see the patient either as client or developing into a consumer (Expert Patients Programme, 2007).

In classic agent-client relationships (for example: law, accountancy and architecture) it is important that the client fully discloses their intentions and relevant information. In these situations clients bear the full financial cost of most decisions. Shared care therefore requires better patient access to high quality, understandable sources of information, and more open sharing of information and concerns by patients. However, options may be constrained by public affordability (Sculpher, Watt, & Gafni, 1999). Opposing camps in the shared care debate may see better information as empowering or oppressive (Rifkin, 2001). Certainly, there is much debate surrounding patients’ ability to understand and interpret medical information without assistance or what might be described as ‘translation’ from technical language (Apter et al, 2008) (Schwartz, Woloshin & Welch, 2005).

On the one hand a patient may be the best judge of his own healthcare needs and thus patient centred care requires (Stewart, 2001):

- exploration of reasons for consultation and information needs;
- integrated understanding of the patient’s world;
- common ground on problem statement and mutual agreement on management;
- enhanced (secondary) prevention and health promotion (primary prevention);
- an enhanced relationship with the doctor (or other professional).

The tangible benefits of such care are reported to be patient satisfaction, adherence and health outcomes (Stewart, 1995). Concordance may, therefore, be used *instrumentally* to produce adherence, even if the two are not synonyms. On the other hand, a systematic review of the influences on doctor-patient relationships shows little consistency, except to say that warm, friendly and reassuring doctors are the most effective (Di Blasi, Harkness, Ernst, Georgiou, & Kleijnen, 2001). This emphasises the most basic *communicative* aspects of concordance.

#### **2.1.4 Scope and limitations of self management**

Fluid monitoring and adherence to medicines taking are central self management activities in heart failure. In addition, the following recommendations contribute to a healthy lifestyle for heart failure patients (Gibbs, 2000) (Cowie & Zaphiriou, 2002): good general nutrition and weight reduction if required; avoiding high salt foods and use of table salt; moderate alcohol consumption; smoking cessation; regular exercise; and influenza vaccination. Social activities should also be encouraged (Gibbs, 2000), which may help adoption of lifestyle measures (for example, regular exercise) and prevent social isolation.

Full clinical self management is, therefore, very comprehensive. I believe that for professionals to be more effective facilitators of this behaviour they should adopt a concordance model of consultation. Without either (a) open shared decision making with professionals and/or (b) additional generic self management (cf. **Section 2.5**) it seems that clinical self management will retain some fundamental limitations and practical barriers:

- it is focused on evidence based interventions directly related to heart failure or similar long term conditions (cf. NICE CG5), but many people have multiple long term conditions affecting different body systems;
- the outcomes of interest are medical or organisational, for example: adherence, weight control and hospital admission; and
- functional and social outcomes of importance to patients are not well monitored, especially social outcomes;

- it provides no guidance on the best way to learn self help skills, except to say that clear doctor-patient communication is important; and
- it provides no guidance on resolving patients' social problems or the nature of social activities that might be beneficial.

Resolving these important issues requires in depth consideration of the whole healthcare system: patients, professionals and institutions (Kennedy, Rogers, & Bower, 2007).

### **2.1.5 Education and experience**

Incorporating clinical self management, or indeed any complex intervention, into routine care must build on existing education and experience. The following sections (**Sections 2.2 to 2.4**) review the formal evidence related to these issues. Patient related issues are considered first. In **Chapter 1**, I defined patients by their help seeking behaviour or reception of care. In fact adopting (or fighting against) the role of a patient can be a long process. It may begin with a question: "Why am I ill?" and/or "What can be done?" It may continue with a series of actions (perhaps largely those demanded by more knowledgeable professionals?) and related judgements about effectiveness. Greater knowledge (education) and greater capacity to judge effectiveness (experience) are what seem to define (apart from payment) the professional role and what I think self managers need to more consciously develop.

## **2.2 Patient education**

To participate safely in clinical self management, heart failure patients require appropriate knowledge, skills and attitude; which are the major domains of any learning linked to practical action (Kaufman, 2003). What it is considered (professionally) appropriate for patients to learn is outlined in **Section 2.2.1**. Quantitative assessments of patients' heart failure knowledge are discussed in **Section 2.2.2**. **Section 2.2.3** concerns heart failure patients' specific knowledge about self management and their adoption of behaviour (skills). Potential limits on patients' capacity to learn are discussed in **Section 2.2.4**. In **Section 2.2.5** the concept of health literacy is outlined. Patient attitudes towards heart failure and its self management appear not to have been quantitatively assessed but are discussed in context in **Section 2.3**.

### 2.2.1 Learning needs

Patient education without purpose is potentially redundant. In a traditional model of healthcare people might only need education about how to be a patient, for example, by providing an accurate description of symptoms and following instructions accurately. The concordance model explicitly recognises the value of patients' beliefs and experiences (Concordance Coordinating Group, 1998), in which case patients may need further education about what broader information is relevant and how best to express themselves. In the course of a concordant consultation, professionals may provide patients with brief education about the clinical details of their condition. A self-managing patient may actually use these clinical details (and other sources of information) to inform their independent decision making (Expert Patients Task Force, 2001).

The broad components of medical knowledge relate to aetiology, diagnosis, treatment and prognosis. To enable participation in clinical self management providing patients with good information about diagnosis (in relation to signs and symptoms) and treatment (that is, medication required to control signs and symptoms) may be sufficient. However, comprehensive guidelines on topics for education are available from at least two sources:

- the European Society of Cardiology (ESC) (Swedberg et al., 2005); and
- the US Agency for Health Care Policy and Research (AHCPR).

Eight education topics in the AHCPR guidelines were the basis of related Heart Failure Learning Needs Inventories developed and tested by research teams in the US and Australia (Hagenhoff, Feutz, Conn, Sagehom, & Moranville-Hunziker, 1994) (Frattini, Lindsay, Kerr, & Park, 1998) (Wehby & Brenner, 1999) (Clark & Lan, 2004). The topics are prognosis, diet, activity, medications, signs and symptoms, risk factors, psychological factors (stress, support systems, emotional response to illness) and general heart failure information (Konstam et al., 1995). All of the studies demonstrated a discrepancy between patients' and nurses' perceptions of topic importance and assessment of whether it was realistic to learn more in the clinical setting. In general, it was *patients* who rated both importance and realism more highly than nurses. The

Australian study (Clark & Lan, 2004) was the only one targeted at out-patient settings rather than medical in-patients. They noted a few discrepancies between patients in different settings, but struggle to explain the influence of context using only *ad hoc* quotes collected from patients. Information on signs and symptoms (diagnosis) and medication (treatment) were consistently rated most highly by patients, which should support involvement in clinical self management.

The ESC education topics are similar in scope under the headings: general advice, drug counselling, rest and exercise, vaccinations, travel and dietary habits (Remme, Swedberg, & European Society of Cardiology, 2002) (Swedberg et al., 2005). Self weighing is specifically included in general advice and self management is incorporated into drug counselling. However, to my knowledge there has been no attempt to investigate the perceived importance of patient education in relation to ESC topic headings.

### **2.2.2 Patients' general level of knowledge**

Very few studies have explored patients' general level of knowledge about heart failure and understanding of heart failure management (Strömberg, 2005). However, appropriate knowledge is recognised as an important requirement of effective self management (Artinian, Magnan, Christian, & Lange, 2002). Quantitative assessments are reported in this section and qualitative studies are summarised in **Section 2.3.2**.

Artinian et al used the AHCPR guidelines as the basis for their Heart Failure Knowledge Test (HFKT). They found low levels of knowledge (mean score 5.83/15, 41% correct responses) and that patients (n=123, aged 36-84, 72% male) had difficulty applying knowledge to select effective self management options (Artinian et al., 2002). However, they believe that some patient difficulties related to pure low literacy, that is, the reading level (measured by US school grade) of their questionnaire was too high. Knowledge was not correlated to age or gender, however, patients from a "suburban community hospital" (mean score 8.23) had significantly higher levels of knowledge than patients from an "urban teaching hospital" (mean score 4.78). The authors speculate that special education provided *to nurses* at the suburban hospital may have

had an impact on *patient* knowledge. Most positively, Artinian et al found that 68% of patients could identify one to three symptoms of heart failure. Low levels of knowledge about medication found by Artinian et al were consistent with a previous findings for elderly patients in Europe (n=22, aged 70-97) (Cline et al., 1999) and the US (n=41) (Bushnell, 1992). In Artinian et al only 26% of patients understood the importance of daily weighing and only one-quarter of Bushnell's patients weighed themselves daily.

Ni et al report that 50% of patients (n=113, mean [sd] age 51 [12.8], 74% male) they surveyed from a heart failure clinic weighed themselves daily but that 40% didn't appear to understand the importance of daily weighing (Ni et al., 1999). Despite 71% of patients being provided with written information, 75% with verbal advice and 60% with both; only 14% said they knew "a lot", 49% "some" and 38% "little or nothing". Over 85% recognised the major symptoms of heart failure (Ni et al., 1999). Higher levels of knowledge (on a 17-item test) were associated with: recent hospital admission; receiving both information and advice from a professional; and female sex. Self perception of knowledge did not correlate with assessed knowledge (Ni et al., 1999).

In a US mail survey of patients attending a heart failure clinic or participating in clinical trials (n=178, aged 19-86, mean age 55.6, 62% male) 89% had received written information about heart failure and 91% had received verbal advice. The mean knowledge score on an 18-item test (extrapolated from Ni et al 1999) was 67.4% but only 38.6% reported knowing "a lot" about heart failure. No support was found for the hypothesis that higher knowledge should be reported by those who had made behaviour changes (Sneed & Paul, 2003). Patients' perceived and reported self care behaviours were at higher levels than objective assessment could demonstrate (Sneed & Paul, 2003).

The results of these studies must be applied cautiously because they are from the US, participants tended to be male and recruitment was via secondary care settings. However, assessed knowledge is consistently low and low confidence in that knowledge was also identified. Positively, patients could identify the symptoms of heart failure. Knowledge could either not be used to support or was not linked to behaviour change.

These results are important because it seems that successful self managers will need: basic knowledge, confidence to apply their knowledge in practice and well-founded self management behaviours.

### **2.2.3 Assessment of self management knowledge and behaviour**

For professionals, a simple practical intuitive first-step towards increasing a patient's level of self management behaviour could be to objectively assess current behaviour, thereby establishing a baseline. This step should, however, follow a dialogue in which the patient's need, willingness and ability to self management are broadly established (Coulter, 2001 cited by (Expert Patients Task Force, 2001)). Six tools have been identified for the potential measurement of concepts related to self care and self management in heart failure:

- an unnamed set of items used by Ni et al in their survey of knowledge and adherence (Ni et al., 1999);
- Riegel et al's Self Management of Heart Failure Instrument (SMHFI) (Riegel, Carlson, & Glaser, 2000);
- Bennett et al's Beliefs about Medication Compliance Scale (BMCS) and Beliefs about Dietary Compliance Scale (BDCS) (Bennett et al., 2001);
- Artinian et al's Revised Heart Failure Self Care Behaviour Scale (RHFSBS) and Heart Failure Knowledge Test (HFKT) (Artinian et al., 2002);
- Jaarsma et al's European Heart Failure Self Care Behaviour Scale (EHFSBS) (Jaarsma, Strömberg, Martensson, & Dracup, 2003); and
- Riegel et al's Self Care of Heart Failure Index (SCHFI) (Riegel et al., 2004).

Note that although the *RHFSBS* precedes the *EHFSBS* in publication order it was reportedly founded on earlier work by Jaarsma et al, hence its designation by Artinian et al as "Revised" (Artinian et al., 2002). Jaarsma et al were aware of Ni et al's work, the *BMCS/BDCS* and the *SMHFI*; however, none were considered short and practical enough for general use. Riegel et al themselves describe the *SMHFI* as a tool for professional clinical assessment and developed the *SCHFI* as a short self report instrument (Riegel et al., 2004). Jaarsma et al's *EHFSBS* and Riegel et al's *SCHFI*

appear, therefore, to be the most practical well-founded tools for self report of clinical self management behaviour.

The theoretical bases for the EHFSBS and SCHFI are different; the terminology used in them also reflects different definitions of self care and self management. As a reminder, I have defined: *clinical self management* as agreed behaviours related to a specific long term condition (heart failure); *generic self management* as general behaviours that could be that related to any long term condition; and *self care* as a set of behaviours related to any attempt to maintain (or improve) health. Jaarsma et al define self care in a similar way (based on Orem, 1995 cited by the authors), but components of what I call clinical self management they call heart failure related self care (HF-Sc) behaviour. Riegel et al claim that there is a difference between everyday *maintenance* behaviour (which EHFSBS measures) and *management* (that is, decision making processes in their terms) required occasionally in response to symptoms. The SCHFI measures both aspects but gives more weight to decision making. A side by side comparison of the EHFSBS and the SCHFI is given in **Table 2.1**. This clearly show the usefulness of the EHFSBS for patients receiving more routine heart failure care with instructions to contact a professional if troublesome symptoms arise and the usefulness of the SCHFI for patients taking full clinical self management responsibilities.

Psychometric testing of the SCHFI (n=760, mean [sd] age = 70.3 [12.3], 51.3% male, hospital and clinic patients from 7 US sites) showed it to be valid and “adequately” reliable. The authors explain that (in their opinion) low internal consistency of the instrument reflects health behaviours that were “largely independent of each other, controlled by different motivators and unstable over time.” In particular, they claim that activity and weight control were clearly subject to influence by factors unrelated to heart failure. This interpretation of the quantitative analysis adds weight to the (qualitative) view that it is important to capture the overall context of care for individual heart failure patients.

**Table 2.1:** Comparison of EHFScBS and SCHFI

Item content	Instrument	
	EHFScBS (Jaarsma)	SCHFI (Riegel)
<i>A. Regular behaviour</i>		
Daily weighing	✓	✓
Low salt diet	✓	✓
Regular exercise	✓	✓
Medication adherence	✓	
Keep weight down		✓
Get flu immunisation	✓	✓
Take a rest during the day	✓	
Limit fluid intake	✓	
<i>B. Symptom recognition</i>		
Symptom noted quickly		✓
<i>C. Contingent behaviour</i>		
Contact doctor or nurse	✓*	✓
Rest	✓	
Reduce salt intake		✓
Reduce fluid intake		✓
Take extra diuretics		✓
Effectiveness of action		✓
<i>D. Confidence...</i>		
...in symptom evaluation		✓
...in recognising change		✓
...taking action		✓
...evaluating effectiveness		✓
	12 item 5-point scale	15 item 4-point scale

\* Four separate items. Contact in response to: increased shortness of breath, ankle/leg swelling or fatigue; or 2kg weight gain in 1 week.

For Riegel et al the key to successful real world decision making is symptom recognition, which studies reported in **Section 2.2.2** suggest is the most positive feature of patients' current knowledge. However, they thought that heart failure patients are prone to false assumptions about their health status, because the initial symptoms of

decompensation can be subtle, which leads to hospital admission. The SCHFI excludes rest after symptom recognition, which the EHFScBS includes, because its authors believe this action is intuitive and requires little thought. If so, rest should be universally reported among heart failure patients as one of the very first things they do when symptoms become troublesome.

A set of questions asking how “worrisome” or “important” (both qualifiers were independently tested) certain common symptoms were for patients was deleted from the final version of the SCHFI. Riegel et al still think that such symptom evaluation is important but couldn’t find a reliable way to measure it. They suggest that parallel completion of a knowledge scale could be enough to assess patients’ abilities in this regard. Some such scales are noted above and others have been developed (Lainscak & Keber, 2005) (van der Wal & Jaarsma, 2008). The SCHFI authors state that their questions about confidence (**Table 2.1**, Section D) measure self-efficacy, which is predictive of performance. The source of this understanding is literature influenced by and reviewed by Lorig and Holman (Lorig & Holman, 2003), which is also the source of the UK’s Expert Patients Programme (cf. **Section 2.5**). Four items were deleted from the final instrument because they showed little response variability:

- take medications as directed;
- keep medical appointments;
- avoid tobacco; and
- avoid drinking alcohol.

It is suggested that positive responses to these items were seen as socially desirable by volunteers completing the instrument following a medical request. It is also suggested that reducing alcohol and tobacco consumption is widely understood general health advice.

The existence of these scales shows that there are practical ways to assess self management behaviour. However, in my opinion the variable conceptual underpinnings reflect different professional attitudes towards to engagement of patients in active

decision making. It seems that US practice is more positive towards patient involvement, which may relate to a more consumer focused healthcare economy.

#### **2.2.4 Capacity to learn about self management**

Cognitive, physical and affective capacities are the abilities or willingness to learn in the respective domains of knowledge, skills and attitude. For heart failure patients, who are typically older (Cowie et al., 1997) and suffer from other long term conditions like lung disease (Dan et al., 2008), there are *prima facie* reasons to question each component of overall capacity. Stereotypically, older people may be expected: to have failing memories and reduced physical function; and be unwilling to learn new things. Co-morbidities such as arthritis in major joints can clearly make many practical tasks more difficult, for example, bending to pick up objects or use weighing scales. Co-morbidities may also add to the complexity of treatment, making patients feel less able to understand their own care.

Stereotypical perceptions are reflected in comments older people themselves made to Rogers et al, who report feelings that heart failure symptoms were an inevitable consequence of growing older (Rogers et al., 2000). The same patients reported transport difficulties that prevented access to healthcare premises and hence verbal advice, for example, walking long distances, using buses and not liking crowds. They also reported confusion and short term memory loss, meaning that intentions to ask questions were not reflected in behaviour. Barry et al report so called “unvoiced agendas” as a common feature of patient-professional consultations in general (Barry, Bradley, Britten, Stevenson, & Barber, 2000). However, they relate this to social issues such as the difference in language used during (a) the artificial context of the consultation and (b) the real world in which a patient is more fully herself. The authors imply that the research interview is located more in the real world than the medical one.

Heart failure has been associated with cognitive impairment independently of age (and other risk factors) (Cacciatore et al., 1998), which can have an affect on mortality among patients admitted to hospital (Zuccalà et al., 2003). A review of the literature suggests an inconsistent relationship between LVSD and cognition; and interpretation

of studies is hampered by poor design (Bennett & Sauv , 2003). Even so, moderate to severe cognitive impairments are common in heart failure patients (reported prevalence is up to 25%), which include: memory and attention deficits; slowed motor response times; and difficulties in problem solving (Bennett & Sauv , 2003).

The functional status of adults with common long term conditions has been investigated in a large US study (n=9385 patients, n=362 physicians in three cities). For eight out of nine conditions, patients with long term conditions had worse physical, role, and social functioning than patients without long term conditions. The profile of heart disease patients was the worst and the profile of hypertension patients was the best. The adverse effects of multiple conditions were synergistic, however, within group variations could not be explained (Stewart et al., 1989). Therefore, although on average patients with long term conditions could expect to have worse functional status than controls, there were individuals who had relatively good levels of function. The functional status of advanced heart failure patients (NYHA Class III or IV) can be improved by a comprehensive disease management programme that includes daily weighing and diuretic dose adjustments with other components of clinical self management (Fonarow et al., 1997). One independent risk factor for poor functional status in heart failure may be anaemia (Horwich, Fonarow, Hamilton, MacLellan, & Borenstein, 2002).

Self evidently, affective capacity can be influenced by serious and enduring mental health problems (psychoses), less serious mental health problems (neuroses such as anxiety, depression and phobias), and personality. The likelihood is that a diagnosis of psychoses would be at least as serious as heart failure itself: respective specialist-led treatments could take equal priority. Therefore, the influence of serious and enduring mental health problems on heart failure is of less interest in the context of this thesis. Dementia can be included in the category of serious mental health problems (Soliman, 1998) or considered a group of neurological symptoms with various causes (National Collaborating Centre for Mental Health, 2007). It will no doubt have a growing impact on the treatment of (non-neurological) long term conditions as the UK population ages, but in my opinion the nature of dementia precludes a lot of self management activity.

Depression is a common less serious co-morbidity, 13-48% prevalence in heart failure out-patients (Gottlieb et al., 2004), which is usually treated by generalists. Its influence on heart failure has been investigated, more so than anxiety – which appears to be less problematic (Coelho et al., 2005). Depression in heart failure patients is reported to be a strong predictor of worsening short term outcomes (Rumsfeld et al., 2003). Gottlieb et al state that in their study (n=155 out-patients, aged 33-85) depression was more common in young patients, matching a pattern in the US general population. They explain that, adverse life events are common for older people (death of others, loneliness, losing physical strength), but that younger people experience a greater disparity between functional status and expectation. Accepting symptoms and associated functional decline seems to help maintain (or even improve) overall quality of life in older people (Gottlieb et al., 2004).

In the scenario just outlined heart failure may lead to depression but depression may also have an adverse impact on heart failure management. For example, depression may contribute to poor self care behaviour (diet, smoking, exercise, adherence) or have a direct clinical effect on the immune system, which thereby increases infection rates and acute cardiac events (Lane, Chong, & Lip, 2005). Regardless of the direction of influence, interventions that improve the symptoms of depression are likely to have a significant impact on quality of life in heart failure patients. However, I think that the central principle of clinical self management, that one's own actions can influence outcomes, has the potential to destabilise older people's health expectations. The thought that heart failure symptoms are under one's locus of control could increase short term depression (via frustration in reduced physical capacity), which would only be alleviated if and when self management strategies were effective. An additional complication is that women with heart failure appear to be more likely to be depressed than men (Gottlieb et al., 2004) (Riedinger, Dracup, Brecht, Padilla, & Sarna, 2001). Men and women appear to cope differently with heart failure symptoms, but the mechanisms of influence are far from clear (Murberg, Bru, Aarsland, & Svebak, 1998) (Riedinger et al., 2001). More general variations in heart failure management care between the sexes are also poorly understood (Rumsfeld & Masoudi, 2004).

The final broad influence on affective capacity is personality, which many psychologists now classify into 5 general factors (Digman, 1990): openness, conscientiousness, extraversion, agreeableness, and neuroticism (OCEAN). The model is descriptive rather than explanatory, but the factors do have potential links with illness coping strategies in general and clinical self management in particular. Openness relates to the acceptance of new ideas and experiences; conscientiousness relates to self discipline and planned behaviour; extraversion is the extent to which one interacts with others; agreeableness suggests a desire to be co-operative and not seek ulterior motives; neuroticism relates to the tendency for adverse events to trigger emotional responses (Digman, 1990). *A priori* it appears that clinical self management may appeal most to people with: high scores for openness, conscientiousness and agreeableness; balanced scores for extraversion (learn from others, potentially cope alone); and low scores for neuroticism.

### **2.2.5 Health literacy**

As a consequence of their capacity, education and experience people are endowed with and/or develop what is often known as ‘health literacy’. The definition and importance of health literacy require some explanation because the concept is contested (Nutbeam, 2008) (Tones, 2002). In common use ‘literacy’ usually refers to the skills required to read, write and speak; whereas to be ‘literate’ implies a high level of education (Tones, 2002). When first conceptualised ‘health literacy’ expressed the desirability of school health education that would allow students to understand health to the same level as more traditional academic subjects (Simonds, cited by Tones, 2002). The concept then generally acquired a more limited meaning as the skills required to read and comprehend patient information, for example, labels, leaflets and letters (Selden, Zorn, Ratzan & Parker, 2000) (Tones, 2002). Subsequently, the concept broadened again to include decision making based on prior reading and comprehension (Zorn, Allen & Horowitz, 2004) and/or emancipatory action to achieve political change (Tones, 2002) (Nutbeam, 2008).

In so far as health literacy has become an emancipatory concept, it is (in some circles) almost synonymous with (or at least a pre-requisite for) patient empowerment (Tones, 2002). Tones (2002) argues that this conceptualisation is too broad, and encroaches on

territory already occupied by more useful specific concepts, for example, problem solving, decision making and community empowerment. Nutbeam (2008) describes narrow definitions of health literacy that reflect 'clinical risk' and broad definitions that reflect 'a personal asset'. If viewed as a clinical risk, we could consider a patient's (relatively stable) level of health literacy as a limiting capacity that allows education up to a certain level. If viewed as a personal asset, we could consider health literacy either as a goal or a developmental capacity. Nutbeam (2008) describes how the former has roots and application in clinical care, while the latter has roots and application in public health.

Health literacy as a risk factor can be measured in various ways and even considered a 'vital sign' alongside one's pulse or blood pressure (Weiss et al, 2005). There is some evidence from systematic review that assessed health literacy is associated with poor health outcomes, but study design in this field is relatively weak; studies are generally cross sectional and fail to account for confounding factors (DeWalt, Berkman, Sheridan, Lohr & Pignone, 2004). Two high quality studies have linked low health literacy to low levels of disease state control and medication adherence, but (as well as weaknesses in design and analysis) people with low health literacy are underrepresented in many studies (Keller, Wright & Pace, 2008). It seems that the poor quality of evidence (in conventional scientific terms) leaves measures to improve health literacy (narrowly defined) resting on a moral and philosophical imperative. Health literacy can be considered desirable for its own sake, but we cannot (thus far) prove its development is either necessary or sufficient for good clinical outcomes.

Despite conceptual conflicts and scientific limitations, developing health literacy in healthcare practice may also act as a gateway to more active patient participation in their own clinical management. A 'narrow' definition of health literacy equates to the first level (functional literacy) in a framework promulgated by Nutbeam (2000), which is reproduced here:

- functional literacy - sufficient basic skills in reading and writing to be able to function effectively in a health context;

- interactive literacy - more advanced cognitive and literacy skills (with social skills) used to participate actively in health care, to extract information and derive meaning from different forms of communication, and to apply information to changing circumstances; and
- critical literacy - the ability to critically analyse and use information to participate in action to overcome structural barriers to health.

In this framework, the higher levels incorporate and transcend the lower. Hence, the development of health literacy becomes a force for personal empowerment and collective change, especially with respect to improving the health of disadvantaged populations (Coulter & Ellins, 2006). However, improving health literacy is only one of seven “patient-focused quality enhancing interventions” (Coulter & Ellins, 2006), the others being improving:

- clinical decision making;
- self-care;
- patient safety;
- access to health advice;
- the care experience; and
- service development.

It is easy to see from this list, and other discussions in this chapter, how these activities can overlap and interact in complex ways. More straightforwardly we may be able to tell patients that developing health literacy involves the following sequential activities:

- obtaining written and verbal information (access);
- listening and reading;
- comprehension (understanding)
- evaluation and/or adaptation;
- decision making and communication with others;
- taking personal action based on intentions; and
- encouraging change in care services and information provided.

Arguably, all healthcare professionals have a valuable role to play determining patients' current position on this ladder and supporting (if not actively encouraging) progress to higher levels: if this is both desired and achievable. For me, this poses difficult questions about the appropriate level of paternalism and empowerment for each individual patient and in each individual situation. Also, given limited resources should we devote increased time to supporting some patients at higher levels of self management, or alternatively to bringing all patients up to some more equal lower level?

## **2.3 Patient experience**

Patients with heart failure are called upon to continue and/or adapt their lives in the face of pervasive symptoms requiring complex treatment. I think that it is important to review this experience in context and identify any gaps or uncertainties in their own awareness. Major features in this landscape are: symptom experience, associated functional limitation, knowledge about the condition, knowledge about treatment, the potential for self management and general coping strategies. Several qualitative studies have explored the area, some in a more focused way than others. Each study is discussed separately to maintain its integrity and keep clear links with context. However, the section headings provide a guide to study focus wherever possible.

### **2.3.1 Symptoms and limitations**

Thornhill et al investigated the experience of diagnosis and living with heart failure among 25 in and out-patients (aged 35-83, 21 male) from a UK hospital (Thornhill, Lyons, Nouwen, & Lip, 2008). Most qualitative studies in this context claim to use some variation of grounded theory and constant comparative analysis, leading to data saturation. Thornhill et al (2008) claim to use interpretive phenomenological analysis (IPA), which seems to reflect their interest in recommending psychological support for patients (IPA is used mainly by psychologists). They cite prior qualitative studies (Stull et al, 1999; Mahoney, 2001; Zambroski, 2003 all cited by Thornhil et al, 2008) as demonstrating a process of adjustment for heart failure patients. Descriptions of the process vary but the broad stages relate to: the crisis of an acute event; the initial uncertainty about diagnosis and treatment; and effective long term care.

Thornhill et al (2008) identify four main themes: the diagnostic process; change in activities; the role of others; and emotional reactions. Symptoms were initially attributed by patients to non-cardiac causes, which was consistent with previous work. Some medical confusion was apparent around diagnosis but this did not appear to influence patient satisfaction. It was difficult for some patients to come to terms with their diagnosis as a serious condition. Activity limitation showed some gender specific characteristics. It appears that the relative level of limitation (old self perception versus new reality) may be more important than absolute functional status. Patients often coped by maintaining the nature of activities but slowing the pace down. While some expressed regret over limitations, others were determined to remain positive and adapt their lives. For those in prior employment, a change in the nature of routine activity was particularly significant. Some felt that their identity and outlook had changed, but for others identity was unchanged and internal. Functional limitation could lead to significant changes in social roles for patients and their carers. Social relationships (and activities) were reported as particularly important aspects of coping, but help from others could be unwanted and intrusive. Despite this risk, the authors conclude that more emotional support from similar patients or healthcare professionals could be beneficial. It is suggested that avoiding the potential consequences of their condition helps patients manage in the short term but could make long term adjustment problematic.

Thornhill et al (2008) conducted their study to fill perceived gaps in the literature about the “lived experience” of heart failure in UK patients. The authors were sensitive, therefore, to the contextual limitations of qualitative research work and they explicitly discuss the need for reflexivity during data collection and analysis. They describe their interviewer as a young female who was naïve with respect to heart failure. This naivety is seen as beneficial: leading to wide ranging discussion with participants. However, since most of the participants were older men, it was thought that some topics may have been avoided. The interviews were also conducted in the hospital setting (among patients currently receiving hospital care, for example, rehabilitation); it was thought that this context may have influenced the nature of the discussions. The possibility is raised that different responses would have been elicited if interviews had taken place in the home and participants were not so clearly labelled ‘patients’.

### 2.3.2 Knowledge about heart failure

Rogers et al (2000) carried out a qualitative study of heart failure patients' knowledge (n=27, aged 38-94) in the UK; their patients were recruited from out-patient clinics and hospital wards. The authors had difficulty recruiting older females and 20 of their patients were male. The main lack of knowledge identified was the erroneous belief that nothing could be done about heart failure symptoms. Patients had problems applying a well-founded general knowledge about cardiovascular risk factors (what is called 'coronary candidacy') to their own personal experience. Instead people explained decreasing capacity (physical and cognitive) in terms of increasing age. Patients had little idea about their prognosis although some showed an interest in such information.

Whereas, Thornhill et al (2008) did not target or report on patients at any particular stage of heart failure (**Section 2.3.1**); Rogers et al (2000) targeted patients with NYHA classification II, III or IV (cf. **Section 1.3.1**) and all those recruited had at least one co-morbidity. Rogers et al (2000) used hospital admission within the past 20 months as a participant inclusion criterion. Like Thornhill et al (2008), Rogers et al (2000) comment that most studies reporting on heart failure from the patients' perspective have been conducted in the USA. Rogers et al (2000) used a constant comparative approach in which data was collected and analysed concurrently. Although this allows emergent themes to be incorporated in subsequent interviews, the authors do not explicitly consider the impact of context on those themes. They do state that their findings are not necessarily representative of a larger (or different) population, but claim some reliability from the identification of general themes, for example, poor public knowledge of heart failure and doctor-patient communication issues.

Agard et al investigated medical knowledge and attitude towards information among 40 heart failure patients (aged 60-80, mean age 75, 25 male) recruited via the cardiology department of a Swedish hospital (Agard, Hermeren, & Herlitz, 2004). The general level of knowledge was low, and many did not want to be better informed. In this regard patients could be indifferent, unaware, consider themselves incapable or prefer professionals to take charge. Patients were generally satisfied with information that they had received (only two were critical), some encouragement revealed unvoiced agendas.

Further prognostic information was unwelcome because, for example, it was unalterable or led to hopelessness. A minority considered the right to be informed and plan ahead important. The authors recommended a measured education strategy, providing essential information that can be built upon when the patient is ready, that is, to both tell the truth and preserve hope.

Agard et al's (2004) paper is published in a specialist medical journal (Heart and Lung) and the authors felt the need to justify a qualitative (or as they actually call it "empiric") approach. They think that normative ('should do') analysis needs to be informed by careful consideration of situations that arise in everyday life. Their methods of data collection were a little irregular and leave them open to a (surprisingly) justifiable charge of bias. I say surprisingly, because I have heard (as Chair of an NHS research ethics committee) medical professionals describe qualitative methods as biased, when they fail to understand the value of work carried out in particular context. However, Agard et al's interviews were not tape recorded and only "statements regarded as essential were written down literally." This runs a risk of missing important statements (which may seem trivial at the time) and making inaccurate contemporaneous notes; both of which are likely have a direct (and limiting) impact on the findings.

### **2.3.3 Knowledge about treatment**

Simpson et al explored the beliefs and attitudes influencing adherence behaviour in Canadian heart failure patients (n=26) in four focus groups recruited from heart failure (n=3) and family practice (n=1) clinics (Simpson, Farris, Johnson, & Tsuyuki, 2000). Heart failure had caused patients to make many changes their daily activities, which were unexpected and could be frustrating. However, several developed coping strategies and monitored limitations carefully. The effects of diuretics were particularly troublesome and doses were modified to minimise disruption of social events, confirming previous findings (Stromberg, Brostrom, Dahlstrom, & Fridlund, 1999). Patients reported that their medication adherence improved if they: knew and trusted their professional carers; learned all they could about their disease and its treatment; experienced few side effects; had good social support; and professionals used clear lay language. Patients used written information from initial consultations as an accessible

reference source. Some patients used their own systems or containers (for example, cups) to facilitate medicines taking. Professional contact by phone was considered acceptable, if the professional was known to the patient and had prior permission to call. Patients strongly supported support groups where they could learn from each other.

Simpson et al (2000) tried to be inclusive by recruiting both asymptomatic (low NYHA classification) and symptomatic (high NYHA classification) patients; and including some patients from family practice. However, only five patients came from family practice and the majority of discussion was focused on medicines use rather than more general experience of heart failure. The way in which the authors guided the topic and the use of focus group methodology led to the identification of practical barriers to medicines adherence. These barriers are, however, presented in a way that is (largely but not completely) abstract and decontextualised. We learn a little about why people behave as they do with respect to medicines, but almost nothing about what might influence them to change more generally.

Rogers et al (2002) reported that patients (a separate report but the same patients as those above in Rogers et al, 2000) understood little about their medication. The symptoms patients reported (shortness of breath, fatigue and pain being the most common) were attributed to age, heart failure or side effects; but patients found it hard to distinguish between causes. None of the patients recalled being given information about when to contact their doctor, and symptoms were tolerated for sometime before seeking help. Patients showed little understanding of the importance of fluid retention and only one had been given advice about diuretic dose adjustment. Most patients could confidently modify the *timing* of diuretic doses to avoid embarrassing incontinence in social situations. Some patients were alarmed after reading their medicines' patient information leaflets, especially if they seemed to be taking unapproved doses and combinations. This contrast with Simpson et al's US study (Simpson et al., 2000) regarding written information might be explained by the different content of medicine leaflets in the UK and US (Raynor, Svarstad et al., 2007). Critical comments already made in **Section 2.3.2** about Rogers et al (2000) apply equally to this aspect of their over arching study.

Varma et al explored knowledge, medication, lifestyle and medical care with 29 older (over 65) heart failure patients (13 female, 16 male) from six Northern Irish general practices in seven focus groups (Varma, McElnay, & Hughes, 2001). Patients' lifestyles had been dramatically affected by the condition. Walking was the activity most limited by shortness of breath and fatigue. Knowledge was found to be generally poor, indeed 8 patients knew nothing at all about heart failure. Smoking was viewed as harmful to those with heart failure, rather than an important cause of the condition. Patients were generally happy with their medication but rarely demonstrated detailed knowledge of it. Only patients with lower grades of heart failure (NYHA I and II) reported side effects. Most patients wanted more information about their medicines. Smoking and drinking were generally avoided, salt and fluid were not mentioned as dietary changes. Control of the condition was felt to be the doctor's responsibility and most were pleased with the care they received. Although more information was considered desirable, patients felt they should ask professionals for it as and when required.

From my perspective Varma et al's study has many positive features: recruitment is from general practice, all grades of heart failure are included, there is gender balance and it is from the UK. However, some reflection (by the authors) on the potential impact of the researcher on data collection would be beneficial. The authors do state: "At the beginning of the focus group session, the moderator created a thoughtful, non-threatening atmosphere and the set the tone for the discussion." They do not state how this was achieved. There is a contrast between this positive/neutral assessment of researcher impact and Thornhill et al's (2008) (**Section 2.3.1**) more considered judgement. Also the focus groups were conducted in a medical setting, assumptions underpinning the analysis were not considered and in the results 'key phrases' (which patients used) are listed largely out of context.

Reid et al (2006) investigated medicines management among 50 heart failure patients (aged 41-80, mean age 67.1) recruited via out-patient cardiology clinics in Scotland. Poor knowledge was apparent and few patients used the term heart failure, which was interpreted by some (but not all) as a finite event rather than a process. Patients reported not being given a direct diagnosis or seeing many professionals before it became apparent (Clark & Lan (2004) similarly reported that 25% of their patients didn't have a

diagnosis). Patients experienced the usual range of symptoms but only the effect of diuretics on these symptoms was well understood. Patients experienced two general medication related issues: remembering to taken daily medicines; and ensuring an on-going supply of medicines. They had two types of strategy to deal with this complexity: the creation of routine, including box (MCA) systems recommended by carers; and back up checks (visual clues and verbal prompts) to ensure that medicines were taken at the appropriate time. Adherence was high apart from diuretic dose timing (as previously reported) and occasional distractions breaking the usual routine. Adherence was, therefore, flexible and linked to particular daily circumstances; fluctuations in adherence did not indicate a lack of commitment to medicines taking.

A number of factors support the quality and relevance of Reid et al's study: it is from the UK; the authors stated a specific theoretical approach (constructivist); numbers of patients were relatively large (50); separate carer interviews were conducted; most interviews were conducted in the home; and methods of analysis were clearly stated (constant comparative method and data saturation). The inclusion criteria seemed likely to capture the perspective of the average or typical patients, but exclude extremes. Recruitment was from patients with LVSD only (the most common cause of heart failure) with NYHA classification II or III: excluded the asymptomatic (NYHA I) and the most symptomatic (NYHA IV). Patients over 80 were excluded (along with those cognitively impaired) because of the *risk* of cognitive decline. In addition, those recruited were current out patients with a history of admission.

Field et al have investigated understanding about medicines in 37 UK patients (aged 35-85) recruited via generalists and specialists in primary and secondary care (Field, Ziebland, McPherson, & Lehman, 2006). Field et al recruited patients from around the UK and sought maximum variety in their sample. All stages of heart failure are represented and some patients were uncertain of their diagnosis. The researchers had no access to medical notes to confirm or support any findings or demographics. Strangely the gender balance in the sample is unreported; but most of the participants were White British (n=32); and those in professional, skilled and non-manual jobs predominated. The analysis is comprehensive and results are presented in some individual context, but organisational context is lacking because of the sampling method employed.

Patients expressed uncertainty about their diagnosis, often calling it a “heart problem”. All patients understood the importance of medicines and had developed systems to facilitate adherence. Men sometimes left this organisation to their partners. The authors identified three levels of medicines awareness:

- Level 1, did not know name, purpose or side-effects;
- Level 2, knew name and main side effects, but relied on doctor;
- Level 3, understood diagnosis and committed to learning more.

Those at Level 1 and 2 did not demonstrate interest in learning more, nor did they have unanswered questions. All levels included people with different characteristics, rather than there being a clear relationship with education, occupation or age. Gradually deterioration led some patients towards the point of hopelessness, at which point they might prefer professionals to support them. Field et al think that their levels corresponded to the coping strategies identified by Buetow et al (Buetow, Goodyear-Smith, & Coster, 2001), which are set out below. However, the conceptual correspondence appears weak apart from ‘Level 1’ and ‘avoidance’. It is not clear whether Field et al have missed the point of Buetow et al, or if the latter’s data is being selectively interpreted.

### **2.3.4 The potential for self management**

Riegel and Carlson (2002) set out to: explore the impact of heart failure on people’s lives; assess self care behaviours; and determine how life situations influence care. They interviewed (one to one and in small groups) 26 patients (aged 56-91, mean age 74.4, 65.4% male) recruited from patient records and research study lists in a large US health system. They assumed that previously hospitalised patients (all 26) received heart failure education during admission and that study participants received additional education. This method of recruitment means that those interviewed were both sure of their diagnosis and familiar with attempts to improve disease management. However, they are described as mainly “elderly, retired, male and poor” and thus not (perhaps) typical self managers. Transcribed interviews were subjected to content analysis. However, the authors make some attempts to link themes identified and relate them to patients’ personal circumstances.

Heart failure was associated with: physical limitations, problems coping with treatment, lack of knowledge, distress, co-morbidity and personal struggle. Concerning self care, patients recognised a range of symptoms but had problems attributing them to a particular condition. Keeping daily weights and understanding their significance was rare. Adherence with recommended treatments was high (for example: medicines (especially), diet and exercise). Diuretic doses were adjusted to fit in with activities and a range of prompts were used to facilitate medicines adherence. Patients adapted their lives by walking less, trying to learn about their conditions and drawing support from others. Health monitoring behaviour was evident and few complained about their professional care. General coping strategies reported were: ignoring the problem, withdrawing from social interaction and accepting inevitable consequences. They suggest that patient motivation to self care requires enhancement and that barriers to self care are not fully acknowledged professionally (Riegel & Carlson, 2002).

Bennett et al also focus on symptom experience and self care strategies for 23 US heart failure patients (16 male, mean age 60) in 6 focus groups with 18 family members (17 female) (Bennett, Cordes, Westmoreland, Castro, & Donnelly, 2000). Participants were out-patients recruited from a specialist heart failure clinic and a general medicine clinic. The specialist clinic was associated with a veterans (military) health centre and all patients from this source were men. However, the general clinic served a mixed population, and overall one third of the participants were African American. This helps to provide a voice in the literature for minority ethnic groups. The method of analysis was similar to Riegel and Carlson (2002), but Bennett et al (2000) make less effort to link themes and contextualise their findings.

Concentration and memory problems were the most frequent symptoms apart from shortness of breath, swelling and diuretic side effects. The unusual report of loss of balance or falling (as common as pain and tiredness) caused the authors to speculate about potential side effects from anti-hypertensives and diuretics. Depression was reported and some sessions were tearful. Sleep and sexual activity were disturbed. Some management strategies were common to other conditions, for example, reducing activity levels. Timing of diuretic doses was adjusted to fit with planned activity, but patients used varied methods to facilitate general medicines adherence. As might be expected

self monitoring of symptoms was more common and consistent for heart failure clinic patients, which may be influenced by both the quality of care and the fact that the patients were armed services veterans (or their relatives). Women were helped by children or siblings, whereas men were helped by their wives. Some patients used “positive talk” to maintain hope, which seems similar to disavowal (see below). An accepting attitude was important for both women and men. The nature and range of symptoms, limitations and strategies reported by Bennett et al is somewhat atypical, which seems likely to be a function of holding focus groups together with family members.

### **2.3.5 Coping strategies**

Buetow et al (2001) specifically set out to identify the coping strategies (as conceptualised by Lazarus and Folkman (1984) cited by the authors) employed by heart failure patients (n=62) from 30 general practices in New Zealand. Buetow et al (2001) used a multi level (practice, GP, patient) quantitative sampling strategy that could have produced a representative sample with larger numbers of participants. As it is they claim to have maximized variability in response but less efficiently than by using (qualitative) theoretical sampling. Why they decided to use a less efficient sampling strategy is unclear. What is clear is their specific purpose to generate a framework for coping by systematically editing the patients’ narratives. The results, therefore, while interesting and useful for the purpose, are a little abstract and stripped of (some but not all) context. The authors created the narratives from written field notes, because of concern that audio taping might distress elderly patients. This does make it difficult to ensure the completeness of the analysis and to verify their interpretations.

With particular regard to the need patients have to mentally manage the threat of heart failure, they identified avoidance (Field et al’s Level 1, see above), disavowal and acceptance. The deliberate avoidance of information minimised the risk of an emotional response. This strategy was important for older patients (over 70) with a long standing diagnosis (over 3 years) and mild limitation; but also if limitation had recently worsened. Patients using avoidance asked few questions, were happy to take medicines

as directed and remained unconcerned about dependence on others. This reduces short term anxiety at the expense of long term decision making capacity.

Disavowal is a rather more subtle process of “healthy denial”, in which the perception of threat is accurate but its meaning is re-framed more positively. This wasn't influenced greatly by age, duration, severity or sex; which may suggest it is a function of individual personality type. However, Buetow et al report that it was most important for younger patients (under 65) with a recent diagnosis (less than 3 years). Holistic concepts of health (physical, mental, social or spiritual) and medical uncertainty were sources of disavowal. The conspicuous success of modern medicine influenced recently diagnosed patients in their 50s with well controlled symptoms: one man talked about his diagnosis in the past tense following successful surgery and medication, without denying the potential seriousness of the situation. Spirituality could blur disavowal and acceptance, especially in very old patients with long standing illness, who might look forward to a ‘new life’ beyond. Whether intended or not, medical euphemism or failure to communicate a clear diagnosis could help patients maintain a positive outlook.

Acceptance takes on the validity of medical advice without any positive re-framing. Mainly older patients (in their 70s) resigned themselves to the threat of heart failure, especially if diagnosed for some time (over 3 years) and causing only mild limitation. This approach could be characterised by a certain fatalism and lack of regret; or else dread relieved by distracting activities including humour. The strategies employed were not mutually exclusive. The effectiveness of the strategies (alone or in combination) is not well understood, but maintaining hope (for example, by disavowal) is reported to improve quality of life and may be an ethical imperative. Buetow et al suggest GPs implement individualised hope-focused strategies, for example, story telling and involvement in generic self management activities.

Horowitz et al interviewed 19 patients (aged 52-89, 9 female) from a US hospital to identify knowledge and beliefs about heart failure, and understand what supports self care activity (Horowitz, Rein, & Leventhal, 2004). The hospital was an academic tertiary care centre so we can expect the patients to have received a high standard of

specialist care. Initial sampling from patient records was random (n=50) and interviews then conducted with all those that could be contacted and were willing. Around half the interviews took place in the patients' own homes and half at the medical centre. The coding scheme was developed independently by two investigators and inter-rater reliability confirmed. Study findings were also discussed with participants and clinical experts. White Americans formed a minority of the sample and no one interviewed was NYHA class I (asymptomatic). The analysis presented is detailed and comprehensive.

In their analysis, Horowitz et al explicitly compare the themes they identify with Leventhal's model of self regulation; Horne and Weinman (1999) use the same model to understand medication adherence in chronic illness. Unusually for a qualitative study Horowitz et al have three prior hypotheses, which perhaps reflect their intention to apply a psychological model to the data collected. These hypotheses are (paraphrased for brevity and, slightly more, clarity):

- patients should connect their signs and symptoms to the label "congestive heart failure";
- the timeline, causes and consequences of labelled symptoms should be understood; with a knowledge that worsening symptoms can be controlled by appropriate action; and
- the representation of the symptoms (all the above) should inform planned behaviour to manage short and long term outcomes.

They conclude that patients have an acute model of the condition, whereas a chronic model is appropriate. The three dominant themes from 60 identified were: patients lacked the information required to conform to the prior hypotheses; patients didn't have the tools to prevent exacerbations; and at the point of crisis the emergency room (ER, the equivalent of A&E) was the easiest route to care. Confusion about the nature of symptoms led logically to ineffective action, with the exception of high medicines adherence. US patients at least seem to limit salt in their diet, even if they do not know why, but one patient described using a stock cube as a salt substitute. Of the few patients that weighed themselves regularly, one did not know why or what to do if it increased, as it did by 9 pounds (4 kg) in 1 week. One patient did modify diuretic doses in response to weight changes, but only under the close direction of her cardiologist

grandson and without understanding the rationale. As in Varma et al's study, controlling symptoms was thought to be the doctor's responsibility, and they provided the only regular source of feedback about the condition and its management. Patients didn't lack capacity and seemed to manage other conditions more coherently, for example, variable medicines dosage in relation to angina or diabetes was understood. This seemed to suggest that self-efficacy was insufficient to ensure participation in self care and that patients needed help to develop concrete action plans. Patients commented positively on the standard of care received in the ER (tests, technology, good doctors), compared to the difficulty of organising an office consultation at an appropriate time. Patients also complained about the number of doctors involved in their care and a lack of clarity about who was in charge. Family support did help patients to identify symptoms and take appropriate action, providing a necessary 'push' when the 'pull' towards formal care was wavering.

### **2.3.6 Summary of patient experience**

The published literature reviewed here provides a comprehensive examination of patient issues related to the self management of heart failure. An account of the specific context is often lacking in reports. We also see that studies tend to be focused on specialist care, males and people who have already received a considerable amount of patient education. Consistent features are found to be symptom experience, activity limitation, poor knowledge and variable adherence. A range of coping strategies are reported and some of the (apparently) more successful imply a re-framing of objectively bad news to maintain hope. Managing medicines is an important aspect of the heart failure experience. Most studies reported high levels of medicines adherence and the development of bespoke routines by patients to facilitate adherence. The studies reviewed suggest, adherence does not depend on knowledge, rather it is lowered when normal routines fail. Jerant et al (2005) have investigated the impact of long terms conditions more generally on self management behaviour, they found similar issues to heart failure studies reported above and also financial problems. In general, it seems patients have an acute rather than a chronic model of heart failure: they deal with short term issues; but don't take control of long term outcomes.

## **2.4 Professional and organisational issues**

Whereas **Sections 2.2** and **2.3** have reviewed evidence for patient education and experience, this section reviews professional perspectives on the management of heart failure. This allows us to compare and contrast (different) issues traditionally considered important for patients and professionals. It also provides further details of the context in which the patient perspective has been investigated. The methods used for my later empirical investigation will imply that the division of issues into patient and professional perspectives (that is apparent in much of the literature and used for convenience in this review) can be unproductive.

### **2.4.1 Disease management programmes**

Comprehensive disease management programmes seem to improve outcomes for heart failure patients but results are inconsistent (Yu, Thompson, & Lee, 2006). Yu et al's systematic review (n=21 randomised controlled trials focused on older patients) suggests that successful programmes should be complex, including: a hospital in-patient phase, intensive patient education, self care support, optimisation of medicines, on-going monitoring and management of exacerbations. Self care support included self monitoring activity and interventions focused on medicines adherence. Optimisation of medicines included flexible diuretic therapy. Comprehensive education was defined as covering four or more of: nature of heart failure, risk factor modification, self monitoring, manage exacerbation and drug. Yu et al believe that their results reinforce previous findings that intensive education, self care support and medicines optimisation are the core interventions for elderly heart failure patients.

Concern is sometimes expressed about the ability of patients with low literacy to cope with intensive education (Mayeaux et al, 1996). DeWalt et al (2006) have explicitly addressed this issue in a randomised controlled trial of heart failure self management for patients of all literacy levels. They enrolled 123 patients from North Carolina (64 control, 59 intervention) aged 30-80 who had heart failure and took furosemide (the most commonly used diuretic). Intervention patients received education on daily weight measurement, diuretic dose self adjustment, symptom recognition and response. To reinforce adherence they used picture based education materials, digital weighing scales

and planned telephone follow-up. Control patients received a generic heart failure book and usual care. Rates of hospitalisation and death were significantly lower in the intervention group and the difference was larger (not significantly) for patients with low literacy. They found no differences in health related quality of life.

In DeWalt et al's study 79% of intervention patients (versus 29% of controls) were taking daily weights at 12 months. However, Wright et al (2003) note that in multi-disciplinary heart failure programmes the degree to which individual components are taken up is variable. They investigated the uptake of self management strategies in their programme by assessing (in a randomised controlled trial) diary use, self weighing and knowledge. One hundred (out of 197) patients received the intervention and 100 used the diary of whom 51 weighed themselves regularly. Patients in the intervention group who didn't perform these activities attended clinic less frequently, received less education and had worse outcomes. They recommend that scales should be provided to help self weighing.

#### **2.4.2 Professional education and communication skills**

My search of the literature has revealed that professionals' knowledge about and attitudes towards self management are much less well studied than patients. **Section 2.2.1** reviews the most comprehensive published examination of these issues: various comparisons of patients' and nurses' learning needs assessments. I have been able to find one other study specific to heart failure self management, which assessed nurses' (n=300; 38% university hospital, 44% community hospital, 18% home/hospice) knowledge of education principles (Albert et al., 2002). The authors identified significant gaps in nurses' knowledge and concluded that better education may help them to encourage self management. Doctors' knowledge of self management education principles does not appear to have been investigated. However, GPs' knowledge of evidence based prescribing principles in heart failure has been investigated (cf. **Section 2.4.3**).

It was proposed above (in Section 2.2.1) that to enable participation in clinical self management providing patients with information about diagnosis and treatment may be

sufficient. Professionals may also want to impart *desirable* information about aetiology to promote behaviour change in those with particular risk factors (for example, smokers and those overweight); and prognosis to prepare patients for gradual or sudden change in health status. Communication issues in the context of heart failure have been investigated among a group of patients and professionals in four areas of England (two Northern and two Southern) (Barnes et al., 2006).

Forty four patients (from a larger survey of palliative care services, 23 male, mean age 77) were interviewed one-to-one and nine professional focus groups were conducted for a total of 39 GPs and 37 nurses (Barnes et al., 2006). Communication was particularly influenced by diagnostic uncertainty and complex terminology. Patients generally lacked information, and few had discussed prognosis with a professional. The general opaqueness of communication was contrasted with the clarity observed in cancer care. Symptoms were not specific to heart failure and GPs reported that consultation with different specialists disrupted the flow of information about diagnosis and prognosis. Pragmatic symptom by symptom treatment caused patients to drift towards “heart failure” without needing to hear the actual words.

Their own anxiety caused some GPs to use *more* complex descriptions (for example, left ventricular dysfunction), which left patients confused. Simple euphemisms were also used but not in a consistent way. Some patients found it easier to talk to nurses, who reported that specialist clinics were a good place to give information and discuss problems. A lack of clear early information led patients to be confused and upset if given the diagnosis later, perhaps by professionals they didn't know well in hospital. Some professionals had tried to be both clear and accurate in their descriptions.

Perhaps unsurprisingly, GPs felt prognosis was hard to discuss because the outcomes are so variable and they didn't wish to worry patients. Nurses also felt that the terminal nature of heart failure would cause patients to become depressed and anxious; GPs perceived that patients thought heart problems could be fixed. The problem with this sensitivity is that the main effect of ACEIs is to prolong life (not improve short term well being), so understanding the prognosis might increase levels of adherence. GPs wanted more education that they could pass on to patients. One nurse thought patients

had a right to a clear prognosis, as they would with cancer care. There was professional support for tailoring information to meet individual patient need, noting that older patients may be less proactive in asking questions.

Clearly, the communication difficulties outlined by Barnes et al (2006) are highly important. For patients with long term conditions, confusion from the first point of contact can be magnified and distorted throughout the patient journey (Bodenheimer, 2008). For heart failure, there appears to be a plausible chain linking: vague symptoms, unclear diagnosis, poor understanding, low medicines adherence and early death. In this context, patient education to self manage may not seem a high priority, yet it is a component of most successful disease management programmes (cf. Section 2.4.1). Professionals may hold the view that sharing more decision making with patients can lead to misunderstanding and sub-optimal treatment choices (Guyatt et al, 2004). The promotion of self management seeks to capture the long term benefits of this (perhaps) short term risk, but I think we could understand if frontline professionals were often a little reluctant to set the ball rolling. It appears to me that communicating even the most basic elements of diagnosis and treatment may be fraught with difficulty.

### **2.4.3 Diagnosis and prescribing**

There are a number of studies about barriers to evidence based prescribing in heart failure, which tend to focus on professional knowledge (or perceptions) about effectiveness and side effects (Phillips, Marton, & Tofler, 2004). Pont et al (2003) report more evidence based therapies being used (n=78 GPs) for patients (n=769) with less severe heart failure. Overall, only 36% of patients received the minimum set of evidence based therapies appropriate for their disease severity. More general barriers to providing comprehensive clinical management for heart failure patients have also been investigated. In structured interviews, Horne et al found that for English GPs (n=100) major barriers to optimal management were: uncertainty about diagnosis, lack of awareness of ACEI properties and poor hospital discharge information (Horne, Coombes, Davies, Hankins, & Vincent, 1999).

The role of ACEIs has since become more widely understood. However, Kasje et al show that GPs (n=58 in The Netherlands) still have problems starting this medicine and optimising its dose. Interestingly, variations in practice could not be explained by the barriers reported (Kasje, Denig, *de Graeff*, & Haaijer-Ruskamp, 2005). In another study, Kasje et al report that variation in ACEI prescribing is more closely linked to patient (n=735) than GP (n=95) characteristics, for example, young age, male sex and existence of co-morbidity. Patients who visited a cardiologist or specialist heart failure clinic were also more likely to be prescribed an ACEI (Kasje, Denig, *Stewart*, *de Graeff*, & Haaijer-Ruskamp, 2005).

Fuat et al conducted 4 focus groups with 30 GPs in the north-east of England to explore barriers to heart failure diagnosis and management (Fuat, Hungin, & Murphy, 2003). They identified the following types of difficulty: lack of confidence (about diagnosis) and worry (about drug effects); lack of awareness about research findings and concern about their applicability to primary care; and the influence of personal preference or organisational factors. Local factors included: interaction between primary and secondary care; access to diagnostic services; and accessibility of specialist care. All of which seemed to influence decision making. Khunti et al interviewed 38 GPs in central England, and like Fuat et al their focus was diagnosis and management of heart failure (Khunti, Hearnshaw, Baker, & Grimshaw, 2002). Obstacles to management included: diagnostic uncertainty, lack of time, confidence in ACEI initiation, the cost of medicines and selection bias towards young people. A qualitative postal survey of 200 primary care physicians in five European countries also reaches similar conclusions highlighting as barriers to good care: a “low tech” approach to diagnosis based on symptoms; lack of access to diagnostic equipment; and under use/under-dosing of ACEI (influenced by risk perception) (Hobbs, Jones, Allan, Wilson, & Tobias, 2000).

To resolve under-performance, related to diagnosis and subsequent prescribing, by GPs and hospital doctors, Hobbs (2000) suggests guidance is needed on how to select people for specialist referral; and enhanced diagnostic tools to stratify patients by risk. I think it is probably safe to assume that GPs’ recommendations to self manage are as variable as their prescribing performance. From the GP’s perspective specific barriers to self

management may be analogous to (or even the same as) more general barriers identified by Khunti et al (2002), for example, we can derive:

- uncertainty about diagnosis, so that self management of “heart failure” cannot be easily discussed;
- lack of awareness about the benefits of self management;
- worry about the adverse effects of self management;
- lack of confidence to guide patients in self management;
- lack of time to explain self management;
- assuming that only younger patients will be interested; and
- poor communication with secondary care, so that self management messages are inconsistent.

In a general qualitative assessment of why GPs (n=18 in south-west England) do not implement evidence six themes were identified (Freeman & Sweeney, 2001):

- personal and professional experience, for example, ill health in the GP’s family and prior treatment success or failure;
- the patient doctor relationship, including some paternalistic judgements about what certain patients want;
- perceived tension between primary and secondary care, reflected in a believe that consultants treat diseases not patients;
- feelings about patients and evidence, including anxiety about doing the right thing;
- logistical problems, for example, the “hassle” of extra consultations after treatment changes; and
- use of language, that is, the precise words needed to “sell” an idea or persuade a patient.

Generally, it seemed that GPs saw their role as interpreting or modifying evidence based treatments to match the assumed preferences of patients. Rutten et al noted that GPs often treat more elderly female patients than cardiologists, use fewer investigations and prescribe less effective medicines (Rutten, Grobbee, & Hoes, 2003). Since patient

demographics only explain some of this variation, they suggest that physicians' attitudes are an important factor. For GPs, maintaining a stable positive relationship with individual patients may be the over-riding concern, rather than rigidly applying evidence based management strategies. Patients strong negative associations with the words "heart failure" are significant in this regard (Cowie & Zaphiriou, 2002) (Barnes et al., 2006). Whereas communication between primary and secondary care (inter-organisational) has been identified as a barrier in a number of studies, more recently the role of specialist nurses has been growing, this raises the possibility of inter-professional barriers. In the context of heart failure, Sanders and Harrison (2008) reported that specialist doctors and nurses are engaged in a (covert) discourse to establish practice scope and organisation.

Noting the health policy support for self care Greaves and Campbell (2007) provide a general review of steps GPs can take to support related activities. In their opinion the important issues, for practices that have made a commitment to self care, are:

- group or individual intervention, groups may be cost-effective if the messages are simple and apply to all patients;
- matching intensity to need, targeting intensive interventions at high risk patients or conditions;
- lay-led or shared decision making, the concordance model (see above) is recommended as sensible;
- practice systems, preparing the practice team for changes in practice;
- letting go, allowing patients to make an informed choice not to participate in self care.

There has been at least one investigation into professionals' views about self management action plans, however, it is in the context of asthma rather than heart failure (Jones, Pill, & Adams, 2000). Nurses (n=13 asthma nurses) consistently noted the importance of patient education and monitoring, which they had the time and expertise to provide in specialist clinics. They all claimed to provide some sort of written self management plan for patient who understood their condition, had high levels of medicines adherence and were regularly reviewed. GPs (n=11, six with an

interest in asthma) were unenthusiastic about self management plans in general and standard (rather than bespoke) plans in general. They supported patient education but thought patients had limited capacity to cope with self management. They worried about the adverse effect of written plans on the doctor-patient relationship, seeing them as a potential signifier (perhaps a prescription also has this function) that discussion is closed. Patients (n=32) in this study thought self management plans were useful for others but not themselves, and very few recorded and monitoring their symptoms (this behaviour had lapsed). They felt that they were already self managing in other ways and saw nurses as useful in a crisis when doctors weren't available.

## **2.5 Generic self management**

Thus far this chapter has focused on issues and evidence more or less specific to heart failure. However, I think this should be seen in the context of broader policy and initiatives concerning long term conditions in general (cf. Section 1.4.2). Heart failure patients in the UK have both generic and clinical self management available for use. In many cases they may be considered complementary rather than competing activities, a possible relationship is explained briefly below.

### **2.5.1 What is generic self management?**

The developing literature on clinical self management of heart failure (and cardiovascular disease more generally) reflects a logical approach to self care decision making (Deaton, 2000). Predictable and universal processes link: recognition of symptoms, association of symptoms with disease processes, selection of treatment strategies and evaluation of effectiveness (Riegel et al., 2000). Initiatives to educate patients about clinical self management are almost always professionally led (cf. **Section 2.4.1**). Clinical self management can fit strategically with a biomedical model of practice and its objectives are closely allied to those of professional clinical

management, for example, reducing hospital admissions and lowering mortality (“adding years to life”<sup>§</sup>) (cf. Wright et al, 2003).

There is, however, an alternative generic approach to self management exemplified by the NHS Expert Patient Programme (EPP). Generic self management programmes (like EPP) tend to be lay-led and more social; they work with (and through) lay knowledge and networks (Expert Patients Task Force, 2001). The main aim of generic self management appears to be patient empowerment (Patient Liaison Group and General Practitioners Committee, 2007). However, there also seems to be an argument that feeling empowered can “add life to years” (Lorig, 2001). Clinical self management is often a component of disease management programmes for heart failure (Yu et al, 2006), and anecdotal evidence suggests that specialists recommend self management for some patients. Generic self management forms a major plank of public and clinical health policy (cf. **Section 1.4.2**).

However, it is my assessment that neither type of self management seems to have become a successful and sustainable part of everyday practice for heart failure or any other condition. Clinical and generic self management have different philosophies, educational methods and management practices; therefore, we should expect that they have different barriers and facilitators. In particular, some patients might be more comfortable with one philosophy than the other.

### **2.5.2 Philosophy, organisation and delivery of the EPP**

The EPP is a six-week course in which a group of patients learn together how to manage symptoms, build physical fitness, adopt healthy behaviours and communicate. Sessions are facilitated by a lay-leader, who has a long term condition, using a tightly regulated script (NHS Expert Patients Programme, 2002). Following successful independent evaluation of a pilot phase begun in 2002 (Kennedy, Gately, Rogers, &

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<sup>§</sup> “Adding years to life and life to years” has been adopted as the Department of Health’s slogan for World Class Commissioning (Department of Health, 2009b).

EPP Evaluation Team, 2004), the EPP has been rolled out and transformed into a Community Interest Company (a type of non-profit making organisation) with plans to dramatically increase generic provision from 12,000 course places per annum to 100,000 by 2012 (Expert Patients Programme, 2007).

The EPP has elements drawn from both cognitive and social theory, which have been developed over many years by Kate Lorig at Stanford University (cf. (Lorig & Holman, 1989) and (Lorig, Mazonson, & Holman, 1993)). Lorig's Chronic Disease Self-management Programme (CDSMP) was in turned based on work begun by Halsted Holman (Chairman of Stanford's Department of Medicine) in the 1970s (Shoor & Lorig, 2002). Holman's involvement in experimental (community-based) models of healthcare and clinical experience (treating patients with lupus) led him to the conclusion that the success of healthcare reforms depended on teaching patients with chronic disease to become active partners in their care. He used this insight to create (with colleagues) the first CDSMP in 1976, for patients with diabetes, hypertension or arthritis. In 1978, Lorig went to Stanford to develop an education programme for people with arthritis in collaboration with Holman.

To understand the reasons for the success of these programmes Lorig and Holman began to study the components of the interventions. They hypothesised that self-efficacy (defined as "perception of confidence in one's ability to achieve success") was a possible explanation, and then worked with Albert Bandura (also at Stanford) to investigate this. The incorporation of self-efficacy improved the effectiveness of CDSMPs, which went on to be developed in their modern form. The five core self-management skills in Lorig's CDSMP are:

- problem solving;
- decision-making;
- resource utilisation;
- formation of a patient-professional relationship; and
- taking action.

It should be noted that although some CDSMPs are disease specific the EPP is generic (Expert Patients Task Force, 2001). However, even disease specific CDSMPs do not teach the knowledge or skills required for dose adjustment in a particular clinical condition. The assumptions underlying generic CDSMPs are:

- people with chronic disease have similar concerns and problems;
- people with chronic conditions must deal not only with their disease(s), but also with the impact these have on their lives and emotions;
- lay people with chronic conditions, when given a detailed leader's manual can be as effective as professionals; and
- the process or the way CDSMP program is taught is as important, if not more important, than the subject matter that is taught.

Self-efficacy, which is key to the reported success of CDSMPs, is an important component of Bandura's broader theory of social cognition (Bandura, 1997). In relation to learning, Bandura observed that it took place after observation of others and modelling of their behaviour. Models of health beliefs based on social cognition seek to explain individual health related behaviour with reference to outcome expectations, beliefs about oneself and beliefs about the attitude of others. The individual models (for example, the theory of reasoned action and planned behaviour) represent attempts to operationalise in healthcare the more general psychological construct of motivation (Madden, Ellen & Ajzen, 1992).

### **2.5.3 Evaluation of generic self management**

A published review of self management approaches for people with long term conditions was led by a member of the Expert Patients Task Force (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). The authors reviewed 145 papers (selected from 1129 titles reviewed) including 82 from the USA and only 2 with a focus on cardiovascular disease. The majority of tutors were professionals, apart from in work influenced by Lorig whose lay-led model dominated studies in the field of arthritis. Courses had both clinical and generic components to varying degrees. The review finds broad support for the potential effectiveness of self management, regardless of the

approach taken. It was unclear which aspects of complex interventions had a consistently positive effect on patient outcomes.

Although this review is cited in support of the EPP (Chief Medical Officer, 2006), it is not actually well focused on the generic approach adopted in the UK. Lorig herself (and her current team) has evaluated the wide spread dissemination of the six-week peer-led CDSMP in a large healthcare system. Unfortunately, the system is the Kaiser Permanente (KP) in the US rather than the NHS, but strategic thinking about long term condition management in the UK is clearly influenced by KP, which serves 8 million members (3 million more than Yorkshire and the Humber SHA). They conclude only that a proven programme can be replicated and disseminated nationally in a large healthcare organisation. However, the programme was offered to 12 regions, taken up by nine and only five met pre-determined criteria for success (Lorig, Hurwicz, Sobel, Hobbs, & Ritter, 2005).

Bury et al have produced a more comprehensive review of lay-led self management programmes published by NICE, but which does not constitute official guidance (Bury, Newbould, & Taylor, 2005). They concluded that: the benefits of the CDSMP may have been overstated and distorted; that the context in which people suffer from ill health has been inadequately investigated; and that to date only short term benefits have been demonstrated. They suggest that the sociological characteristics of communities should supplement economic and epidemiological information used by healthcare decision makers. Thus, lay-led programmes represent just one useful approach among the many that patients should be allowed to choose from.

The EPP's internal evaluation (n=1,000 post-course questionnaires) shows that four to six months after completing the course (Expert Patients Programme, 2007): GP consultations decreased by 7%; outpatient visits decreased by 10%; A&E attendances decreased by 16%; and pharmacy visits increased by 18%. In terms of health service utilisation such results would be remarkable if representative and reproducible.

An independent evaluation (randomised controlled trial with 629 patients) of the EPP carried out by the National Primary Care Research and Development Centre is vague by comparison, finding that course participants have: improved partnerships with doctors; increased confidence to manage their condition; improved quality of life and psychological wellbeing; increased energy; and high satisfaction with the course. The authors find it likely that the EPP is cost-effective over a six-month period (Expert Patients Programme, 2007) (Kennedy, Reeves et al., 2007).

## **2.6 Socio-economic issues in self management**

This final section provides the highest level of contextualisation to be presented here. Movements towards clinical and generic self management imply a certain view of the world. I assert that understanding what that world view is and how it has been formed is required for either successful implementation of self management or the suggestion of alternative courses of action. Patients and professionals have to make sense of conflicting issues in the context of their everyday life and work. At the level of the patient-professional partnership individual clinical issues naturally dominate; along with some consideration of psychology perhaps in the form of effective communication. We all experience this at some point as patients. At the level of professional-government partnership collective economic issues tend to dominate, which we see in many media reports about healthcare. Sociology helps us to understand how these levels relate to each other and patients' actual experiences of ill health, because it is a discipline which explicitly considers how individual agency can build and sustain collective patterns of care (structure) (see, for example, Cockerham, 2005).

### **2.6.1 Independence, choice and empowerment**

The standard (neo-classical) economic model emphasises the role of independent rational consumers making decisions to buy goods and services from independent rational providers. The model allocates resources optimally, providing (among other conditions) consumers and providers have perfect knowledge about the commodities traded, and consumers know how the commodities will improve their welfare. It is well recognised (see, for example, Donaldson et al, 2004) that healthcare fails to meet the requirements of a commodity that can be fairly traded in an open market, because:

- health (which is what people actually want) cannot be directly traded;
- the demand for healthcare is uncertain, we are not ill everyday;
- understanding healthcare requires specialist knowledge and training;
- the effects of healthcare on health are uncertain.

Therefore, insurance is often purchased to provide for healthcare needs (the NHS can be considered a large public insurance scheme) and the assessment of healthcare needs is placed by patients and/or their insurers in the hands of agents, that is, healthcare professionals. Patients in the UK seem emotionally attached to the NHS as part of the “welfare state”, enjoy free care at the point of need and often express great willingness to trust (be dependent on) their professionals. Arguably, as a consequence of this individual patients have been relatively uninvolved (cf. Elwyn et al, 2003) in healthcare decision making.

Against this backdrop healthcare costs have been rising everywhere in the developed world because of factors such as: increasing patient expectation, more effective healthcare technologies and the ageing population (The OECD Health Project, 2004). Whereas governments and insurers should certainly want their citizens and customers to enjoy longer healthier lives, they would obviously prefer it if healthcare costs could also be minimised. Broadly, there seem to be two (more or less) socially acceptable ways to achieve these ends: primary prevention of disease by the promotion of healthy lifestyles; and restricting use of healthcare technology (medicines, surgery etc.) to what is proven to be cost-effective. These strategies are not mutually exclusive (Wanless, 2004).

In the shared decision making/concordance model professionals engage patients directly in choices about healthcare technology, so that individual patient values or preferences can be incorporated into decisions about cost-effectiveness (cf. **Section 2.1.3**). These preferences may (for example) concern the need for any active healthcare intervention (versus watchful waiting for example), the type of healthcare intervention to be used (for example, medicines, surgery or counselling) and the way in which interventions will be provided (for example, by whom, in which location and at what intensity).

Self management and self care philosophies directly support moves towards shared clinical decision making and re-emphasise the primacy of individual choice over matters influencing personal welfare. To make effective independent choices patients need: more information about health and healthcare (patient education); confidence in that information and their ability to make decisions using it and their ability to evaluate outcomes (self-efficacy); and for their decisions to directly influence care (control over resource use) (see, for example, Bryan et al, 2006).

The choice agenda seeks to limit patient dependence on professional decision making and progressively engage patients in more active health maintenance. It is believed that patients with “voice” who can exercise “choice” will not only feel more personally empowered, they will also encourage greater professional effectiveness. It is also argued that effective choices have always been available for those with the ability to pay directly for (additional) care but need to be extended to those with fewer financial (and cultural) resources (Le Grand, 2006).

The issues outlined in this section are crucial to understanding the objectives of self management and indeed healthcare in general. Reviews and discussions (from different viewpoints) can be found in a number of published papers (which include (McGregor, 2006) (Koelen & Lindstrom, 2005) (Greener, 2003)). There is a current public awareness campaign (Summer 2008) promoting patient choice over healthcare providers for elective consultation, investigations or surgery. This is likely to be the beginning rather than the end of a long process of cultural change. We should seek to understand patients’ current preferences (cf. Benbassat, Pilpel & Tidhar, 1998) much more clearly to ensure that the direction of travel is desirable and that the route is well chosen.

The EPP as a method for patient involvement and empowerment has been criticised for supporting a biomedical (rather than a social) model of care and failing to reach those most in need (Wilson, Kendall, & Brooks, 2007). However, analysis of qualitative data from 66 people in the UK with a long term condition reveals some surprising and complex views. Evidence was found suggesting EPP both enforces the medical

paradigm *and* supports the subjective experience of living with chronic disease. In addition, while EPP emphasises individual empowerment (it is built on a psychological model), there is evidence that it is triggering a health consumer movement (Wilson et al., 2007). The future landscape of care is always uncertain and seems likely to be influenced as much by the (patient and professional) response to policy implementation (which can be unpredictable) as the policies themselves (which are subject to political forces).

### **2.6.2 The sociology of long term conditions**

Bury (1991) provides a review of the sociology of chronic illness, which is summarised in this section, and tries to standardise some of the terms associated with patient adaptation over time. The phrase “long term condition” has (more recently) replaced “chronic illness/disease” in the policy context and emphasises the key aspect of duration. Bury explains that a classic functionalist framework sees *illness* as characterised by dependence, regression and recovery (through the medium of healthcare). However, *chronic* illness may have poor or limited recovery prospects. Hence, there is an interaction between illness and the patient’s life course. Chronic illness commences with disruption (to established health status, functions and role), which turns into a process of explanation and legitimation, before becoming concerned with treatment and adaptation. So a person who is well may be confused and worried by a destabilising incident, they look for reasons why they are unwell and perhaps to be excused from normal roles, finally they seek to improve their health status or adapt roles to suit new abilities.

This sociological understanding relies on the impact of illness not only on the physical self but also on identity (Charmaz (1983) cited by Bury (1991)). Hence, Bury describes the onset of chronic illness as “*biographical* disruption”. This concept suggests an intimate relationship between the meaning of illness, the setting where it occurs and the resources available to the individual: meaning and context are entwined. Meaning may concern both practical consequences (for example, physical limitation) and the symbolic significance of a particular diagnosis. The latter may be manifest in the response of others when informed about an individual’s illness and the expectations that they then

have. The response of others influences the personal experience of disease and *vice versa*.

The information and explanations that people seek are likely to be imperfect, particularly with regard to aetiology and prognosis. Since both past and future are uncertain, people may adopt a fatalist attitude and (perhaps) doubt their ability to influence the course of illness. Studies show that people may construct a more detailed personal narrative around more basic medical facts. People seek to regain control and find explanations that make sense in their circumstances. Consequently personal and medical treatment goals may differ. The general success of many medical treatments may lead to longer life in which chronic illness is common, and influence people to seek stable explanations where none can be found.

New treatments offer hope, while failures frustrate and cause patients to re-visit initial experiences and feelings. Direct comparison with others can be a source of both worry and comfort. However, patients may become more knowledgeable and confident over time, particularly as they explain their story to different professionals. Patients form clear views about aspects of treatment that they consider to be successful. Treatment expectations may vary with both age and stage of disease: sometimes emphasising the instrumental aspects of intervention (wanting something to be done) and sometimes emphasising the communicative aspects (wanting to be heard). Patients may seek help with the physical and emotional work required of them.

Bury suggests that aspects of adaptation to chronic illness be called coping, strategy and style. In his schema: *coping* is reserved for the cognitive processes involved in tolerating illness (which may incorporate the illness into one's identity or push it to one side); *strategy* is about what people do rather than their attitudes (which involves choice and constraint as people seek to utilise resources); and *style* refers to the way people respond to illness and treatment (drawing on culture, symbolic meaning and class). It has not proved possible to be as prescriptive as Bury in the use of this language, because these elements are entangled and Bury's is not the only model. However, the distinction between different aspects of adaptation is important.

In a much later paper, Taylor and Bury (2007) turn to a sociological understanding of chronic illness, expert patients and healthcare reform. They provide a critique of healthcare policy and the psychology underpinning the EPP. They appear to understand and even accept the new focus on personal agency, but at the same time warn against the neglect of the structural determinants of health (for example, relative levels of deprivation). Townsend et al also suggest that self management policies must be capable of both recognising the tensions people experience as they negotiate life with chronic illness and adapting to provide context specific support (Townsend, Wyke, & Hunt, 2006).

## **2.7 Chapter summary**

### **2.7.1 Findings**

This review identifies the place held by clinical and generic self management within the overall package of care for heart failure patients. Whereas, clinical self management can be bolted on to traditional care for heart failure patients, most successfully as part of a comprehensive disease management programme; generic self management has the potential to more radically reform the demand for and supply of healthcare. Changes instituted by either type of self management are not without risk and the evidence suggests that successful implementation is heavily dependent on context.

With respect to patients we know that the experience of symptoms and consequent limitations on function are the only universally understood aspects of heart failure. Poor knowledge limits the potential for self management and coping strategies may flow from an emotional response rather than careful logical consideration. In fact, this may not be a bad thing since developments in neuroscience suggest that people can be happier with complex decisions made unconsciously or by gut instinct (Douglas and Jones, 2007). If we want patients (and professionals) to be happy with logical objective decisions, then the factors influencing those decisions must be made as simple as possible.

The exploration of professional roles in heart failure management is more or less restricted to deficiencies in diagnosis and prescribing. However, the education of nurses has been investigated. Trends in policy development currently emphasise the importance of personal agency and exclude structural determinants of health. However, it may be that (generic) self management gives people unexpected tools to explore their condition and its treatment, which go beyond the self-efficacy construct at the core of CDSMPs.

The literature is limited in its consideration of heart failure patients receiving general rather than specialist care, which also tends to exclude women. The literature says little about the attitudes of professionals towards self management and the assessment of self management benefits is focused on patient volunteers. Finally, although there have been attempts to implement generic self management across large healthcare systems, there is a lack of detailed investigation regarding implementation for a specific disease or in a specific area. These gaps have helped to inform the aim and objectives stated in the following chapter.

### **2.7.2 Strengths and weaknesses of the narrative review**

The different types of literature review each have their own strengths and weaknesses. In the biomedical literature, a systematic literature review is normally a robust synthesis of all relevant studies that address a specific narrowly defined clinical question (Cook, Mulrow & Haynes, 1997). A popular format for the specific clinical question is ‘PICO’: patient/problem, intervention, control/comparison and outcome (Sackett et al, 2000). The systematic review, therefore, seeks to confirm the specific treatment that has the greatest impact on specific outcomes for patients with specific characteristics. When meta-analysis is added to the systematic review, then statistical methods are used to summarise comparable results (Cook, Mulrow & Haynes, 1997); otherwise, the results of systematic review may be reported ‘narratively’ (Rodgers et al, 2009). However, because (biomedical) systematic review (with or without meta analysis) is necessarily focused, it could not provide sufficient context for the broad scope of this study.

My narrative literature review seeks to describe a landscape in which an empirical study can be located. The rationale and methods for the review are outlined in the introduction to **Chapter 2**. It is not a systematic review in the biomedical sense, nor is it narrative in the pejorative sense that it lacks explicit description of systematic methods (Cook, Mulrow & Haynes, 1997). A qualitative synthesis will necessarily reflect the context in which further empirical work will be carried out and the choice of the researcher. For some, this choice has implications for the reliability and validity of the findings presented; for example, the findings of a narrative review may be considered less reliable because the study selection is more prone to 'bias' (Cook, Mulrow & Haynes, 1997). I would agree that the wide ranging nature of this narrative review (including many different types of study) may make it hard to come to judgements about its internal validity, that is, were the reviewers' choices and methods appropriate (Collins & Fauser, 2005)?

The readers' problem is less difficult when the choices made have been explicit, transparent, clearly stated and reproducible (Collins & Fauser, 2005). This is easier to achieve in a systematic review, but at the expense of comprehensive coverage (Collins & Fauser, 2005). I would argue that for my purposes (understanding the landscape of self-management in practice) the narrative approach to review has external validity and allows the 'state of the art' to be judged (if imprecisely). Narrative review allows the coverage and contextualised choices required to discuss evolving concepts and controversy (Collins & Fauser, 2005). I have structured my narrative review so that links between topics are clear, logical and contextualised.

It is worth noting that because there was no single specific clinical question, one systematic review could not have been conducted to meet the requirements, that is, to provide a basis for further qualitative enquiry about general barriers to service development in a particular context. It may have been possible to conduct (or to update) systematic reviews on particular aspects of interest, for example, patients' levels of adherence to heart failure medication. Such reviews, if it were possible to conduct them according to appropriate standards (for example, Higgins & Green, 2008), could provide unbiased estimates of quantitatively assessed variables; for example: adherence levels, self-care knowledge scores or mortality in disease management programmes.

Clearly, these estimates would be very desirable for designing or delivering optimised clinical interventions. It has also been suggested that authors of narrative reviews could arrange their topic as a series of objective questions, each answered using explicit methods and tied together with descriptive links (Collins & Fauser, 2005).

It is claimed that the quality of all reviews (systematic or narrative) “depends on the extent to which scientific methods have been used to minimise bias and error” (Cook, Mulrow & Haynes, 1997). However, I believe there is also merit in a review (like the one presented) that seeks to describe the range of influences on an area of interest, and which may report the more highly systematic approach taken by others with respect to particular issues. The main uses of narrative review in medicine and related fields are (Cook, Mulrow & Haynes, 1997):

- obtaining a broad perspective on a topic;
- describing the history or development of a problem or its management;
- describing cutting edge developments when good quality evidence is scarce; and
- drawing analogies and integrating independent fields of research.

Indeed, procedures for a “meta-narrative approach to systematic review” have now been developed, and may make the synthesis of complex information more common if they are found to be robust and practical (Greenhalgh et al, 2005).

From a qualitative perspective in fields related to education, Hammersley (2001) argues not just that traditional narrative reviews are useful but that the assumptions underpinning systematic review are flawed. In systematic review, explicit replicable procedures of study selection and assessment are meant to reduce bias and enhance reliability (Hammersley, 2001). However, critics of systematic review (and positive models of science more generally, see **Section 3.6.1**) believe that the procedures used to synthesis studies don’t reflect the way the original authors actually worked and may not be a sensible way to study human interaction (Hammersley, 2001). Polanyi (cited by Hammersley, 2001) argues that science cannot operate using fully explicit procedures, relying instead on personal or tacit knowledge.

In my review precise conclusions are hard to reach and a single theoretical framework cannot hope to explain the complex web of relationships. Yet the field of enquiry is highly interesting and the broad relationships are worthy of further investigation. As personal enquiry moves towards recommendations for the practice of others it seems to make good practical and moral sense to *move towards* knowledge that is (or can be) more reliable and systematic. However, what is in theory valid and reliable also needs to be practical and relate to the world in which people operate. So there are important roles for both (biomedical) systematic and (qualitative) narrative review: each complements the other.

### 3 Aim and methodology

The main purposes of this chapter are:

1. To state the aim and objectives of an empirical investigation
2. To describe and justify the methodology and methods for that investigation

The literature review (**Chapter 2**) found that patients' knowledge of heart failure and its treatment were generally inadequate to support safe and effective clinical self management. In addition, even when patients have adequate knowledge of self management principles, adherence to self management behaviour may be low. For a variety of reasons some patients may lack the capacity to learn about and implement self management. However, this is not the principal reason for the inadequacies identified. Rather the vague and confusing symptoms that characterise heart failure allow patients and professionals to persist with sub-optimal management practices, even though the effectiveness of comprehensive disease management (of which self management is a part) is rigorously demonstrated.

*A priori* the implementation of self management as part of routine care (*mainstreaming*) seems more likely to be successful if patients start their education about heart failure and its treatment soon after diagnosis. Attempting education about self management in the middle of a clinical crisis seems doomed to be ineffective. However, much of the literature is focused on patients who have: been treated by heart failure specialists; participated in previous clinical research studies; or completed generic self management courses. The perspectives of patients cared for in a primary care setting and those who are 'initiative naïve' are under-represented in published work. The professional perspective on self management, for patients in their clinical care, is barely described at all, but clearly very important if change is to be facilitated. The aim and objectives identified below (**Section 3.1**) are designed to fill these gaps in the literature, regarding knowledge of and attitudes towards self management among: patients in primary care, professionals in all sectors and those (patients and professionals) who are self management naïve.

In addition, the specific context in which the aim and objectives are investigated adds to the repository of case studies in health policy implementation. A relative lack of investigation in context is apparent in the literature. The context provided by a detailed case study may help people (that is, readers) to explore issues in other situations of which they have knowledge; whereas over-generalised findings may leave people struggling to find personal meaning in published evidence. This emphasis on context and the interactions that generate healthcare, imply that the appropriate means of investigation (outlined in **Section 3.2**) are both qualitative and informed by sociological thinking. When putting the aim and objectives into practice, the identified gaps in the literature also influenced the participant inclusion criteria and topic guides described in **Section 3.3**.

The description of data collection (**Section 3.3**) and analysis (**Section 3.4**) with respect to patients and professionals are integrated wherever possible. However, for the purposes of practical project management the study was split into two distinct stages (1) a patient focused stage and (2) a professional focused stage. A Galen Award from the Royal Pharmaceutical Society of Great Britain provided funding for Stage 1, which was granted ethical approval in November 2002 and sponsored by the Leeds Teaching Hospitals Trust. Stage 2 was unfunded, granted ethical approval in July 2004 and sponsored by the University of Leeds. The process of approval is described in more detail in **Section 3.5**. Finally, **Section 3.6** concerns issues of quality, rigour and appropriate generalisation.

### **3.1 *Aim and objectives***

#### **3.1.1 Aim**

The routes of this investigation (**Section 1.2**) lie in a practical healthcare problem: frequent exacerbation (for some heart failure patients) causing potentially avoidable hospital admissions. Self management is offered as a potential solution to this problem. In particular, clinical self management would engage patients in monitoring weight changes and making appropriate guided adjustments to diuretic doses. However, it appeared that clinical self management was not a routine part of care for heart failure

patients and that generic self management courses were not being accessed by those with the greatest capacity to benefit.

Thus, my original motives in conducting this research (cf. **Chapter 1**) were to:

- illuminate the cause of repeated hospital admissions for heart failure;
- analyse a perceived problem in the implementation of health policy, that is, the slow adoption of self management;
- obtain a ‘thick description’ of a health problem from the patient’s viewpoint;
- learn more about the use of qualitative research methods.

Through review of the literature (**Chapter 2**), these motives developed into an aim to compare and contrast patients’ and professionals’ knowledge of and attitudes towards self management of chronic heart failure in the context of their daily life and work.

Patients helped to identify which professionals should be approached to participate, and this then developed into a case study of heart failure management with the concept of self management at its core.

### **3.1.2 Objectives**

The empirical investigation had two stages. The specific objectives for Stage 1 of the empirical investigation were:

- to explore the impact of heart failure on patients’ daily lives;
- to explore patients’ knowledge of and attitudes towards possible self management of heart failure;
- to identify differences between patients’ expectations of good care and models of self management that are currently being promoted; and
- to describe current care pathways for patients with mild-moderate heart failure and identify methods used by healthcare professionals to support patients.

The specific objectives for Stage 2 of the empirical investigation were:

- to explore professionals' knowledge of and attitudes towards possible self management of heart failure, and in particular to assess their reflections on patients' previously identified knowledge and attitudes; and
- to compare and contrast the nationally promoted ideal of heart failure self management with both the realities of current practice and local views about service development.

The aim and objectives of this study are policy orientated. The verb "explore" is intended to be comprehensive, but could also be criticised for being vague, so I will define it. I want to describe what people (patients and professionals) think, feel and do in relation to heart failure and its management. I want to explain these elements with reference to each other and the context in which people live and/or work.

Health policy in relation to self management of chronic disease is supported by economics and biomedical research. Biomedical research showing the effectiveness of CDSMPs is in turn supported by self-efficacy: a motivational construct used in psychology. The failure to extensively mainstream self management suggests that either it is not socially desirable *per se* (for many but not all patients) or that other important considerations have been over looked. Viewing self management as an opportunity for learning it seems that policy makers are clear about: why *they* want patients to learn, what *they* want patients to learn and why patients *should* want to learn. However, the social aspects of how and why people actually learn in everyday settings have been relatively neglected. There is a relationship between Lorig's model of chronic disease self management and general theories of well-being and learning (cf. **Section 2.5.2**). However, these relationships lack a collaborative or interactive element apart from an individual's perception of the 'subjective norm', that is, what others are believed to think. Furthermore, the concepts in models of well-being are rarely defined in everyday terms but rather as psychological constructs.

The study objectives significantly refer to “knowledge of and attitudes towards” self management. Knowledge refers to what one is acquainted with or takes to be true, often on the basis of some external authority or investigation. Thus there are ‘facts’ about clinical self management, which are ‘known’ because they are supported by research or expert opinion. However, an attitude is a habitual mode of thought or feeling, which may be influenced (for example) by knowledge, beliefs, hopes and expectations. Knowledge and attitudes are operationalised in the topic guide for patients (**Appendix 1**) simply as what people think or feel, that is, the information and motivation required for action. I make the basic assumption that actions are based on thoughts, feelings and the availability of resources. If a patient lacks appropriate information (on which to base thoughts), or external input (on which to base feelings), or resources (to facilitate action) then they may choose to:

- ignore the deficiency and carry on regardless; or
- substitute the professional’s thoughts, feelings and resources for their own; or
- engage with the professional (or others) to create the missing elements.

A belief that professionals acting by themselves in the patients’ best interests can ensure effective management is located in the biomedical school of thought. That is, good clinical outcomes (improvements in morbidity and mortality) flow from good clinical practice (processes). A belief that patients ought to be involved in technical aspects of management (rather than just assenting to professional opinions), and that this involvement can improve outcomes, is located in a more social view of medicine.

## **3.2 Study design**

### **3.2.1 Why interpretive social inquiry? (Paradigm)**

The traditional paradigm of medicine in the English-speaking developed world is based on understanding basic mechanisms of disease and observing everyday clinical practice (Evidence Based Medicine Working Group, 1992). The scientific principles involved are those of *empirical* positivism, that is, logical reasoning is assumed to flow from sound observation and application of known theories. Randomised controlled trials (RCTs) are now almost always required before medicines can be marketed; they are

also considered the ‘gold standard’ for investigating the effectiveness of most medical and surgical interventions. RCTs are underpinned by a positivist scientific methodology. That is, hypothetico-deductive reasoning in which hypotheses are generated (based on reliable observation or plausible theory) and tested in an experimental study. The purpose of the experiment in this model is to try and prove wrong (falsify) the hypotheses. If they cannot be proved wrong, then confidence that they are true is increased, but hypotheses can never be proven true (cf. Karl Popper, for example in (Magee, 1973)).

Evidence based medicine (EBM) values RCT (and related experimental) data above traditional authority and requires that individual clinicians have the skills to appraise original published literature. EBM also calls for clinicians to use the techniques of behavioural science to determine what patients really want from a consultation (Evidence Based Medicine Working Group, 1992). Thus, the RCTs that demonstrate the effectiveness of self management of heart failure assume a cause/effect relationship that can be measured empirically. However:

- self management interventions are complex, so even within this ‘standard’ model it is not clear what aspects of the intervention drive effectiveness; and
- the experience of getting research into practice (GRIP) suggests much more complex determinants of success than the nature of the intervention itself.

Within medicine, there is now a widespread (though not universal) belief that evidence based practice should incorporate scientific evidence, professional experience and patient values (Sackett, Straus, Richardson, Rosenberg, & Haynes, 2000). In this model, the most appropriate intervention for a particular person depends not only on science. It also depends on a professional interpretation of what that science means for the individual, and the patient’s assessment of how the proposed intervention may (or may not) fit into her social world. This can perhaps (from an uncritical standpoint) be seen as an attempt to combine the best of traditional personalised caring medicine with the best of modern evidence based therapeutics. Mainstream medicine may therefore be moving towards a paradigm of social constructionism, in which the mind/body duality of biomedicine (the orthodoxy of the late 19<sup>th</sup> and 20<sup>th</sup> centuries) is replaced by a more complex understanding of disease/treatment located in the world of the patient (Wilson,

2000). More critically, one can think of some 'new' models of medicine as a way for professionals to maintain power when faced with more demanding consumers and pressure from (economist assisted) decision makers.

It is social constructionism that generally underpins this study (Blaikie, 2007: 22). I take the (ontological) view that healthcare is not a thing that can be handled and described in complete objective detail, but is rather something created in the interactions between patients and their carers (formal and informal). The nature of these interactions means that healthcare is not only constructed but is also in a state of continuous change or revision (Bryman, 2008: 19). The interactions and their impact are in turn moderated by the social and political context, which may impose rules and boundaries. A consequence of these assumptions is that the version of reality presented in the following 'data chapters' (**Chapters 4, 5 & 6**) is reliable (for reasons described in **Section 3.6**) yet not definitive nor the only account available (Bryman, 2008: 19). Since healthcare in this context is taken to be a relative concept, an appropriate means of investigation relies on establishing the meanings that patients and carers attach to their actions. That is, the epistemological assumptions I make are interpretive not positive (Bryman, 2008: 16). Typically, reasoning in interpretive studies is inductive not deductive: theory flows from the data rather than being applied to the data (Bryman, 2008: 9).

The assumptions just outlined lead naturally to a form of interpretive social inquiry. I believe interpretive social inquiry is also justified by the complexity of the issues and a perception of slow progress towards the long-term goals of health policy. The economic imperative is probably the most important driver of health policy in the UK. A belief that self management is normative can also be found in the literature of positive psychological (Ryan & Deci, 2001) and the sociology of health (Antonovsky, 1984). Self management is believed to offer not only more effective clinical management (better control of symptoms) but also greater satisfaction with treatment (enhanced well-being). It seems clear that the aggregation of traditional evidence and application of accepted general principles are not sufficient (though they may be necessary) to ensure high levels of uptake. The nature of specific social interactions that facilitate change should also be explored. In this case, my interest in heart failure led to my interest in self management. However, the self management of heart failure provides just one

practical example of the impact of policy initiatives on clinical practice, so I hope this study may also provide some contribution to more general thinking about GRIP.

### 3.2.2 How is this inquiry being conducted? (Strategy)

Social theory and sociological research methodology offer many inter-related ways to structure, understand and interpret ideas about human relationships, our actions and their meanings. The method of reasoning most closely associated with constructionism is sometimes called “abductive” (Blaikie, 2007: 68), the possible layers of which (format in original) are summarised thus (Blaikie, 2007: 90):

*Everyday concepts and meanings*  
provide the basis for  
*social action/interaction*  
about which  
*social actors can give accounts*  
from which  
*social scientific descriptions can be made*  
from which  
*social theories can be generated*  
or which can be understood in terms of existing  
*social theories and perspectives*

Blaikie (2007: 99) counts Glaser and Strauss’s Grounded Theory as an example of qualitative data analysis using abductive reasoning. Grounded Theory has proved the most widely used framework for qualitative data analysis, and is practiced in (at least) three different forms (Bryman, 2008: 541). However, data from outside the particular cases examined is not easily incorporated into Grounded Theory. This makes it problematic for investigating the impact of health policy, which necessarily incorporates some sense of prior objective norms. “Framework” is a general strategy for the thematic analysis of qualitative data (Bryman, 2008: 554), which has been specifically developed with policy impact in mind (Ritchie & Spencer, 1994). The application of “Framework” to the qualitative data collected in this study is described in **Section 3.4**.

In all types of research the case (often a person or an incident) is an essential element and cases have characteristics or variables. It is usual in scientific research and some social inquiry to focus on objective comparison between cases. In interpretive social

inquiry the individual case may be examined primarily for its own intrinsic interest; and comparisons only made either as a secondary objective, or in the course of re-interpretation by readers. Where a case is a specific bounded system the investigation of that case and/or the associated report may be called a ‘case study’ (Stake, 2005). The case under investigation in this study is a local system for the clinical management of patients with mild-moderate heart failure.

As initially envisaged this study was more comparative (patients versus professionals) but the strategy was re-thought in response to recruitment problems (cf. Section 4.1). In a comparative study the popular concept of theoretical saturation might have been applied; in which data collection and analysis continues until categories (themes) are well developed, no new categories emerge and relationships between categories are established (Bryman, 2008: 416). A desire for theoretical saturation (for example in Grounded Theory) is often aligned with the constant comparative method, in which emerging theories are tested as further data is collected (Bryman, 2008: 542). Theory testing in the constant comparative method directs participant selection, so called theoretical sampling (Bryman, 2008: 515). Note, however, that in this study patient selection was purposive (Section 3.3.2), that is, based on criteria linked to the stated objectives (Bryman, 2008: 515); and that in “Framework” there are alternative ways to ensure that all relevant data contributes to the analysis (Section 3.4.2).

Calling this investigation a case study draws attention to its particular nature and context, but case study methodology is very flexible (Stake, 2005). There is no agreement on a single strategy of inquiry or set of approved methods for case study (Hammersley & Gomm, 2000). As this study develops, I am drawn into identifying the ‘virtual organisation’ involved in delivering chronic disease management to a group of patients under the care of one medical general practice. The boundaries are not clearly defined *a priori*, and must be determined (like knowledge) as the study progresses.

Knowledge is socially constructed – or so we constructivists believe (see Schwant 2000) – and through their experiential and contextual accounts, case study researchers assist readers in the construction of knowledge.  
(Stake, 2005) (citation embedded in original)

Stake (2005) considers three types of case study: intrinsic (studied for its own sake), instrumental (studied to provide insight into broader issues) and collective (in which interest in the particular case is low). This case study is instrumental in that the (complex) case is being examined to provide insight into the issue of chronic disease management, more than for the case's intrinsic interest. Alternatively one might think of the work as a collective case study (the individual patients being the cases) to study the phenomenon of self management. In any case both the individual viewpoint and interactions that make up the local system are considered important. Considering the local system as the case, the participants are thus 'informants'. Information drawn from the informants includes: background, setting and context (Stouffer (1941) cited by Stake (2005)).

The case study gains credibility if it has multiple sources of description and interpretation, that is, triangulation (Stake, 2005). This is normally acquired in the course of prolonged observation; data collection may also include interviews, surveys and document review. However, in this context direct observation of day-to-day disease management in peoples' homes or the clinic is problematic for practical and ethical reasons. Instead triangulation is provided by first capturing the knowledge and attitudes of patients, second allowing professionals an opportunity to respond to patient interpretations and third some document review (cf. **Section 3.2.3** and **3.3**).

The narratives provided by patients were used to identify and select professionals (related to them or their care) for further study. Data from both groups was used to engage in construct development and build a picture of local healthcare as it relates to the self management of heart failure. With regard to the focus of the study my particular assumptions were:

- there will a range of views regarding the acceptability of and effectiveness of self management for individual patients;
- these views can be explained (at least partly) by the social context in which patients live and professionals work; and
- the interplay between the patient's life and the professional's work is where active dissemination of 'good practice' occurs.

The methodology seeks to create a research world or ‘zone of interpretation’ from which understanding and explanation can be abstracted. As the research is driven by pragmatic health policy concerns there are *a priori* questions seeking answers; questions will also emerge from the data as it develops. I will continue to consider ‘data’ as a singular noun denoting the body of information collected and analysed. Seeking views about chronic disease management from both patients and professionals helps to provide triangulation, which clarifies meaning by identifying different ways in which the case is seen (Stake, 2005).

### **3.2.3 What data will be collected? (Methods)**

There are no particular restrictions on the type of data (quantitative or qualitative material) that can be incorporated into a case study. However, some researchers take a more quantitative (Yin, 2003) and some a more qualitative (Stake, 1995) approach. The preceding sections clearly state and justify my intention to take a mainly (although not exclusively) qualitative approach. Experimental study design is clearly inappropriate in these circumstances because there is no prior hypothesis to be formally tested (Polgar & Thomas, 1995: 73) (Lilford & Stevens, 2001). A survey would be capable of quantifying the various components of knowledge, attitude and behaviour in a sample (Polgar & Thomas, 1995: 86), especially if the nature those components were well established in other studies (Fowler, 2001: 4). Statistical methods could also be used to establish the nature of associations or relationships between variables quantified in a survey (Polgar & Thomas, 1995: 237). However, gaps in previous work cast doubt on what is likely to be found in this setting and which issues potential participants will perceive as most important (cf. **Chapter 2** and the introduction to this chapter). I am also interested in peoples’ experiences and how these are realised within the context of social relationships, in preference to experiences described in abstract isolation.

A characteristic of most social surveys is that participants respond to the investigator’s conceptualisation of a problem (Polgar & Thomas, 1995: 127), which is also a danger in qualitative research. In a survey, response choices and the ability for participants to comment freely may be restricted to ensure a standardised response and reliable analysis (Fowler, 2001: 5). It can be argued that if one has research ‘participants’ rather than

‘subjects’, then they should also be given the fullest possible opportunity to influence the conduct and findings of the study (Mason, 2002: 66). Faced with conceptual uncertainty and a desire to privilege the participants’ point of view, I deemed qualitative (and interpretive) methods most appropriate because they are capable of providing both wide descriptions (excluding little) and deep explanations (including much) (Polgar & Thomas, 1995: 109). Interpretive analysis allows the researcher to develop an understanding of how people make sense of who they are within a social context (Mason, 2002: 62).

Focus groups and one-to-one interviews are alternative qualitative methods (Flick, 2002: 73). Focus groups can be efficient since they allow diverse opinions to be expressed and contested over a short time period (Flick, 2002: 113). Therefore, they may be a good way to capture normative values and assumptions, but this was not the purpose of this study. The interaction between participants can also set off novel lines of thought and lead to unexpected insights (Baker, 1994: 188) (Flick, 2002: 120). These advantages do not fit well with my aim and objectives, which are focused on individuals and their relationships. A practical difficulty of focus groups, is the need to assemble a group of participants at a particular time and place. The symptoms and limitations described by heart failure patients suggested that such organisation would be problematic (**Section 2.3.1**), as did personal knowledge of the way in which professionals organise their work diaries. In focus groups, the strength of preference and confidence of some participants may lead to the relative exclusion of others (Breakwell, 1990: 75). Additionally, avoiding exclusion, conflict and undue emotional stress requires the investigator to manage group dynamics and have excellent facilitation skills (Wisker, 2001: 177).

Conducting interviews takes up more investigator time than focus groups (Bowling, 2002: 378), but they can be organised around the needs of individual participants (Wisker, 2001: 169). Participants are given the opportunity to contribute their individual experience, ideas and understanding (Bowling, 2002: 378). The data collected can be more biographical or narrative in nature, than that collected from focus groups (Bowling, 2002: 378), which does fit with the aim and objectives I have stated. Conducting interviews in people’s homes or places of work also provides an

opportunity to observe their everyday surroundings; I thought that this familiarity might make the participants feel more comfortable than they would in a room with strangers. Active research interviews look like a conversation (Holstein & Gubrium, 1995) and clearly the conventions of conversation vary from culture to culture, for example, greeting, establishing rapport and polite departure. However, this investigation was not focused on the needs of any particular (majority or minority) ethnic group, and it seemed likely that all the participants would share (at least some) dominant cultural references with me.

In consultation with supervisors, one-to-one (in-depth) interviews were established as the method of choice in this context to provide qualitative data for interpretive analysis. Topic guides were written to provide a semi-structured framework of specific but open ended questions (Bowling, 2002: 378). The contents of the topic guides for patients and professionals are briefly described in **Sections 3.3.2** and **3.3.3** respectively. The patient topic guide used during interviews is reproduced in **Appendix 1**, and an outline of the less structured professional topic guide is provided in **Appendix 2**. Although presented as an appendix the *patient* topic guide can be considered an integral part of this chapter as it details the main way in which the aim and objectives were operationalised. It is the key document responding to identified gaps in the literature and (to some degree) the study as a whole succeeds or fails on its merits.

Effective questioning techniques are required to collect data suitable for analysis, regardless of the topic being discussed. What is considered 'effective' may depend on the type of analysis planned. Here I mean questioning that allows interviewee and interviewer to build together a contextualised mutual understanding (Holstein & Gubrium, 1995). In the patient topic guide, prompts for further information were written alongside major topics of prior interest. For each topic, three key components were sought from participants: concrete experience, explanation and feelings. So rather than simply stating facts or opinions, participants were asked to: describe situations they had experienced; explain how and why things had occurred; and state their interpretation of the event.

As experiences, explanations and feelings were revealed, or new topics raised by participants, it was possible for these to influence future interviews. In particular, incidents and topics discussed by patients informed the questions put to relevant professionals in the second stage of interviewing (cf. **Section 3.3.3** and **Appendix 2**). The ability of participants to correct or comment on raw or processed data can provide an internal check on the reliability of data collected and the validity of its interpretation (Breakwell, 1990: 87). Data transcripts were not provided for participants to check. My view is that data from interviews is constructed in dialogue with the participants and although their comments would provide another interpretation, their further opinion doesn't necessarily provide validity. Comments from participants would have to be incorporated as interpretation, rather than being privileged as objective truth. This would add to the complexity of the final analysis, especially since views are likely to change over time and the need to produce transcripts would delay re-contact with participants. Summaries of findings were sent to all patients and any professionals that requested them.

Consistent with the assumptions described in **Section 3.2.1**, I prefer *not* to view the interview data as a 'snapshot of reality' to be verified. Rather, it is something created between participant and investigator, which builds on the experience of both (Holstein & Gubrium, 1995). The 'recycling' of ideas through different interviews, therefore, gives a second opportunity for related data to be created; similar perhaps to the exchange of views that might occur in focus groups. The practical result of this preference is that I do not claim the interviews are a faithful reproduction of prior participant experiences. I would claim that the discussion and interpretation of the issues are comprehensive and honest within the confines of the setting. The field is semi-natural in that interviews take place in the home or practice but the actual process of self management or care is not observed.

For the patients, additional clinical notes were made from their GP-held computerised medical records. These are treated as a factual record of events, even though in practice such notes can be incomplete and inconsistent (de Lusignan & van Weel, 2006). These records are principally used to check the standard of care (diagnosis and treatment) against established clinical standards, and report on the (objective) health status of

patients. On its own, this activity would be a small scale audit rather than research (Closs & Cheater, 1996), and would require positive assumptions, rather than those of constructionism. Here, the use of clinical notes: contributes to the case study; provides additional context for the findings; and allows some comparisons to be made between the quality of clinical care in this setting and in other settings for which published data exists.

### **3.3 Sampling and data collection**

#### **3.3.1 Practices**

The population prevalence of heart failure has been estimated at 3-20 people per 1000, rising to 80 cases per 1000 in people aged 75 and over (National Health Service, 2000a). Researchers from the University of Birmingham assessed 3,960 randomly-selected patients, all aged 45 or older, from 16 GP surgeries. They found that 92 patients had definite heart failure of whom 63 (69%) were NYHA class II and 14 (15%) NYHA class III (Davies et al., 2001).

A plan was made to recruit patients with NYHA class II and III heart failure (who would be symptomatic but not in the most severe category) from general medical practice lists in one Leeds Primary Care Group ('Trust' status came later in April 2002). From the figures above, the estimated prevalence of class II/III heart failure in the population is 1.9%. The average GP list in Leeds was 1700 patients (Department of Health, 2001), giving around 32 potentially suitable patients per doctor.

Eight practices in a Leeds Primary Care Trust (PCT) were approached to participate in this study and identify patients with class II/III heart failure. It was hoped that half would respond favourably. The Clinical Governance Lead GP for the PCT and PCT prescribing advisor were aware of the study and suggested those practices that might be approached. The PCT was chosen because it covered largely urban (rather than suburban and rural) communities, and the patients would be likely to come from lower rather than higher social classes. From within the PCT, practices were selected on a

convenience basis as those known to have effective information systems and be relatively cooperative.

It was hoped that the number of practices responding would allow 20-30 interviewees to be selected from consenting patients. Advice and published qualitative work suggested around this number of patients would be sufficient to obtain theoretical saturation, if this principle was applied. However, as noted above (**Section 3.2.2**) as the empirical work progressed it took on the characteristics of a case study. Numbers of participants available to be interviewed would be reduced by: poor record keeping, application of inclusion and exclusion criteria, and requests not to participate. If a choice of patients was possible, then balance was to be sought in terms of factors such as: age, sex, ethnicity and time since diagnosis, which implies a more structured sample at this level.

### **3.3.2 Patients**

Consenting practices agreed to write to all patients meeting the inclusion and exclusion criteria on my behalf. The pack sent out included a covering letter from the practice, my covering letter (and *pro forma* to return), an information sheet (**Appendix 3**) and a consent form (**Appendix 4**). Patients who thought that they might participate sent their contact details to me at the University in the pre-paid envelope provided. Contact was made by telephone to confirm willingness to participant, answer any questions and arrange a suitable time for interview. Consent forms were signed at the time of the interview, if the patient agreed and providing no criteria were obviously unmet.

Initial participant inclusion criteria were:

- mild-moderate heart failure (New York Functional Classification II & III), with and without co-morbidity (Criteria Committee of the New York Heart Association, 1994); and
- English spoken to equivalent of secondary school standard.

Initial participant exclusion criteria were:

- aged under 18;
- severe heart failure;
- learning disabilities;
- cognitive impairment (for example, Alzheimer's disease, pre-senile dementia);
- severe mental illness;
- current or previous participation in heart failure research; and
- current or previous self management plan agreed with a clinician.

Patient selection was, therefore, purposive and proceeded according to a clear pre-defined plan. The result of purposive sampling using formal criteria, as in a clinical trial, is a sample in which certain aspects of variety are minimised. In this case, those aspects chiefly relate to: heart failure status, cognitive function and exposure to specialists. The literature review provided some themes for patient interviews. Further themes were developed from the patient interviews. Participants were interviewed in their own homes at a time convenient for them. Interviews were tape recorded and transcribed for thematic analysis using "Framework". Each interview was planned to last up to one hour.

Interviews sought to recognise and explore the dynamic nature of patients' knowledge and attitudes, and the role of social support from friends, family and professionals.

Initial exploration of the literature suggested the following themes:

- ability and willingness to participate in disease management;
- treatment goals for patients;
- support required: in the past, now and in the future;
- effect of disease on social relationships;
- effect of disease on everyday activity;
- unanswered questions about disease or its treatment; and
- preferences for receiving information about the heart and medicines.

This was wide ranging but necessary so that knowledge of and attitudes about self management could be understood, explained and placed in some context. It would also be possible to explore how far current management deviated from suggested strategies. A detailed topic guide is reproduced in **Appendix 1**, note that a short justification is provided for each topic. A research supervision meeting was held after the completion of three interviews to review tapes and discuss progress.

All interviewed patients were asked for permission to access their GP held medical records so that brief clinical case histories could be prepared. The case histories (**Appendix 5**) summarised the recorded 'facts' of each patient participant's circumstances, including:

- age, smoking status, body mass index;
- referrals, test results and related diagnoses; and
- operations and prescribed medication.

Demographic information in the case histories supplemented (and sometimes clarified) the interview data. Prescribed medication was reviewed for its similarity to the evidence based regimens described in **Section 1.3.3**.

### **3.3.3 Professionals**

Professionals were identified as potential participants in several different ways. Patients who were interviewed identified professionals who cared for them now or had done in the past. Professionals responsible for service development were identified from general knowledge of the local healthcare economy and by professionals already interviewed.

Professionals working in consenting practices were contacted directly or with the assistance of practice managers. Initial contact with hospital consultants mentioned by patients in was by e-mail or telephone. I was an employee of the Acute Trust and had routine access to this contact information. Community pharmacists were contacted using information from the NHS website (<http://www.nhs.uk/>). Other NHS professionals were contacted using information from the public local NHS websites.

Professionals who agreed (after first contact) to receive further details about the study were sent a covering letter, information sheet (**Appendix 6**), consent form (**Appendix 7**) and pre-paid envelope. The covering letter included a *pro forma* to accept or decline further participation at this stage, which could be returned using the pre-paid envelope. A single phone call or e-mail was made to follow up contact if no response was received after 2 weeks. For those that agreed to participate interview times and dates were made by phone, fax, letter or e-mail as convenient. Signed formal consent was obtained at the time of interview.

Professional recruitment was, therefore, both purposive (to obtain the range of professional opinion identified in the literature as relevant) and theoretical (a way to follow up ‘leads’ given by the patients and other professionals). Relevant professionals mentioned in the literature include: GPs, hospital consultants, nurses, pharmacists and administrators. No recruitment target was set. It was planned to interview further professionals until all the likely perspectives had been considered and when any novel leads had dried up. Unlike patient recruitment criteria which acted to minimise variety, the result of professional recruitment methods would be to maximise variety. This is appropriate given the lack of knowledge about professional opinions on patient self management.

Themes developed from the patient interviews were presented to the professionals for comment and reflection. Some professionals were also able to comment on elements of the clinical case histories and their perceptions of good practice. The topic guide for professional interviews was not extensive, but mirrored aspects of clinical management already discussed with patients. Interview topics included:

- current role in heart failure management;
- views on future management developments;
- general practice style and care philosophy; and
- reflections on patient perspectives.

More specific questions were formulated for each interview and were dependent on the role of the participant, their relationship with any patient participants and any new

themes emerging from the interviews themselves. Individual patient perspectives were presented anonymously to the professionals where it was appropriate. Interviews were tape recorded and transcribed for thematic analysis. Coding and analysis were carried out in the same way as the patient interviews.

### **3.4 Data analysis**

#### **3.4.1 Transcription and coding**

Coding and analysis were carried out using “Framework” an approach to applied qualitative policy research developed by Ritchie and Spencer (Ritchie & Spencer, 1994). This was considered appropriate because the specified aim and objectives are not just about participants’ experience, but also about the implementation of health policy. This focus would be highly unusual in a pure sociological study, which would be more likely to begin with the observation of an everyday phenomenon and be led only by the data collected. The decision to use “Framework” is influenced by my role as an (evidence based) healthcare professional concerned not only with patient values and professional experience, but also how these should influence the application of evidence from clinical trials. Further justification is provided in **Section 3.6**.

Tapes were listened to after each interview and before transcription. All interviews were transcribed *verbatim* and saved as documents in Microsoft Word. The first patient interviews and later short interviews were transcribed by me. Other interviews were transcribed by secretaries with prior experience of the process. I checked all transcriptions for accuracy while re-listening to the tapes. Transcripts were laid out with interviewer and interviewee statements in alternate paragraphs, which were then numbered sequentially for identification. Missing or unclear words were indicated by single brackets ( ), which contained the probable hearing when appropriate. Explanatory notes were indicated by double brackets (( )). Significant pauses or continuation after interruption were indicated by ellipses (...).

Corrected transcripts were read and re-read to ensure familiarity with the data. Brief notes were made at the time of the interview about: where and when it was conducted,

how long it took and the participants' disposition. These notes were not coded but provided a prompt for the context of each interview, helping me to retain a memory of the face behind each transcript. Occasionally these notes provided demographic details (for example, type of housing) that were missing from the transcripts. Clinical details from the patients' medical notes were transcribed from the practice computer into forms created for the purpose (**Appendix 5**). These summaries of the medical history were not coded; occasionally interview transcripts provided missing details, for example, smoking status.

During the process of familiarisation potential codes were noted as they occurred. Coding was thematic rather than theoretical (Flick, 2002: 185), with codes identified from both the interviews themselves and *a priori* from relevant literature. The transcripts were coded manually rather than using software for data analysis. Codes were typed into columns adjacent to the appropriate paragraphs and key words were highlighted in the text. Data searching and retrieval were possible using standard word processor functions. The initial code was often an identifiable concept and given a definition, for example:

Activity (AC)

Household and other regular activities e.g. personal -care, cleaning, washing and shopping. Occasional activities e.g. holidays. Limitation on activity e.g. SOBE, hearing, vision, immobility, cognition and dyslexia. Relates to patient activity only.

Concepts were usually sub-divided into elements, for example:

AC<sub>H</sub> (household)

AC<sub>O</sub> (occasional)

AC<sub>R</sub> (restriction)

Concepts were sometimes relevant to both patient and professional interviews, in which case any necessary distinction was made at the element level. Finally, concepts were grouped into themes to create an overall conceptual framework (cf. **Section 3.4.2** & **Section 4.2**). A worked example is described in the following sub-section.

### 3.4.2 Conceptual framework and analysis

The conceptual hierarchy (of themes, concepts and elements) was adjusted as necessary throughout the period of analysis and writing up, and only the final version is presented

in this thesis (**Table 4.1** and **Appendix 8**). Transcripts were indexed by applying the final conceptual framework to the data and recording the code adjacent to the text as described above. At this stage all data was kept in its original context. Most significant passages of text required multiple codes. Data from individual interviews was charted by concept using elements as column headings and participant identifiers as row headings. To assist with the main aim, patient participants were not listed primarily in interview order but rather in groups broadly corresponding to overall attitude towards self management and then in interview order. At this stage brief notes and paragraph identification numbers were used in the summary charts; and then whole paragraphs lifted from their original context and placed side by side in a new document.

Concepts were then refined and, in particular, patient and participant concepts (which had been separately identified) were merged. This merger sometimes required the creation of new elements but was otherwise unproblematic. Some concepts only appear in patient or professional transcripts, others are common in both. Charting leads to the identification of the range of opinion and experience around each concept. Where possible this range was used to create typologies, or defined groups of participants clustered around a particular response, for example, patient attitude towards peer group work. When groups could be created this assisted the identification of common and divergent explanatory concepts. Otherwise emphasis was placed on the range of the concept among all the participants and the relationship between concepts for individuals.

Findings are presented so that similar or complementary concepts (or events) from patient and professional interviews are discussed in the context of an overall pattern of care. The nature of the relationships between the patient and professional participants is stated in **Section 4.5.1**. Finally, the patterns and explanations identified were compared with the literature to identify where (and where not) investigation in this context provided support for existing findings. Potential new findings were discussed, as appropriate, in relation to principles underpinning social experience or health policy.

A worked example is provided in **Appendix 9**. This example concerns the *concept* of self management and its *element* dose changes (coded as SM<sub>D</sub>), but note in the same transcript the further concepts of coping (CP) and symptoms (SY). Starting with the coded transcript (**Appendix 9 (a)**), significant paragraph references (the number in the final column) and key words (abstracted from the verbatim text) were copied into cells on a chart (**Appendix 9 (b)**). For each concept a chart was created, with elements as columns and participants as rows. In this way, visual comparisons between and within patients is facilitated; dominant and minority views are easily identified. Viewpoints and interpretations are then clarified by referring back to the transcribed text, including adjacent paragraphs. Written analysis is supported by reference to patients holding a particular view or having a particular experience. As part of the analysis more general themes were generated and are used to organise the findings (cf. **Table 4.1**). In the example given, the concept of self management was eventually grouped (with related concepts) under the theme of self regulation. Edited paragraphs from the transcript (quotes) are incorporated into analysis (cf. **Chapters 4, 5 & 6**) for illustration; and to demonstrate a faithful link between text and interpretation. In **Section 6.2.2** we see how the chart section reproduced in **Appendix 9(b)** leads to the identification of a group of patients labelled ‘doctor trusters’.

### **3.5 Ethical issues**

There was a low risk that psychologically uncomfortable issues would be discussed during the interviews with patients. The interviews were conducted sensitively and sought not to cause distress. If questions seemed to provoke anxiety or patients clearly did not wish to answer, then the topic was changed. At the start of the interview patients were told that they could stop altogether or refuse to answer a question at any time. Should it have been necessary (and with the interviewee’s permission) plans were made to refer for medical or psychological counselling. For example, research suggests that patients with chronic diseases often have ‘unvoiced agendas’ or questions about their disease that the interviews might uncover. Care was taken not reveal the identity of any patients if their quotes were offered to professionals for comment: only the quote, patient gender and approximate age were revealed. Patients had given permission for personal and sensitive (identifiable) details to be discussed with their own doctor, however, this was not necessary.

Participants were usually given at least one week to read the information sheet before being asked for their informed consent. Consent forms and contact details for patients and professionals were stored separately from interview tapes and transcripts. Tapes were only marked with an interview number and the date of the interview. Transcripts are only marked with an interview number, pseudonym and some demographic details. All materials are kept in locked filing cabinets or on password protected computers on University premises.

Ethical approval for the patient phase was applied for and granted by Leeds (West) Local Research Ethics Committee (LREC) on 15 August 2002. The Lead Clinical Governance Pharmacist at LTHT (a multi-centre research ethics committee member) provided advice on the two-stage patient recruitment process made necessary by NHS Research Governance requirements. Initially, it was envisaged that practices could provide lists of patients rather than write to them on my behalf. Further minor amendments proved necessary after willing GPs were identified (cf. **Section 4.1**). LREC approval for the revised documentation and recruitment procedures was granted on 12 November 2002.

Ethical approval for the professional phase was applied for and granted by Harrogate Local Research Ethics Committee (LREC) on 21 July 2004. They advised that the area of Leeds in which patient interviews were conducted should not be revealed to professionals, which would help to provide patient confidentiality. When my substantive contract with LTHT came to an end in 2004 I was granted an honorary contract with the Trust. Managerial approval for both phases of the investigation was provided by LTHT R&D Department and the PCT R&D Unit. An internal audit inspection by LTHT R&D Department on 19 August 2003 was satisfactory and the study was found to be compliant with all local procedures.

### **3.6 *Quality criteria for qualitative research***

It would be inconsistent with the methodology and methods outlined above to seek to defend the absolute objective ‘truth’ of all my interpretations of the interactions described in the following chapters. Nevertheless, it is important to persuade the reader that there is ‘a truth’ in what I write. By which I mean it is important that the reader

believes some of what I write has broader applicability, which is why I have tried to clearly describe my motives, my actions and the context for the findings (see, for example, Chamberlayne & King, 2000: 17-18). This section describes and explains the ways I have attempted to build credibility and application into this study and its report. The first sub-section deals with the quality of methods and methodological rigour. The second sub-section deals with the generalisability and impact of the research findings.

### **3.6.1 Methodological rigour**

Illustrative quotes are often used in qualitative (ethnographic) research to help readers understand the researcher's interpretations. Certainly quotes are provided in the following chapters, which are sometimes extensive and may include the actual question asked. They serve to illustrate, contextualise and verify my interpretations to varying degrees, which are best judged by the reader who brings her own views on and experience of the world. However, by themselves such quotes are not sufficient to confer credibility, in particular because quotes will be selected only if they tend to confirm the interpretations given (Flick, 2009: 384). In comparison to survey and experimental methods, this problem gives rise to an important question: what are the appropriate criteria for assessing the process and outcomes of qualitative research (Flick, 2009: 384)?

The answers to these questions are difficult and complex; and are likely to remain contested and controversial (Guba & Lincoln, 1994) (Miles & Huberman, 1994: 277) (O'Leary, 2004: 56) (Bryman, 2008: 33). The nature of potential answers seems to revolve around four quite different approaches (Flick, 2009: 385):

- seeking to apply positive criteria (for example, validity and reliability) without adaptation;
- reformulating positive criteria to make them applicable to qualitative research in general;
- developing method specific criteria for each type of qualitative research, which are linked to appropriate theory; and

- arguing that any attempt to apply ‘criteria’ is futile as representations of reality are necessarily (and acceptably) unreliable.

The first and last of these represent extremes that in my opinion (and for my purposes) are unconstructive and unworkable for very different reasons. The first may be associated with a rejection of qualitative research as harmless but useless, which I have witnessed occasionally as a member of two research ethics committees. The last seems to move qualitative research out of the realm of practical usefulness, especially in the context of a desire to improve healthcare systems. However, this latter school of thought is gaining ground (Lincoln & Guba, 2000). Not so much as a critique of the criteria themselves, but more as a debate about the meaning and form of social inquiry (Schwandt, 1996) (Lincoln & Guba, 2000).

The reformulation of positive criteria is attractive to me because (1) the fundamental quality issues in positive and interpretative methods can be considered conceptually similar (Bryman, 2008: 31) (McNeill, 1990: 14); and (2) the act of reformulation can perhaps build a bridge between approaches and/or provide support for mixed methods. Reformulation is necessary because (1) within constructionism more than one account of reality is possible (Bryman, 2008: 19) and (2) within interpretivism more than one set of meanings is possible for each account of reality (Bryman, 2008: 16). Thus, conventional (positive) criteria, which assume a stable reality and fixed relationships between factors cannot be helpfully applied (Bryman, 2008: 377). It is also clearly appropriate for researchers working (perhaps rigidly) with one particular (qualitative) approach and specific set of methods (for example, grounded theorists or conversation analysts) to formulate particular criteria (probably by consensus) if they so wish. Although one could draw parallels with the traditional sociology of professions in which the incumbents set up procedures and regulations both to establish quality and as a barrier to entry (Harding, Nettleton & Taylor, 1990: 73).

Perhaps most influentially, Lincoln and Guba (1985: 294-301) have suggested four criteria for the trustworthiness of qualitative research methods founded on constructionism, which are: credibility, transferability, dependability and confirmability. The equivalent criteria in quantitative research are respectively (Lincoln & Guba 1985:

300) (Miles and Huberman, 1994: 278) (Bryman, 2008: 377): internal validity, external validity, reliability and objectivity. Guba and Lincoln (1989) have since developed additional criteria related to authenticity and the wider impact of research. However, I will discuss this (and transferability) in more detail in the following sub-section. Below I present further explanations of their original criteria (except transferability) and a description of how they have been operationalised in this research, much of which is as suggested by Lincoln and Guba (1985: 301-327).

Credibility is about “truth value” but a one-to-one relationship between findings and reality is hard to verify, in experimental studies this problem is resolved by hypothesis testing and reporting probabilities (Lincoln & Guba, 1985: 294-295). When reality is considered a multiple set of constructions, then the reconstructions (findings and interpretations) should be deemed credible by the original constructors (participants) (Lincoln & Guba, 1985: 296). This means both using methods that increase the probability of credible findings and demonstrating that credibility with approval from the constructors (Lincoln & Guba, 1985: 296). Lincoln & Guba (1985: 301-316) suggest seven ways to achieve this:

- prolonged engagement in the field;
- persistent observation;
- triangulation (use of more than one data source);
- peer debriefing as an external check on process;
- negative case analysis;
- referential adequacy (relationship of findings to data); and
- member checking (checks with participants).

In relation to these suggestions, I have tried to achieve credibility by in this study:

- making my personal starting point, assumptions and drivers as clear as possible;
- providing a description of the organisational and policy context;
- following applicable legal and ethical guidelines on research conduct;

- conducting in-depth interviews with a variety of actors and seeking comments in later interviews on ideas raised in earlier ones;
- using routinely held medical records to support some aspects of analysis;
- discussing methodological changes, emerging findings and supporting data at regular intervals with experienced supervisors;
- making presentations based on the methods and emerging findings to academic peers;
- providing all patient participants with a brief summary of the general findings from their interviews;
- using “Framework” to ensure both positive and negative aspects of concepts in retained transcripts were explored;
- providing the general practitioners with a summary of patient comments about their practice; and
- providing the clinical psychologist with a summary of patient comments about peer group work.

Dependability concerns the impact of both instability (in the field of inquiry) and factors (change) introduced by the researcher (Lincoln & Guba, 1985: 299). In conventional studies the equivalent concept of reliability may be demonstrated by (potential for) replication (Lincoln & Guba, 1985: 298) (Bryman, 2008: 31-32). Replication is often taken for granted in scientific reports, but is not consistent with constructionism.

Lincoln & Guba (1985: 316-318) suggest four strategies to support dependability:

- since credibility relies on dependability (and validity relies on reliability) the former may be sufficient to demonstrate (weakly) the latter;
- overlapping methods to investigate the same phenomena, which is in effect the same as triangulation to establish validity;
- establishing parallel research teams that conduct separate inquiries; and
- employing an auditor to check that stated process has been followed.

Some of these suggestions are unconvincing or impractical. Formal external audit of qualitative methods has not become popular but implies a need to retain good records

(an audit trail) (Bryman, 2008: 378). In this study I have tried to achieve dependability by:

- providing a transparent account of the methods and associated decision making
- making and keeping records of progress with recruitment and selection of participants;
- making and keeping verbatim transcripts of interviews;
- making and keeping minutes of supervision meetings including discussions held and agreed action points; and
- systematically charting the indexed transcripts so that as much raw data as possible contributes to the findings;

Confirmability concerns neutrality and freedom from unacknowledged bias (Miles & Huberman, 1994: 278), but may be seen more as characteristic of the data than the researcher (Lincoln & Guba, 1985: 300). The findings should be seen to be influenced by the data, the participants and (perhaps) acknowledged researcher bias. Lincoln & Guba (1985: 318) suggest that an inquiry auditor could examine the report to attest that it is supported by the data and internally coherent, thus establishing confirmability. Like the establishment of dependability this requires an audit trail, confirmability may also require evidence of triangulation and reflexivity (Lincoln & Guba 1985: 318-319). In this study I have tried to achieve confirmability by:

- providing a record of planned and achieved methods;
- describing the process by which raw data was transformed into themes;
- including substantial verbatim quotes in support of the analysis;
- describing how my personal views and health policy objectives relate to the findings; and
- submitting a final report for examination by academic peers.

It can be seen that the concepts of credibility, dependability and confirmability and their operationalisation overlap to certain degree. There are no definitive methods for social inquiry nor are there definitive quality criteria. However, the reader should find this report an open and honest account of what was intended (and what happened) in the process of data collection and analysis.

### 3.6.2 Generalisability and impact of findings

This study was prompted by what one might call a ‘generalisability gap’ in the literature. So it is appropriate to discuss ways in which this gap may be partially filled. In conventional studies there may be a direct trade off between internal and external validity (Lincoln & Guba 1985: 297). For example, the inclusion and exclusion criteria for clinical trials may control for the effect of many factors, but make the experimental sample quite different from the normal practice population. This is a problem when one is seeking to make strong generalisations on the basis of experimental data.

Lincoln & Guba (1985: 297) suggest that in qualitative inquiry only ‘working hypotheses’ are abstracted and that the *transferability* of these hypotheses is an empirical question: depending on the similarity of the study context and a comparator. A judgement about transferability can only be made someone who has detailed knowledge of these two (or more) times and places. This knowledge may, however, be direct (from personal experience) or vicarious (from published reports). Since the original investigator does not know where her work may be used the burden of proof (regarding transferability) may lie with the reader, but sufficient descriptive detail should be provided to make judgements on similarity possible (Lincoln & Guba, 1985: 298). Unfortunately, “what constitutes proper thick description” for this purpose is not resolved (Lincoln & Guba, 1985: 316).

For me, the achievement of a ‘thick description’ (cf. **Section 1.2**) depends on whether the reader is able to extract a credible understanding of time, place and personality from the accounts in the following chapters (Geertz, 1994). Whether the writer intends it or not, it is argued that generalisation based on understanding gleaned from interpretive accounts is “inevitable, desirable and possible” (Williams, 2000). However, the type of generalisation possible is special and has particular limits, which must be explored (Williams, 2000). Williams (2000) argues that this proposition is correct:

Interpretivists deny the possibility of generalisation, or they ignore the issue, but they do generalise and this is inevitable.

Although some (including Guba & Lincoln cited by Williams, 2000) more explicitly deny generalisation, others generalise but will not admit it, and do not

report the basis to justify their statements (Williams, 2000). Mason (2002: 195) argues that such behaviour is unacceptable: morally, politically and intellectually. She suggests that generalisation may be thought of as either empirical or theoretical. The first is often based on statistically representative sampling and is uncommon in qualitative research; the second is more productive but also varies with levels of theory (Mason 2002: 195) (Silverman 2006: 304). Mason (2002) outlines several means to justify theoretical generalisation in order of strength (with the weakest first).

I make the weakest of Mason's claims for my data, there is "no reason to expect atypicality" (Mason 2002: 195) compared to other urban working class areas (where the patients were resident and primary care professionals worked) and large acute hospitals (where the secondary care professionals worked). The patient and professional demographics are detailed in the following chapter to support this claim. I also make the next claim that there are "lessons for other settings" (Mason 2002: 196) in my discussions with self-management naïve patients and professionals found to be variously engaged in the self-management agenda. I do not argue (on the contrary in fact) that I have established "an extreme or pivotal case, or set of processes" (Mason 2002: 196).

I do argue that a "strategic comparison" (Mason 2002: 196) is built into the study by way of patient and professional views on the same topic. The particular nature of any differences may be most interesting in context, but the presence (or absence) and magnitude of differences may be more broadly instructive. Finally, note that participants not only describe what they think, feel and do; but also they (or I) attempt to explain these characteristics in context. The use of specificity and difference (rather than glossing over it) is Mason's strongest form of generalisation (Mason 2002: 197).

These necessary generalisations are neither total (true always and everywhere) nor statistical (true within a range of possibilities) but partial or moderate (true in a sense given the context and/or a chosen comparator) (Williams, 2000). Stake (1995: 7) also

argues that certain generalisations will be drawn from a case, even if a case study seems a poor basis for generalisation. Case studies, he argues, may not make *grand* (sic) generalisations, but can modify them and make *petite* (sic) generalisations. He describes the real business of case study as “particularisation”, since comparative and correlational studies do generalisation much better (Stake, 1995: 8). The emphasis in a case study is on uniqueness but this implies knowledge about differences compared to other situations (Stake, 1995: 8).

Flyvbjerg (2006) goes further than Stake (1995) in a robust attack on the notion that one can't generalise from a case study (cf. Silverman, 2006: 304). He argues that the case study holds up well compared to other methods in social science, but considers case studies complementary to studies with more ‘robust’ sampling (Flyvbjerg, 2006). The generalisations that can legitimately be made determine the impact and importance (Yardley, 2000) of this study as a piece of health policy research (which it is in some senses). Thus, a study like this can present a different perspective on a known issue or be a vehicle for discourse (Yardley, 2000) or give voice to those who are (relatively) unheard. Guba & Lincoln's (1994) authenticity criteria, which concern the wider political impact of research, have not been influential generally (Bryman, 2008: 380), and I do not seek to apply them all to this case. I think that the findings clearly sit in a broader political and social context, but I have largely restricted the interpretation to the health economy where my professional interest and capability lies. In line with Guba and Lincoln's thoughts on authenticity I think that the findings are a fair representation of the participant's views and increase our understanding of an important set of healthcare issues. However, the research process has not been explicitly used to educate the participants, influence them to change or empower them to take radical action.

## 4. Participant profiles and conceptual framework

This chapter describes the response to the recruitment strategy (**Section 4.1**). The final conceptual framework is detailed in **Section 4.2** and **Appendix 8**, and then **Section 4.3** briefly describes how quotes from the transcripts are identified in the data reported. Data reporting begins with the characteristics of those that agreed to participate (**Sections 4.4** and **4.5**). **Section 4.4** includes a brief description of the local area where patient interviews were held (**Section 4.4.1**). Restrictions imposed by the Research Ethics Committee (stage 2 approval) require that the name of the local area (electoral ward, ‘old’ PCT area, ‘new’ PCT locality) be kept confidential.

### 4.1 Response to recruitment

Out of eight medical practices contacted:

- four practices declined to take part for unspecified reasons;
- one practice stated that they were too busy to take part;
- one practice stated that their data quality was too poor for patient identification;
- two practices asked to see a copy of the research protocol.

One practice agreed to assist with patient recruitment. A GP at this practice took the lead for the project and discussed recruitment arrangements with his colleagues. These negotiations revealed a problem with using the words “heart failure” in letters to potential participants and the participant information leaflet, which is consistent with findings from the literature review. The lead GP thought that some patients would not be aware of this diagnosis and that some might find the description “failure” a little disturbing. Therefore, the words “heart problems” were used in revised documentation. Discussion with the practice also identified one further participant exclusion criteria, which was living in nursing or residential home (since the living environment of these patients would not currently allow self management of medicines in any circumstances). In fact it had never been the intention to recruit patients unable to care for themselves, and other criteria would have already excluded most care home residents. Patient documentation was revised appropriately and ethical approval gained for the protocol changes.

Following initial discussions with the lead GP, further contact with the practice was made via the Practice Manager and her staff. Patient recruitment began in December 2002, when the Practice Manager sent out the first batch of 10 letters to potential participants. Recruitment was done in batches of 10 to minimise delays between initial contact, consent and interview. Further batches were posted during 2003 in January, February, March, May and June. At this point there were no more patients to contact who met the study criteria.

From these 60 initial contacts, 24 positive responses were received and 21 interviews carried out. Of the three potential participants lost between positive initial response and formal consent:

- one person was found to be unsuitable at the start of a home visit and was excluded because their heart failure diagnosis was unclear;
- one person denied knowledge of the study when contacted directly to arrange an interview;
- one person could not be contacted before interviews were stopped and case note review commenced.

Professional recruitment started in November 2004 and was completed in July 2005. Potential professional participants were selected initially if they or the service they managed was mentioned by a patient participant. Further contacts were made on the basis of suggestions made by professional participants and to ensure a full range of professional representation. In total, 35 healthcare professionals were contacted and 2 EPP tutors; of whom 19 agreed to participate. No reply was received from 8 healthcare professionals and one EPP tutor; 9 healthcare professionals either declined or deemed themselves unsuitable for interview.

## **4.2 Conceptual framework (index)**

A conceptual framework (index or coding frame) was developed and applied according to the methods described in **Section 3.4**. The coding hierarchy is: *theme*, *concept* and *element*. Six general *themes* characterise the scope of the interviews conducted; 26 *concepts* describe the topics and issues discussed in the interviews; 107 *elements*

provide a detailed breakdown of the concepts. Definitions of the *concepts* and their *elements* are provided in **Appendix 8**. The *themes* are:

- Profiles
- Normal life
- Chronic disease behaviour
- Chronic disease management
- Self regulation
- Professional regulation

*Profiles* refers to standard patient demographic information (age, gender, housing, occupation etc.) and the characterisation of professional roles, that is, relationship with patients, job focus and sector of work.

*Normal life* incorporates the every day activities of patient participants that, whilst influenced by health status, are largely independent of any health service utilisation. This includes the demographic profile, physical activities, assistance with household tasks, lifestyle and financial issues.

*Chronic disease behaviour* describes patients' experiences of heart failure symptoms (and co-morbidities), their knowledge of health-related matters and coping strategies. It includes communication, medicines adherence and utilisation of different forms of medical information, for example, verbal, written and online.

*Chronic disease management* is a counterpart to chronic disease behaviour, which has a largely professional focus. It describes the range of services, professionals and treatments that patients are directly exposed to.

*Self regulation* is the theme at the heart of this study. It includes views expressed about attitudes to the form of self management described to patients, which was unfamiliar to most.

*Professional regulation* includes a range of issues less directly related to personal medical care, for example, relationships between practitioners and/or organisations; methods of working; provider incentives and barriers to service development.

The themes overlap to a greater or lesser degree, and the boundaries are both indeterminate and flexible. However, they are grouped (in **Table 4.1**) according to the type of participant (patient or professional) that they principally relate to. Two pairs of themes exist as counterparts or ‘two sides of the same coin’:

- chronic disease behaviour and chronic disease management;
- self regulation and professional regulation.

Chronic disease behaviour and management are more obviously linked as patient-related responses to professional disease management strategies. Self regulation and professional regulation represent more independent activities such as responded to change, coping with the daily experience of a long term condition and the tension of being a practitioner within an organisation.

### **4.3 Transcript quote identification**

The code subsequently used to identify *patient* transcript quotes is a patient pseudonym and their age. The *professional* identity codes incorporate:

- A pseudonym appropriate to age and culture
- An initial letter for profession (Expert patient administrator, Doctor, Nurse, Pharmacist, Clinical psychologist)
- A number indicating order of interview within professional groups (1 – 6)
- A subscript indicating sector of work (Primary, Secondary, Community)

Long quotes from participants are indented, presented in a different type face (10 point Ariel) and the researcher’s voice highlighted in **bold**. They are deliberately detailed to add contextual information. Ellipses indicate both gaps in the original transcript and editing for report. Specific words used by participants that appear in the body of my text are given inside double inverted commas.

**Table 4.1:** Concepts grouped by theme and type of participant

<i>A) People</i>	<i>B) Patients</i>	<i>C) Professionals</i>
1. Profiles 1.1 Demographics 1.2 Relationship 1.3 Role (professional) 1.4 Sector (professional)	3. Chronic disease behaviour 3.1 Adherence behaviour 3.2 Communication 3.3 Health knowledge 3.4 Medical information 3.5 Medicines	5. Chronic disease management 5.1 Related care 5.2 Diagnostic tests 5.3 Medical care 5.4 Titration
2. Normal life 2.1 Activity 2.2 Assistance 2.3 Diet and lifestyle 2.4 Finance and benefits	4. Self regulation 4.1 Coping 4.2 Mental health 4.3 Self management 4.4 Symptoms	6. Professional regulation 6.1 Environment 6.2 EPP 6.3 Modus operandus 6.4 NHS 6.5 Records and payments

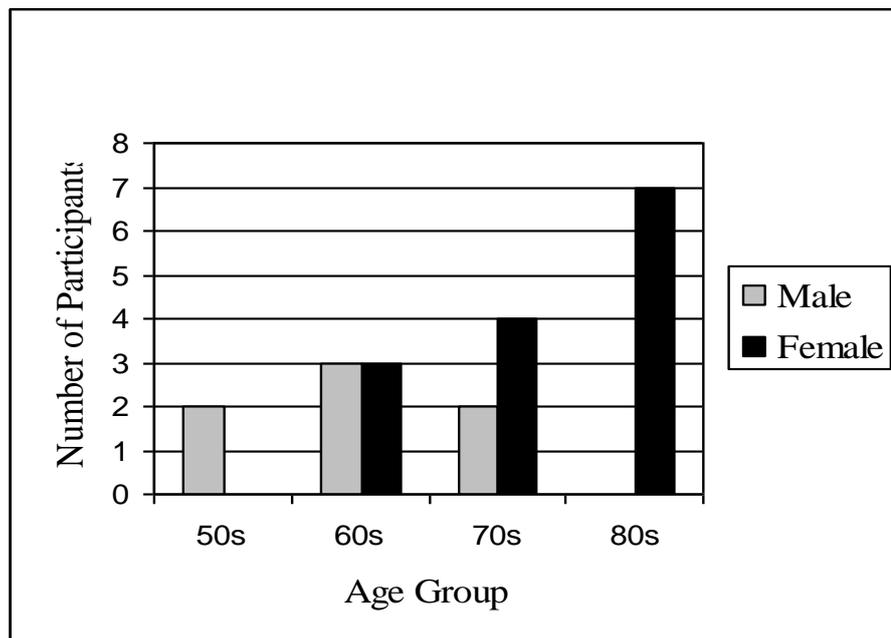
*Chapter 4: Themes 1 and 2 - Chapter 5: Themes 3 and 5 - Chapter 6: Themes 4 and 6*

## **4.4 Patient participants**

### **4.4.1 Demographics**

A description of patient demographics is important to demonstrate that the sampling strategy has filled a gap identified in the literature (primary care, women, older patients) and so that the reader can begin to build a picture of the participants' daily lives (cf. **Section 3.2**). For clarity demographic details are presented using descriptive statistics and a summary of basic information from all available sources.

Patient interviews lasted between 20 minutes and 1 hour 20 minutes. Patient participant demographic details and living circumstances are summarised in **Table 4.2**. Patients' ages on the date of interview are given in this table but to protect patient confidentiality the date of birth, date of interview and real names are omitted. There were 14 female and 7 male participants, whose ages ranged from 55-89. The mean age of 74 matches that found in initial analysis of local hospital admission data, but the gender mix does not (**Section 1.3.1**). Two participants were in their 50s at the time of interview, 6 in their 60s, 6 in their 70s and 7 in their 80s. The participants' age and sex profile is illustrated in **Figure 4.1**. Heart failure is usually diagnosed in late middle age or old age, so the age distribution probably reflects the disease burden. It is thought that more older women than men may be cared for in the primary care setting. It is unusual for the majority of patients to be female in heart failure studies, and this sample helps to provide a view that is under reported in the literature.



**Figure 4.1:** Age and Sex of Participants

**Table 4.2:** Patient participant demographics and living circumstances

<i>No.</i>	<i>Month of interview (2003)</i>	<i>Pseudonym</i>	<i>Age</i>	<i>Gender</i>	<i>Living in</i>	<i>Living with</i>
1	January	Ethel	83	Female	Sheltered Flat	Alone
2	January	Maria	76	Female	House	Alone
3	January	Edward	71	Male	House	Alone
4	February	Florence	78	Female	Flat	Alone
5	February	Clara	86	Female	Flat	Alone
6	February	Patricia	63	Female	House	Partner
7	February	Jean	76	Female	Sheltered Flat	Alone
8	March	Lillian	78	Female	Sheltered Flat	Alone
9	March	John	67	Male	House	Partner
10	March	Harry	75	Male	Sheltered Flat	Alone
11	April	Mike	56	Male	Flat	Alone
12	April	Philip	65	Male	House	Partner
13	April	Tony	55	Male	Flat	Alone
14	April	Ruth	86	Female	Flat	Alone
15	June	Olive	62	Female	Flat	Alone
16	June	Anne	64	Female	House	Partner
17	June	Doris	88	Female	House	Family
18	June	Rose	82	Female	House	Alone
19	June	Margaret	89	Female	Sheltered Flat	Alone
20	July	Pete	65	Male	House	Family
21	July	Vera	84	Female	House	Alone

Type of home wasn't noted in any of the previous qualitative studies reviewed in **Chapter 2** but did appear to have an impact on patients' lives. Eleven participants lived in flats, of whom 5 were in sheltered accommodation that offered support from a warden. Ten participants lived in houses, of whom 6 shared the accommodation with family members (usually their husband or wife). The residences visited seem to reflect the range of domestic property in the area. The flats were generally owned by the local council or housing associations, rather than owner occupied. Houses on the other hand tended to be owner occupied. All the participants (and their partners) were of white European origin. Former and current occupations were mentioned by some patients, but social class was not assessed or recorded systematically.

Key neighbourhood statistics (based on the 2001 Census) for the electoral ward containing the medical practice were accessed online (Office for National Statistics, 2004). In April 2001, the *ward population* was approximately 50% male and 50% female; one-third were aged over 45; 92% described their ethnic group as white; 19% had a limiting long term illness; 43% lived in rented accommodation; 38% (aged 16-74) had no qualifications; and 35% (aged 16-74) were economically inactive. In the Index of Multiple Deprivation 2004, the Lower Layer Super Output Area (LSOA) containing the practice was ranked among the most deprived (in the highest centile) LSOAs in England (Office for National Statistics, 2004). The key statistics give an indication of the type of area that the patients lived in, which can be described as predominately white and working class. The medical practice workload (patients per GP) was close to the national average for England, but a little higher than the average for Leeds (Royal College of General Practitioners, 2004) (Prescription Pricing Authority, 2007). Note that providing more precise information on the numbers of patients and GP might identify the practice.

#### **4.4.2 Household and occasional activities**

The literature review highlighted experience of symptoms and activity limitation as the common defining features of heart failure for patients. GPs had been asked not to identify patients with severe heart failure, and this sample of primary care patients might be expected to have fewer symptoms than the secondary patients that dominate

published reports. NYHA class was not formally assessed. This sample's experience of symptoms and activity limitation is expected to be one of the main influences on reported care and attitudes towards change. The sample's symptom profile also provides a way to compare the experience of this sample with that described in previous reports.

All the participants had restrictions in the scale, scope or speed of their daily and occasional activities. The restrictions centred on (in order of importance):

- heavy lifting and shopping (all participants);
- walking up gradients, for example, hills and stairs (most participants);
- reaching and extending, for example, to clean windows or curtains (specifically mentioned by: Ethel 83, Edward 71, Clara 86, Tony 55);
- using baths (Ethel 83, Florence 78, Clara 86, Lilian 78);
- coping with heat, for example, hot weather or cooking (Tony 55, Ruth 86).

Problems with heavy lifting and walking up "hills" (that is, steep roads) were reported by almost all the participants. Almost invariably, participants suffered from shortness of breath (the main physical symptom of heart failure), but tiredness and joint pain were also reported as reasons for restricted activity (cf. **Table 6.1**) In relationship to tiredness, Philip 65 and Doris 88 reported improvements following the fitting of a pacemaker. Where shortness of breath limited exertion participants would either completely refrain from the activity or proceed slowly with frequent breaks (cf. **Section 6.1.1**).

At the time of interview six participants were permanently housebound unless they had assistance (Florence 78, Clara 86, John 67, Doris 88, Margaret 89, Pete 65) and one was temporarily housebound due to a twisted ankle (Olive 62). Of these housebound participants only Clara 86, Olive 62 and Margaret 89 were able to do housework, attend to personal care and prepare meals. In addition: Margaret 89 was registered partially sighted; Clara 86 and Maria 76 were hard of hearing (and had hearing aids); and Philip 65 was deaf. Although the participants' GP had considered them all free from cognitive impairment and suitable for interview, it was apparent that Florence 78 and Doris 88 weren't physically and mentally fit enough to engage in detailed discussion about future self management of heart failure. Pete 65 was mentally well but suffered from a

progressive debilitating condition that required expert attention and caused significantly more problems than his heart failure.

Some participants found the physical restrictions frustrating especially in comparison to former levels of high physical activity either at work (Edward 71, John 67) or in leisure activities (Patricia 63, Jean 76, Philip 65). However, many had come to “accept” (Ethel 83, Edward 71, Philip 65) or “live with” (Clara 86) their limitations, which some considered a normal part of ageing (Ethel 83, Clara 86, Philip 65) (cf. **Section 6.1.7**).

**How did it make you feel to become ill so suddenly?**

It was a shock. The first year after I was you know off ill, my mother was alive at the time, I used stand here on a morning ... watch them going to work ... The first year nearly killed me believe me and I mean that. ... I used to dash out on a morning to work and just to stand there at the window watching ... God what have I done to deserve this, but there you are and of course you get used to it obviously. You know you have to so there you are you have to put up with it, get on with life.  
Edward 71

Local visits to shops and friends were commonly reported by participants who were not housebound. Local or regional trips in groups (Ethel 83) or with partners (Edward 71, Philip 65) were described; and in one case a holiday (in the South of England) made possible by advance arrangement of an oxygen supply (Olive 62). Only Patricia 63 described a recent holiday abroad and in one case flight plans had been cancelled at the time of diagnosis (Maria 76).

*A priori*, participants living arrangements would appear to be good indicator of general physical capability. For example, one might expect someone living in a house with a family to be more physically active than someone living alone in sheltered accommodation. The situation is complicated because the level of formal and informal support required to sustain individual living arrangements was somewhat variable. For example, Doris 88 lived in a house but was completely cared for by her (grown up) children, and was only able to make a limited contribution to household activities. However, Harry 75 lived almost without day-to-day support, but in sheltered accommodation that provided some emergency back up if needed.

Age might also be taken as a general indicator of potential activity, but this is modified by the seriousness of a particular disease and co-morbidities. For example: Tony 55 was the youngest participant but also arthritic and morbidly obese; Pete's (65) unexplained degenerative condition had a serious impact on his physical performance and stamina; and Olive 62 had co-morbidities that affected her quality of life rather more than any heart problems (she also had an oxygen concentrator at home).

Overall there was considerable variation in physical functioning, mental functioning, and activity levels, which were not necessarily easy to explain with reference to standard demographic data. What might be considered typical functioning (for a particular age) was modified by disease severity, attitude towards restrictions and the available support network.

#### **4.4.3 Assistance, finance and benefits**

Further context is provided by details of the practical and financial assistance that participants required. For most participants family or partners were the primary source of day-to-day assistance, occasional help and informal advice. Florence 78, Doris 88, and Pete 65 required daily assistance with personal care, which they got from family members. Neighbours and friends also had an important role:

- some participants had local family members who were themselves ill (for example: Ethel 83 – son and daughter, Lillian 78 – older sister);
- Olive 62 and Rose 82 had no local family members or partners;
- some family members already lived or were planning to move abroad (Harry 75 – daughter in Far East, Clara 86 – son moving to Southern Europe).

Participants who had “decent” pensions (for example: Ethel 83, Philip 65, Olive 62) reported using the funds to help maintain their independence. Maintaining the independence of adults living at home is the main function of MDC home care services (that is “home helps”). Two participants commented that the limited range of home care services offered would not be suitable for their needs (Ethel 83, Harry 75). For example, eligibility for home care seemed to depend on ability to wash and shop (services which

are provided), but no help was available with household cleaning. Home care services make a charge when people are eligible but have the means to pay.

Well I mean as we get older we would do with home cares and that but you see they don't do a lot. They would put me down probably for home care but you see I have me retirement pension and then I have a pension from my husband's work you see and so I don't come in for any benefits only rent and so if I got home care they say you have to pay about £7 and like and all they have been told to do is to do your shopping and your washing, well so far I manage that you see cos shopping is fairly easy and you know with little bus ((to go shopping)) and the washing you go downstairs to wash in the washroom store, so far I have managed that.

Ethel 83

Three participants had used medical consultants' assessments to help them have a shower fitted (Ethel 83, Clara 86, Lillian 78). Florence 78 wanted a shower but it couldn't be fitted in her flat and she was unable to have a whole body wash. Ethel 83 and Ruth 86 had been unsuccessful in attempts to have (respectively) smaller and cooler ovens installed in their sheltered flats. One participant's wife was his designated carer (Pete 65) and Margaret 89 was able to use her registration as partially sighted to access some services.

Since walking and carrying heavy shopping were a problem for most participants it is unsurprising that the Access Bus (provided by Metro the Passenger Transport Authority) was highly praised (Ethel 83, Rose 82, Vera 84). It took people from their homes to local supermarkets and back with their shopping. Obtaining resources to facilitate mobility was sometimes a problem. Florence's family reported that she had been offered a mobility allowance to buy a car if she could find a driver but that she couldn't find one. Tony 55 had unsuccessfully applied for Disability Living Allowance, which in couldn't claim because "they say I can walk to my front door." Olive 62 had saved enough money to buy a scooter when needed, Patricia 63 had use of an "electric buggy" and Pete 65 could only get around in his electric wheelchair.

Harry 75, Mike 56 and Anne 64 reported financial worries. Maria 76 and Vera 84 occasionally used paid gardeners, for example, to cut the grass in summer. Ethel 83 had paid for help to fit curtains in her flat. Residents in sheltered flats (for example, Ethel 83

and Harry 75) usually had a pull-cord to contact the warden in case of emergency and Ruth 86 paid a subscription for a personal alarm (neck cord). The ability to pull a cord to obtain help was useful but takes personal control and decision making power away as Ethel's quote illustrates:

**Have you ever been given any particular instructions by the doctor about what to do if you feel badly?**

Of course we have cords to pull if we are in a panic, one there and one in the bedroom and one in the hall, and you pull those and it goes straight through ((to central control)). Someone will come on and they know who you are straight away just by calling: "Hello *Mrs Jones*, are you ill?". And if you can't answer, you see if you are laid helpless and just manage to pull it, they would send someone out like but we have a warden and if she is on duty it goes to her you see and she comes but once she is off duty, during the night or any time, they send an ambulance you know paramedics like. So it's alright in one way but they have changed a lot and it's getting slower getting attention.

Ethel 83 (real name deleted)

The assistance and resources available to the participants varied considerably. Positive features were supportive families, occupational pensions and benefit entitlement. Negative features were absent (or distant) families, inadequate income for needs and difficulty with benefit bureaucracy. With regard to benefit bureaucracy participants' stated difficulties cannot be verified against entitlement criteria.

#### **4.4.4 Diet and lifestyle**

Some general health advice is common to almost everybody, for example, don't smoke, drink in moderation, take a balanced diet and exercise regularly. The first of these are appropriate for the patient participants in this study, however, exercise would need to be carefully tailored to endurance levels. Only two participants (Patricia 63 and Harry 75) were current smokers, seven were former smokers and ten had never smoked. The smoking status of Ruth 86 and Margaret 89 was unverified but there was no evidence of smoking at the time of interview. Three former smokers had COPD and four had a previous MI or CABG.

Harry (75) was one of two participants (the other was Mike 56) who mentioned regular social drinking as an activity. Harry claimed he had been told to "live life to the full",

and given advice on minimising the effect of alcohol on the control (with warfarin) of his blood coagulation. Pete 65 had also been told to “enjoy himself” and reported strange looks from professionals when he asked for dietary advice.

Only two participants had been given exercise advice: as an in-patient for Clara 86 and as part of an out-patient exercise programme for Jean 76. Only two participants had received advice on how to eat a healthy food (John 67, Mike 56). Jean 76, John 67 and Mike 56 had all been admitted to hospital with MI and/or for CABG, which seems to be why they had received some structure advice on diet or exercise. Clara’s advice was really about mobility and probably related to her chronic bone disease.

At least one-quarter of the participants had an estimated or calculated body mass index (BMI) that indicated obesity. A number of participants showed awareness of healthy diets, for example, low sugar (for example, Ethel 83) and low fat (for example, Anne 64). Only one (Olive 62) talked about recipes to actively promote good health, but some said they enjoyed good (or “proper”) food (Florence 78, Vera 84). No one mentioned salt intake, which is an important factor in health failure management. Only Philip 65 associated a question about “weight” with daily variation in water retention. Harry 75, Rose 82 and Margaret 89 had lost weight recently. Patricia 63, Lilian 78 and Mike 56 were aware of gaining weight. Tony 55 had been told that he needed to lose five stone to be eligible for certain medical treatment.

I don’t need a dietician, I don’t want to listen to a dietician. Well I am not dieting am I? I am trying to put weight on.

Harry 75

The lack of systematic advice about diet and exercise is perhaps surprising, given that all the participants had risk factors for cardiovascular events. Both weight loss and weight gain were a worry to different participants. Generally it seemed that most participants understood the components of a health diet and lifestyle, with the exception of salt restriction. However, some had practical difficulties achieving it.

## 4.5 Professional participants

The nature and range of professional participants is summarised in **Table 4.3. Section 4.5.1** concerns their relationship with the patient participants. **Section 4.5.2** concerns their role and place of work.

**Table 4.3:** Professional participant role summary

<i>No.</i>	<i>Profession</i>	<i>Sector</i>	<i>Relationship<sup>a</sup></i>	<i>Role<sup>b</sup></i>	<i>Code/Pseudonym</i>
1	EPP administrator	Primary	Indirect	Service	Jane E1
2	EPP tutor	Primary	Indirect	Patient	Felicity E2
3	Elderly care consultant	Secondary	Direct (Ruth)	Patient	Douglas D1 <sub>s</sub>
4	Cardiology consultant	Secondary	Direct (Patricia)	Patient	Tom D2 <sub>s</sub>
5	Heart failure nurse	Secondary	Direct (Harry)	Patient	Sarah N1 <sub>s</sub>
6	Pharmacist	Primary	Direct (Various)	Patient	Geetha P1 <sub>p</sub>
7	Pharmacy area manager	Primary	Indirect	Service	Susan P2 <sub>p</sub>
8	Heart failure nurse	Secondary	Indirect	Patient	Julie N2 <sub>s</sub>
9	Hospital pharmacist	Secondary	Indirect	Service	David P3 <sub>s</sub>
10	GP	Primary	Direct (Various)	Patient	Mark D3 <sub>p</sub>
11	Practice pharmacist	Primary	Indirect	Patient	Vanessa P4 <sub>p</sub>
12	Practice pharmacist	Primary	Indirect	Patient	Louise P5 <sub>p</sub>
13	GP	Primary	Direct (Various)	Patient	James D4 <sub>p</sub>
14	Respiratory consultant	Secondary	Indirect	Patient	Luke D5 <sub>s</sub>
15	Cardiology consultant	Secondary	Direct (Olive, Pete)	Patient	Brian D6 <sub>s</sub>
16	Development nurse	Primary	Indirect	Service	Nicola N3 <sub>p</sub>
17	Modern matron	Primary	Indirect	Patient	Dawn N4 <sub>p</sub>
18	Modern matron	Primary	Indirect	Patient	Jenny N5 <sub>p</sub>
19	Clinical psychologist	Secondary	Indirect	Patient	Sally C1

<sup>a</sup> Relationship with patient participants, either directly mentioned in interviews or not

<sup>b</sup> Primary role, either patient focused (clinical) or service development

### 4.5.1 Relationships

Seven professionals were identified from comments made in patient interviews and were able to comment on things said about them (or their service) directly. Two of these professionals were GPs (Mark D3<sub>P</sub>, James D4<sub>P</sub>); two were cardiology consultants (Tom D2<sub>S</sub>, Brian D6<sub>S</sub>); and one was an elderly care consultant (Douglas D1<sub>S</sub>). Only one patient participant (Harry 75) had had contact with the Acute Trust heart failure service, which was represented by Sarah N1<sub>S</sub>. Patient comments about the GPs typically reflected on the long term aspects of the relationship (rather than specific consultations), and tended to be more personal than comments about consultants. The pharmacist interviewed (Geetha P1<sub>P</sub>) managed premises linked to the GP surgery, which was where some patients usually had their prescriptions dispensed. However, patients did not always use the same pharmacy and rarely mentioned a pharmacist by name.

### 4.5.2 Roles and sectors

There were: six doctors, five nurses, five pharmacists, one EPP administrator, one EPP tutor and one psychologist; 11 worked in primary care and eight worked in secondary care. One interview was conducted with both 'modern matrons', giving 18 transcripts for analysis. In relation to self management of heart failure patients, four professionals had roles that were mainly managerial or involved service development, whereas 15 had roles that engaged in patient care and advice.

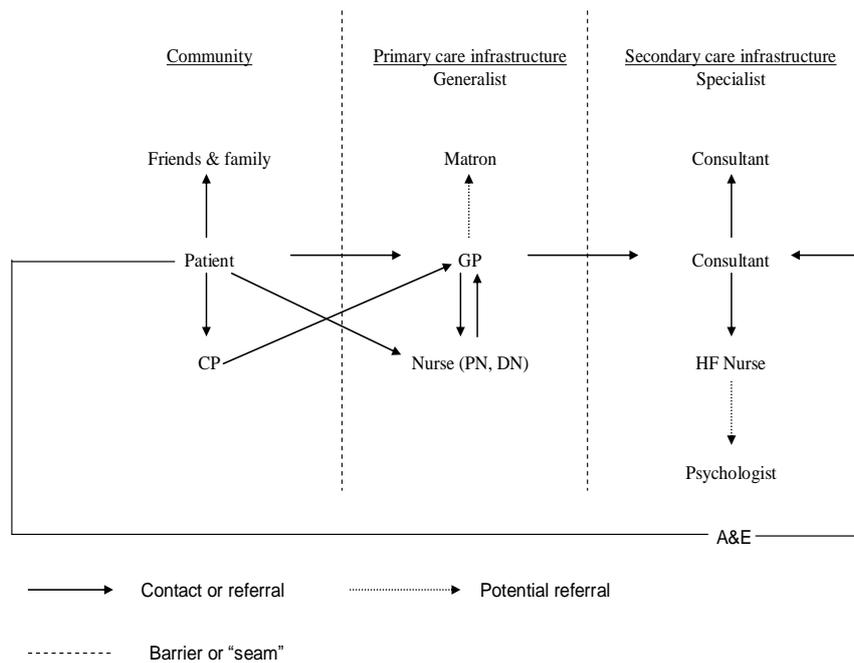
At the time of the interviews the main constituents of the local health economy were five Primary Care Trusts (PCTs), one Acute Hospital Trust (on two main sites) and one Mental Health Trust (cf. **Section 1.4.1**). Only the GPs worked in the practice the patients were registered with. The practice pharmacists and modern matrons worked in a neighbouring practice (in the same electoral ward and PCT). The EPP administrator worked in PCT headquarters and the development nurse had a pan-city role (responsible to all the PCTs, but based in neighbouring PCT headquarters). All the secondary care workers were employed by the Acute Trust (hospital). The pharmacist and area pharmacy manager were employed by (different) large retail chains.

## 5 Chronic disease behaviour and management

**Chapter 4** introduced the participants and described the impact of heart failure symptoms on people's day-to-day activity in and around the home or in domestic social situations. This chapter is about the patient participants' behaviour (literally) as 'patients', that is, interacting with healthcare professionals. It mainly concerns the counterpart themes of chronic disease behaviour (patient focused in **Section 5.1**) and chronic disease management (professional focused in **Section 5.2**). However, analysis of data from patient and professional interviews is integrated as appropriate. The chapter also illustrates some cross-cutting concepts and elements such as communication, continuity and trust.

The purpose of **Chapter 5** is to compare current disease management and styles of interaction with those proposed in models of care such as evidence based practice, concordance, social medicine and self management. Whilst different, these models share some dissimilarity to traditional paternalistic care, chiefly a higher level of patient interaction is assumed or required during and/or after consultation. Analysis of the information provided by participants is needed to determine how far there is to travel from current practice towards a more explicitly interactive or communicative model of care.

I say "explicitly interactive or communicative" because my assumption is that patients and professionals make healthcare as they work together thinking, feeling and doing. A standard economic model would consider healthcare as a commodity 'provided' by professionals and 'utilised' by patients, with the intention of improving health. However, there is no standardised commodity 'healthcare' and the factory metaphor, common in economics, breaks down substantially. It is perhaps better to consider how fluid patterns of care are created as patients tell their story (while the professional listens) and then respond to professional characterisation of their problems (including the results of diagnostic tests). The most common referral pathways (of patients to different professionals) are shown in **Figure 5.1**, this is based on data from the interviews, but in one or two cases use of a path was not actually described by a patient (shown as 'potential referrals').



*Key: CP – community pharmacist; PN – practice nurse; DN – district nurse; HF Nurse – heart failure nurse; GP – medical general practitioner.*

**Figure 5.1:** Common care pathways for participants

## 5.1 Chronic disease behaviour

### 5.1.1 Health knowledge and communication of diagnosis

A good starting point for self management would be an understanding about the nature of the condition to be treated, which may include:

- its medical label;
- degree of seriousness;
- expected duration; and
- basic patho-physiology.

Most patients lacked such an understanding (see below), particularly a clear diagnostic label. The label in itself is not important, since it is in some respects merely professional shorthand for the patho-physiology. However, an accurate label would help patients to both communicate with professionals and independently find information about their

condition, for example, in libraries or using the internet. A label may also help some patients to justify their experience to others. Findings here are consistent with the literature review, which suggested that heart failure patients: generally have poor knowledge about their condition; may not have been given (or do not recall) a clear label; and may view their condition as ‘acute’ (short term) rather than ‘chronic’ (long term). Lack of basic knowledge would imply that patients expect (*and/or are expected*) to rely on professional management.

When asked what they knew about their health problems only three patients (Harry 75, Anne 64 and Doris 88) directly mentioned heart failure. Note that Doris 88 was one of the oldest patients interviewed and that this short list of patients doesn’t include any of the youngest (in their 50s). Age is important, since advanced age is one possible reason why professionals may not want to burden patients with diagnostic information. In the statement below, Harry 75 could not be clearer (atypically) about the nature of his diagnosis:

**Right, and what things are wrong do you know?**

Well I have chronic heart failure.

Harry 75

Six other patients described functional problems (for example, valves not working or fluid overload) consistent with an understanding of heart failure. Ten patients knew that they had cardiovascular problems of some description, for example, “blood pressure” (hypertension). In most of these cases (where patients said they had or expressed either a clear heart failure label, functional understanding or hypertension) some concept of chronic duration was apparent. One patient (Mike 56) believed his MI to be “cured”, which implies an acute model of disease, and he wasn’t sure what was currently causing his chest problems. Another patient (Clara 86) just knew that she was breathless but didn’t know why. Ruth 86 was more typically unclear about her diagnosis:

I stuck it for a long time then eventually I went to t’doctors and he said it were heart trouble like.

And I have had tests and all that like. As far as I know it’s a blocked vessel.

Ruth 86

In this quote, although Ruth said she waited sometime to see the doctor in the first instance, she didn’t seem to care about not having a clear diagnosis. This suggests a

high degree of dependency on the doctor or disengagement from the healthcare process. Commenting on the level of knowledge expressed in this statement, Ruth's consultant suggests that that communication of basic information is often poor:

I think it's fairly typical of how much patients understand. We do try and explain the basis of heart failure to them but I don't think they always pick up what we are actually saying and we probably don't explain it terribly well. It'd probably be better if we, as well as trying to explain it to them, may be give them a leaflet which can describe in general terms what heart failure is and what the various treatment modalities (are) the rationale for them. I suspect we just tend to rush people and say you've got heart failure, a very brief explanation "Here's some...keep taking the tablets and we'll see you again in a month's time."

Douglas D1<sub>S</sub> (Elderly care consultant)

It is obvious from what Douglas D1<sub>S</sub> said ("keep taking the tablets") that he didn't expect much patient input and probably does not have much time to provide further explanation. Perhaps, his suggestion to provide further written information reflects time constraints or lack of confidence in his communication skills? Patients couldn't be asked directly why they didn't know they had heart failure, because this would have been potentially distressing and there were no resources to follow up the breaking of bad news. Later in the context of dose adjustment, patients were asked if they wanted to know more about their condition(s), which many didn't (cf. **Section 6.2.2**).

Symptom confusion and co-morbidity are noted in the literature as potential reasons for the lack of diagnostic clarity. However, all the patients had been clearly labelled in their GP-held medical notes as having heart failure, even if this hadn't been communicated to them for some reason. To see if there was a medical pattern to this communication problem, patients' recorded diagnoses and health status measures were extracted from their medical notes after the interviews were completed (**Table 5.1**). (NB: smoking and body mass index are discussed in **Section 4.4.4** in the context of diet and lifestyle.) Most patients had cardiovascular conditions other than heart failure, which had usually been diagnosed earlier, and illustrate the different causes of heart failure noted in **Section 1.3.2**. One-third of the patients had a diastolic blood pressure exceeding 140 mmHg (latest reading), an accepted target (Joint Formulary Committee, 2008b), thus indicting they were still hypertensive.

The earliest clear diagnosis of heart failure for a patient (structural abnormalities could be noted months before a clinical diagnosis) was in October 1991 and the latest was in November 2002 (recruitment began in December 2002). Heart failure was recorded in a number of different ways, usually as abbreviations for example: LVF or CCF.

Sometimes heart failure was listed on more than one occasion for an individual, using different terminology. It may be, therefore, that even though the general label “heart failure” is applied by the GP, the point of diagnosis and precise nature of the condition for each individual are unclear. This relates to the definition of heart failure as a syndrome or range of related conditions, rather than a single well-defined entity. Unlike heart failure there were consistent labels in the patients’ medical notes for other cardiovascular conditions, for example, hypertension, MI and AF. Generally, patients who had these other cardiovascular diagnoses were aware of them.

Cardiovascular co-morbidity data (from **Table 5.1**) has been re-ordered in **Table 5.2** to group patients with a similar understanding of their heart failure diagnosis. Of those with a relatively good understanding only Harry 75 has hypertension as a co-morbidity, whereas most of those with relatively poor understanding also suffer from hypertension. Hypertension usually precedes heart failure as a diagnosis, which suggests that those who drift into heart failure are particularly badly informed.

The words “heart failure” may also have negative connotations that make communication difficult as suggested by Patricia 63 and Anne 64 in the quotes below. Patricia’s idea of “simple heart failure” may imply that other cardiovascular problems are less serious, more complex or have less (dreadfully) predictable consequences. She may also be contrasting “simple heart failure” to her own complex diagnosis, since she was relatively well informed and knew the label heart failure had been attached to her condition in the past. Anne was very well aware that she had heart failure and is contrasting her initial thoughts with what she knows now.

**Table 5.1:** Patient general health indicators and recorded cardiovascular conditions

<i>No.</i>	<i>Code</i>	<i>Smoking status</i>	<i>BMI*</i>	<i>Latest BP</i>	<i>Repeatable medicines (CV)</i>	<i>Recorded cardiovascular conditions (earliest date)</i>	<i>Condition at June 2005</i>
1	Ethel 83	No	Low	135/68	6 (2)	CCF (Jan 2001).	Stable
2	Maria 76	No	27	156/84	8 (6)	Angina (1995); CCF, AF (Jan 1999); Hypertension (Jan 2000).	Stable
3	Edward 71	No	High	130/70	7 (7)	Hypertension (Jan 1982); AF/LVH <sup>+</sup> (Mar 1985)	Stable
4	Florence 78	Former	High	130/80	7 (1)	CCF (Jan 1994); Hypertension (Sep 2000)	Unstable
5	Clara 86	No	Low	135/85	3 (2)	Hypertension (Dec 2000); CCF (Feb 2001).	Died
6	Patricia 63	Yes	-	150/45	11 (6)	AF, CCF (Feb 1999); cardiomyopathy (Oct 2000).	Stable
7	Jean 76	Former	-	128/79	7 (5)	MI (Jun 1982); CCF (Dec 1998); AF (Apr 2002).	Died
8	Lilian 78	Former	-	131/64	12 (5)	AF (Jun 2000), LVF (July 2000).	Stable
9	John 67	Former	31	80/60	15 (7)	Angina (Oct 1997); CCF (Jan 1999).	Stable
10	Harry 75	Yes	Low	198/112	10 (5)	Hypertension (Oct 1998); CCF, AF (Feb 2002).	Died
11	Mike 56	Former	33	110/70	11 (6)	LVF, Inferior MI (Nov 2002).	Stable

<sup>+</sup> Left ventricular hypertrophy, then HF listed Oct 1991.

**Table 5.1:** *continued*

<i>No.</i>	<i>Code</i>	<i>Smoking status</i>	<i>BMI*</i>	<i>Latest BP</i>	<i>Repeatable medicines (CV)</i>	<i>Cardiovascular conditions (earliest date)</i>	<i>Condition at June 2005</i>
12	Philip 65	No	Low	140/80	10 (9)	MI (Mar 1993); Angina (Oct 1995); CCF (Jun 2001).	Died
13	Tony 55	No	45	110/70	8 (4)	LVF (Aug 2000).	Stable
14	Ruth 86	-	-	146/70	10 (5)	Hypertension (Aug 2000); CCF (Mar 2002).	Stable
15	Olive 62	Former	Low	110/70	10 (4)	Cardiac failure (Nov 1999); AF (Jan 2000).	Died
16	Anne 64	Former	28	102/62	8 (7)	MI (Jan 1976); Angina (Oct 1999); LVF (Jun 2002).	Stable
17	Doris 88	No	-	165/89	5 (3)	Heart failure (Feb 1996).	Died
18	Rose 82	No	Low	160/80	3 (3)	AF (Mar 2000); Cardiac failure (Nov 2000).	Stable
19	Margaret 89	-	-	170/70	6 (4)	Hypertension (Sep 2001); LVF (Sep 2002).	Stable
20	Pete 65	No	29	-	7 (3)	Cardiac failure (Mar 2001).	Stable
21	Vera 84	No	29	130/80	5 (3)	Heart failure (Mar 1999); Hypertension (Dec 1999).	Stable

\*Low/high indicates estimate. Figures are actual calculated values from height (in metres) and weight (kg/m<sup>2</sup>).

Terminology as used in clinical notes: CCF (congestive cardiac failure); AF (atrial fibrillation); MI (myocardial infarction).

**And have you got any idea how it may further develop have you been given any clues from the doctor?**

Yes, if it's left alone then it's inevitable what will happen, a heart attack or just a simple heart failure and death so the operation is necessary.

Patricia 63

**You said, you were talking about the word heart failure and you know what you thought it is and what you know it is now.**

Well, yeah, because I mean if you say heart failure your heart fails, you drop dead don't you? That's what you think any how.

Anne 64

Anne and Patricia's GP agreed that heart failure was hard to explain, he described both the psychological problem of breaking bad news and the practical consequences of a longer consultation:

I think a lot of time we don't actually give them a diagnosis. I think we just, we frequently say that the heart just isn't working as well as it should be now and that we need to give them extra support to enable the heart to work better. They don't know what heart failure (is), or they have not been told they have heart failure, I think it is a fear of the reaction that people, the reaction we are going to get from people and the extra time we are going to have to spend talking (to) them. As soon as you say "heart failure" the look of horror on their eyes faced with the, they're given that diagnosis that it does mean that they are probably going to, that the heart has failed and that there is nothing we can do about it.

Mark D3<sub>p</sub> (GP)

The comments from Mark D3<sub>p</sub> (above) and Douglas D1<sub>s</sub> (earlier) suggest that, rather than forgetting what they have been told, many patients have either not been told about their diagnosis or are confused by *ad hoc* explanations. Both Mark D3<sub>p</sub> and Douglas D1<sub>s</sub> offered time as a barrier to clear communication; for Mark D3<sub>p</sub> this was time dealing with highly emotional patient reactions. For clinicians the reasons to give clear information (respecting autonomy, allowing patient input, prompting self management) may not outweigh the disadvantages (psychological impact, increased consultation time, need for diagnostic precision). Mark D3<sub>p</sub> and Douglas D1<sub>s</sub> are generalists in their respective settings of primary and secondary care who saw many heart failure patients in the context of a more varied workload.

**Table 5.2:** Knowledge of heart failure diagnosis and prevalence of other cardiovascular conditions

<i>Knowledge of heart failure</i>	<i>No.</i>	<i>Code</i>	<i>Recorded cardiovascular conditions (earliest date)</i>	<i>Condition at June 2005</i>
Used the words 'heart failure' in relation to their current diagnosis.	10	Harry 75	<b>Hypertension</b> (Oct 1998); CCF, AF (Feb 2002).	Died
	16	Anne 64	MI (Jan 1976); Angina (Oct 1999); LVF (Jun 2002).	Stable
	17	Doris 88	Heart failure (Feb 1996).	Died
Described functional problem specifically related to heart failure.	6	Patricia 63	AF, CCF (Feb 1999); cardiomyopathy (Oct 2000).	Stable
	12	Philip 65	MI (Mar 1993); Angina (Oct 1995); CCF (Jun 2001).	Died
	13	Tony 55	LVF (Aug 2000).	Stable
	15	Olive 62	Cardiac failure (Nov 1999); AF (Jan 2000).	Died
	18	Rose 82	AF (Mar 2000); Cardiac failure (Nov 2000).	Stable
	20	Pete 65	Cardiac failure (Mar 2001).	Stable
Described problem with heart or circulation not specifically related to heart failure.	1	Ethel 83	CCF (Jan 2001).	Stable
	2	Maria 76	Angina (1995); CCF, AF (Jan 1999); <b>Hypertension</b> (Jan 2000).	Stable
	3	Edward 71	<b>Hypertension</b> (Jan 1982); AF/LVH <sup>+</sup> (Mar 1985)	Stable
	4	Florence 78	CCF (Jan 1994); <b>Hypertension</b> (Sep 2000)	Unstable
	7	Jean 76	MI (Jun 1982); CCF (Dec 1998); AF (Apr 2002).	Died
	8	Lillian 78	AF (Jun 2000), LVF (July 2000).	Stable
	9	John 67	Angina (Oct 1997); CCF (Jan 1999).	Stable
	11	Mike 56	LVF, Inferior MI (Nov 2002).	Stable
	14	Ruth 86	<b>Hypertension</b> (Aug 2000); CCF (Mar 2002).	Stable
	19	Margaret 89	<b>Hypertension</b> (Sep 2001); LVF (Sep 2002).	Stable
	21	Vera 84	Heart failure (Mar 1999); <b>Hypertension</b> (Dec 1999).	Stable
Didn't describe diagnosis.	5	Clara 86	<b>Hypertension</b> (Dec 2000); CCF (Feb 2001).	Died

Harry 75 was the only patient to have attended the Acute Trust's nurse-led heart failure clinic. With regard to the lack of clear communication about the diagnosis of heart failure, one of the specialist nurses said:

I feel very strongly that heart failure is like cancer was 20 years ago. You know when we used to say you had a growth or you know something like that, you would never quite say the 'C-word'. Whereas, now we are very open and honest about it and I think hopefully in 20 years time people will be told they've got heart failure as soon as they've got it. I think you know we live in a day and age now where we should, we can't withhold diagnosis from patients, people need to know, for whatever reason, be it planning their life or their career or you know any aspect of their life it's very important.

Julie N2<sub>s</sub> (Heart failure nurse)

The difference between then and now with respect to cancer seems to be that people understand that cancer outcomes are variable, and people perceive that there are some effective treatments. Therefore, when given the diagnosis of cancer one is more likely to ask "How bad is it doctor?" or "What can you do?" (and listen to at least part of the answer) than breakdown completely. Lack of (lay) familiarity with heart failure may lead people to conclude quickly what seems most obvious and trigger a more emotional response.

In addition to heart failure's perceived awfulness and its lack of diagnostic precision, the difficulty of clear communication is compounded by confusion with other conditions especially lung problems. This is illustrated by Mike 56 a patient recently sent by his GP to the local chest clinic:

**So what do you know about your health. What do you know about what's up?**

Well according to the doctor ((GP)), he says everything seems to be getting a lot better and he's advised err he sent me to the chest clinic two or three weeks ago. Cos I can't breathe very well. He said well you should be alright cos everything's alright so I'll send you to the chest clinic. Got reports back, it says there's nowt wrong with my chest.

Mike 56

In the above quote, we see that Mike 56 perceived himself and his GP as being equally baffled by the nature of his symptoms. Luke D5<sub>s</sub> (a respiratory consultant) explained that this type of confusion is frequent, partly because smoking (Mike 56 was a smoker until he had an MI) is a common primary cause of heart and lung disease.

... so if you've got a group of people that have smoked for twenty or thirty years it's not surprising that there will be some people who've only got heart problems, some people who've only got lung problems and a group of people who've got both and that is an accurate situation. The problem I think, certainly in COPD, when we screen GP practices about 20% of patients labelled as having COPD don't even have it so there's a big mis-diagnosis rate in the community ... I can think of a couple of patients referred to me for query "Should this person have home oxygen for COPD?" they've actually had heart failure and no evidence of COPD at all so I think the answer is, it is difficult for some of the non-specialist healthcare professionals to tackle this and one of the ways that we've been getting round this is, we've now got community COPD teams promoting spirometry in GP surgeries which is like...which is basically an objective test and if that's normal you don't have COPD so I think step one in allowing patients to self-manage is to make sure that you're clear what disease they're self-managing.

Luke D5<sub>s</sub> (Respiratory consultant)

Luke D5<sub>s</sub> was an advocate of self management and saw himself as able to identify and treat those heart failure patients referred to him for whatever reason (cf. further quote below). He clearly identified the clinical need for diagnostic clarity, which implies spirometry in the case of COPD and an echo in the case of heart failure. Providing such tools in the primary care setting clearly has resource implications, but this is the direction that the health service is travelling in (Darzi, 2008). Harry 75 also had detailed consultations with respiratory specialists before being referred to cardiology. Luke D5<sub>s</sub> said (below) some patients with heart failure did not see a cardiology consultant, which he thought could be clinically appropriate. However, it may not aid patient understanding, if patients' knowledge of their condition is influenced by the speciality of their consultant. This seems likely and was apparent elsewhere in a reference by John 67 to the "lung man" he had seen.

You have to remember that a lot of patients ... if you're a GP and you see somebody who's got chest pain and it's vaguely possibly angina, you'll be sent to a cardiologist and that cardiologist may well discover heartburn or a lung problem. If you're just breathless, most GPs will send you to a chest consultant and therefore we actually pick up a large number of people with heart failure as part of our routine and we would consider that we are able to manage that so we would put them on their diuretics, their ACE inhibitors, beta blockers, spironolactone, whatever else; we'd arrange the echo; the ECG and do all that; we wouldn't cross refer to a cardiologist necessarily unless we thought it was valvular heart disease.

Luke D5<sub>s</sub> (Respiratory consultant)

Regardless of Luke's professed competence, it seems self evident (if specialist training has a purpose) that patients should normally be cared for by a consultant in a speciality matching their primary long term condition. What may overcome the lack of clear communication, influenced by diagnostic confusion and concern about patient anxiety, is if professionals perceived that patients had an obvious 'need to know'. James D4<sub>P</sub> (a GP) suggested that a poor immediate prognosis is one such need:

I think if they've got severe heart failure its easier to, I think it's important that they know, it's like, it's a bit like, I think you can compare it to the cancer thing can't you? I mean there's certain (cancer like) disease, you treat and they can form invasive cancers years later but you wouldn't be able to tell if they're going to die from that, probably not but if somebody's got a melanoma then I think you've got to tell them exactly (why) it is so severe. Heart failure's like that really and they're obviously very symptomatic. I think they must, I think you've got to tell those people what's going on. Like that lady really ((Vera 84)), didn't know she had anything wrong with her heart, she err people like that, it's not really that helpful to tell them I would say.

James D4<sub>P</sub> (GP)

Vera 84, who James D4<sub>P</sub> referred to, was puzzled to be told by me that her GP thought she had heart problems of any description, although she knew she had "blood pressure". She was relatively active (but needed help with heavy shopping and some gardening) and mentally very alert. It may be "helpful" in her case to explain the reasons for the symptoms of breathlessness she had been experiencing, and perhaps prepare her for future deterioration. However, there may not be anything practical she could currently achieve armed with the additional information.

Tom D2<sub>S</sub> (a cardiology consultant) hinted at similar reasoning to James D4<sub>P</sub> as he explained the range of physical functioning covered by the heart failure label:

I think the words do seem scary, and I think, and I think sometimes people, don't, don't use the words when they should do; and sometimes they use them inappropriately. One of the difficulties is that the, the heart failure diagnosis has been extended recently. Heart failure used to mean symptoms; heart failure used to mean breathlessness, ankle swelling, you know couldn't lie flat and all that kind of stuff and that was heart failure and those were the symptoms of heart failure. And, and that's caused by your left ventricle not pumping properly and what's happened is that as we've had techniques to investigate that, with echo and things, a huge number of patients have been unearthed where the left ventricles don't

function properly, may be because of coronary disease, or hypertension or valve disease but actually they don't have much in the way of symptoms. They're not very breathless, you know they can have fairly normal activities and there's a kind of issue about whether you call them heart failure and most people tend not to call them heart failure and most people say this is, left ventricular dysfunction or sub-normal functioning of the left ventricle or something but they try to steer, steer, away from the heart failure label. Heart failure really is the group with symptoms, breathlessness, but if you look at the studies, often the studies will include this large group of relatively asymptomatic patients.

Tom D2<sub>s</sub> (Cardiology consultant)

Despite such concerns and even if patients' role in clinical management is limited, it could be argued that they 'need' (instrumentally) some basic knowledge about their health status, diagnoses and treatment (Raynor et al 1993). This should allow them to notice any worsening of symptoms and communicate facts to others as necessary (for example, at the dentist or community pharmacy). The majority of patients seemed to know just enough to prevent medical mishap. In fact, problems in communication were not necessarily restricted to heart failure; for example, Margaret 89 reported that she had never been told she'd had a stroke but had seen it written down.

To participate in self management, much better understanding than that demonstrated above is required, which only a minority of patients had and many professionals would not willingly provide. It's not clear whether professionals' 'need to know' strategy is self-serving (for example, to limit consultation length) or merely paternalistic. Luke D5<sub>s</sub> cautioned against "truth dumping" in which patients are told the full truth (usually bad news about a terminal prognosis) for no particular purpose and with no time to assess the psychological consequences. Truth dumping is believed to be bad by some doctors partly because it takes away hope (Ardalan, 2005) (Christakis, 1999).

Hope is a positive consequence of the coping strategy 'disavowal', that is, the positive reconstruction of the meaning or significance of a threat, which was described in **Section 2.3.5** (Buetow et al., 2001). Aspects of this and the other coping strategies described by Buetow et al are apparent in patients' interview statements. In addition, professionals seem to be engaged in disavowal on behalf of patients: fearing that

patients' own coping strategies in the face of bad news will be sub-optimal. The ethics and sustainability of this management strategy may be questionable.

Perhaps 'planned disclosure' would be a better goal of patient-centred practice in most circumstances? Planned disclosure is more usually associated with patient choice about when to tell others about their diagnosis, and for what reasons. For example, Charmaz (1991) (cited by Joachim & Acorn, 2003) states that 'protective disclosure' is planned disclosure with the hope of a positive outcome. It seems that a fear of negative outcomes prevents professional disclosure to patients. Paradoxically, the myth that heart failure relates to immediate and/or certain death is perpetuated by this.

If more time were taken to explain more details to more patients, then in time a folk understanding of heart failure should build up. This seems preferable to changing the name of heart failure to something more palatable, which has been suggested without consensus being reached (Lehman, Doust, & Glasziou, 2005). Words matter but there is a general understanding of the term 'heart attack', used openly by professionals, the unpleasantness of which is illustrated by a Stroke Association awareness raising campaign that renamed 'strokes' as 'brain attacks'.

### **5.1.2 Medicines and adherence behaviour**

Most patients interviewed were not clear about their diagnoses, but they were all certainly being prescribed treatments for their various conditions. A column in **Table 5.1** provides the total number of medicines (and in brackets the number of these related to cardiovascular conditions) each patient was able to order on a repeat basis without further medical consultation. Medical information and perception of clinical need are believed to have a positive influence on patients' medication adherence (cf. **Sections 2.1.2** and **2.3.3**). A wish to encourage adherence behaviour may provide one reason for professionals to communicate more clearly with patients. This is not apparent in professional quotes above that question the point of giving more (or clear) information to patients with few symptoms. This implies that doctors may rely on the authority of their recommendations to encourage adherence not the patients' reasoned actions. It is important, therefore, to understand both what medicines are being prescribed and if

patients report adherence to this therapy. The literature suggests that both prescribing and adherence will be sub-optimal, however, medication adherence is likely to be better than adherence to healthy lifestyles (cf. **Section 2.1.2**).

The basic components of drug therapy for people with heart failure are described in **Section 1.3.3**. In practice the most important medicines are ACEIs or ARBs, since evidence suggests they reduce mortality, and diuretics, which reduce fluid overload and control breathlessness. The use of beta-blockers (especially issues around initiation of therapy) has been more controversial (Petty, Silcock, Zermansky, & Raynor, 2007), even though it is recommended in most cases, and the use of digoxin (historically used for stimulating heart function) has declined. The range of cardiovascular medicines patients were taking is summarised in **Table 5.3**.

Comparison of **Table 5.3** and evidence based treatment for mild-moderate heart failure (**Section 1.3.3**) suggests possible under treatment with ACEIs (or the equivalent) and beta-blockers. By June 2005, of six patients not prescribed an ACEI or ARB three were dead (Jean 76, Philip 65, Olive 62), one was in an unstable condition (Florence 78) and two were in a stable condition (Lillian 78, Margaret 89) (cf. **Table 5.1**). Although these outcomes are worse than the group in general this is not a representative sample and the reasons for not prescribing particular drugs for individuals (which may have been valid) were not explored in this study.

Non-cardiovascular co-morbidity was common, but has not been reported in detail because distinctive combinations of (sometimes rare) diagnoses together with details presented elsewhere might compromise patient confidentiality. Only four patients were only prescribed medicines for cardiovascular disease. One-third were being treated for respiratory conditions (COPD or asthma), two-thirds were prescribed painkillers (for example, for osteoarthritis) and one-third were prescribed laxatives. Therefore, the total amount of medication prescribed presents patients with a significant burden and risks possible disruption of domestic or social activities.

**Table 5.3:** Summary of cardiovascular medicine taken by participants

<i>Medicine</i>	<i>Primary mechanism of action</i>	<i>No (%) taking</i>
Diuretics	Reduce fluid overload	20 (95)
ACE inhibitors	Reduce blood pressure	13 (62)
Aspirin	Decrease platelet aggregation	11 (52)
Nitrates	Dilate blood vessels	10 (48)
Warfarin	Reduce blood clotting	8 (38)
Statins	Reduce blood cholesterol	7 (33)
Digoxin	Stabilise heart rhythm	6 (29)
Beta-blockers	Slow heart rate	5 (24)
ARBs	Alternative to ACEIs	2 (10)
Alpha-blockers	Reduce blood pressure	2 (10)

Patients were usually aware that they took “water tablets” and that these helped to remove fluid from their ankles (for example, Ethel 83) or lungs (for example, Philip 65, Olive 62 and Pete 65). This basic understanding may be facilitated by the obvious effects (going to the lavatory) and common name for diuretics (“water tablets”). So patients may understand the (obvious) effects of some treatments even if they do not fully understand their diagnosis or the reasons for fluid accumulation. It was unusual to link fluid build up to poor functioning of the heart, which is to be expected given most patients limited diagnostic awareness. Exceptions to this were Philip 65, Tony 55 and Pete 65 – all three of whom had relatively good diagnostic awareness (cf. **Table 5.2**), for example:

Well what they're doing ((his medicines)) is what they're doing it's. One's bringing the thickness of the blood down, one's keeping the heart pumping and one's keeping the fluid going round. It don't always bloody work but it's supposed to.  
Tony 55

Because my heart wasn't strong enough to get the liver working properly. With the liver not working properly I was getting fluid in my lungs.  
Pete 65

Tony 55 (above) hinted at some dissatisfaction with his treatment, which was also apparent elsewhere in his comments. Neither Tony 55 nor Pete 65 exhibit total clarity in their statements. Pete's involvement of the liver in his comment probably requires some explanation, which is best provided by a respiratory consultant:

I think he's mis-understanding. What he's probably thinking is, if the left side of your heart doesn't work very well, you get the fluid in your lungs, you then get back pressure through the right lung which then gives you congestive cardiac failure which gives you leg swelling but also an enlarged liver so I think his analysis isn't quite right but the elements are all in there.

Luke D5<sub>s</sub> (Respiratory consultant)

Patients did refer to taking tablets for blood pressure (for example, Patricia 63, Margaret 89, Vera 84) or cholesterol (for example, Pete 65). This information may come verbally from practitioners or from reading the patient information leaflets (PILs) in medicine packaging. The PIL for the ACEI ramipril (prescribed to 7 patient participants) lists three main indications linked to: blood pressure, heart failure and heart attacks. Ethel 83 describes reading a PIL for the first time, which we know most patients do when initially prescribed a medicine (Raynor, Silcock, Knapp, & Edmondson, 2007):

And then they put me on these tablets and then when I read the leaflet for the tablets I realised one were for blood pressure and the other was heart, but actually nobody sat down and explained it to me like.

Ethel 83

Ethel 83 clearly illustrates the capacity to understand more, even if no one considers it important enough to facilitate the process. Patients' expectations for the effectiveness of their medicines were usually quite vague, typical statements included hopes that they would "improve me" (Edward 71) or "keep me going" (John 67). Rose 82 was more specific:

But they said it's ((the diuretic)) to stop water building up around me heart.

Rose 82

With regard to adherence with medicines the patient participants split into three groups, those that said they:

- never vary from prescribed times and doses;
- occasionally or exceptionally vary from prescribed times and doses;
- routinely vary from prescribed times and doses.

These groups are compatible with a more comprehensive classification (including several sub-groups) of accepters, modifiers and rejecters proposed in a synthesis of qualitative studies of medicine taking (Pound et al., 2005). The first group comprises the majority of participants, including 4 out of 7 men and half the women. The second comprises just 1 man and half the women: Ethel 83, Maria 76, Florence 78, Lillian 78, Olive 62, Anne 64, Vera 84 and John 67. Only Harry 75 and Tony 55 are in the later group; Patricia 63 and Pete 65 reported that they had varied times and doses in the past but wouldn't do so now. There is no clear pattern linking this adherence behaviour with heart failure knowledge (**Table 5.2**) or age. In fact, Harry 75 and Tony 55 (who routinely vary from prescribed times and doses) are among the best informed. What they both lack is a respect for rigid authority: Tony 55 is dissatisfied with his medical treatment; and Harry 75 had medical orders to "live life to the full" (in his recollection).

Most patients simply trusted their doctors to prescribe medication that was needed, and did their best to take that medication as directed. Occasional variation was usually linked to the effects of diuretics, which is common in the literature. Participants reported not taking them when travelling (Ethel 83), or going shopping (Maria 76, Lillian 78) or visiting friends (Anne 64). The prompt for this behaviour was sometimes the influence of others. Ethel 83 said she was instructed by letter not to take her diuretics on the day of travel to a seaside convalescent home. Maria's sister insisted she did not take her diuretics if they were going out together (Maria 76). Florence 78 was asked "Have you *got* to take your water tablet?" by a family member (emphasis added). The effects of diuretics are seen by most taking them as a symptom to be managed alongside those of disease. This symptom (the urgent need to urinate) was most troublesome in its social context, hence the influence of others on adherence behaviour. Patients responded to social pressure by not taking diuretics or delaying the dose, they did not try to defend a necessity to take their tablets at a particular time.

The adherence behaviour of Harry 75 and Tony 55 was complex in that they did take some medicines (including diuretics) but not others. They had each identified elements of their regimens that made no discernible difference to their (relatively) short term health status. Harry's example is interesting because one goal of the NICE approved strategy for dyspepsia is to return patients (whatever the diagnosis) to self care and stop

regular acid suppressing medication (Newcastle Guideline Development and Research Unit, 2004). Harry 75 was doing what professionals should probably be asking him to do. However, if he was still ordering tablets that he was not taking, then this would be a waste of resources.

I don't take the heart tablets, I am supposed to take some stomach tablets ((omeprazole 20mg)) but I've stopped taking them.

**Right, you don't take those. Why did you decide to stop?**

I don't know, I just stopped and I have been alright ever since. That's about 3 months since.

Harry 75

They're the ones I can play around with. ((Analgesics?)) ... as long as I don't over do the, but the others are compulsory ... there's no way out of them ... I've tried it once before. ((Laughter))

**It's not a good idea?**

I don't try, I don't try stupid things twice.

Tony 55

Neither Harry 75 nor Tony 55 described a particular rationale for their initial decision to stop taking some medication. However, less fundamental modifications to diuretic regimens are carefully justified: patients had a reason for not taking them, they didn't "just stop". The need to provide justification and blame the influence of others perhaps suggests an awareness of the importance of diuretic therapy, even though this may not be strongly defended at the time of non-adherence (see above). A sense of importance may be reinforced by bad experiences such as the one Tony 55 alluded to in the quote above. Worsening health was the main reasons why Patricia 63 and Pete 65 said they now had higher levels of adherence:

Yes, I am very poor or I was very poor at taking the frusemide because it is so anti-social and we are here, there and everywhere, and of course once you have taken it, you are virtually looking for toilets which is rather difficult. But now because the leaking valve is so much worse I know I have got to take it so it wasn't a problem it was just my arrogance really.

Patricia 63

I did mess about with the tablets ... and I wish to hell I hadn't ... I was convinced it was my tablets that were doing it ((causing side-effects)) and not consulting the doctor to say "Look I've got problems."

Pete 65

Regularly not taking diuretics when prescribed, therefore, tends to reinforce the need for the prescription in the first place and promotes higher levels of adherence. Though it is occasionally a troublesome (pseudo) symptom, diuresis is of course one of the main therapeutic effects of diuretics. Some patients had suffered side-effects in the past, which caused them to stop taking a particular medicine before first consulting a doctor (Maria 76 – ACEI induced cough, Lillian 78 – urinary retention, Margaret 73 – itchiness and dizziness).

The patients' actions in these cases were rational and probably clinically appropriate. However, if patients are not told what particular medicines are for, then their ability to make sensible independent decisions is somewhat restricted. The overall experience of the participants tends to reflect evidence in the literature that low adherence is associated with side-effects or interference with lifestyle, and high adherence is associated with perceived necessity or symptom control (Horne et al., 2005) (Pound et al., 2005).

Sometimes the necessity of medicines was demonstrated to patients by a deterioration in health following unauthorised variation. More commonly it was taken on trust, that is, if the doctors said it was needed then it must be. The foundation of this trust appears to be confidence in doctors' formation (education, training and experience). Trust is not necessarily linked with commitment in this context but both are seen as key factors in (business) relationships that promote co-operation (Morgan & Hunt, 1994). Doctors clearly rely on trust to promote adherence and patients demonstrate their trust handsomely. This means that with few exceptions the initial conditions for concordance or therapeutic alliance are present; patients sometimes reported moving from a GP that they no longer trusted.

However, while taking the tablets was generally perceived as necessary, the tablets themselves were not seen as desirable perhaps because there were sometimes so many to take (cf. Maria 76 and Jean 76). Trust expressed in doctors' abilities to prescribe was not complemented by statements of trust in the companies that actually make the medicines, or the public authorities that allow marketing. This is compatible with views

expressed in a wider survey (Raynor, Silcock et al., 2007). If a doctor expressed support for a policy initiative like self management, then it would add credence to it from the patient's perspective. Similarly, if doctors don't express support in initiatives then patients are unlikely to participate unilaterally.

At least half the participants had some sort of system to help them remember when to take tablets. This is also a feature of literature on adherence behaviour. The use of these systems, or personalised strategies, tends to illustrate both the perceived importance of adherence and the practical difficulty of achieving high levels. Low levels of adherence have been associated with system breakdowns at times of stress, rather than deliberate intention (cf. **Section 2.3.3**). There were formal re-packaging systems in use, that is, so-called 'multi-compartment aids' (MCAs) such as the Dosett box: Maria 76, Edward 71, John 67, Ruth 86 and Rose 82. There were also informal 'placement' systems, in which participants simply placed the medicines in a particular room, order or location to facilitate administration. For example: popped out into egg cups (Jean 76), on a table (Mike 56), lined up in a box (Philip 65), in the bedroom (Anne 64) or on a special tray (Vera 84). The use of egg cups as a compliance aid has been previously reported (anecdotally) (Atkin, Finnegan, Ogle, & Shenfield, 1994).

Informal systems seem to be self-willed attempt to integrate medicines taking into daily life (as the variability in practice suggests). Formal systems were sometimes suggested by (or supported by) family members, for example, a friend (Edward 71), wife (John 67) or daughter (Ruth 86). Lillian's sister had also suggested a MCA which was too small for all her medicines. Such family involvement was usually tolerated rather than welcomed. Use of an MCA suggests reinforcement of a medical model (it is important take medicines at the appointed time) and a level of dependence. Whereas, the timing of diuretic doses can be quite flexible (without harming health) and even high adherence can be coupled with some personal creativity, as the participants' own systems demonstrate.

### 5.1.3 Medical information

So far in this chapter we have seen relatively high levels of reported medication adherence despite relatively low levels of medical knowledge. Patients' behaviour was influenced by their own experience of symptoms and side effects; and by the expressed opinions of friends, family and doctors. Nevertheless, some improvement in levels of knowledge seems desirable if a concordance model of consultation is to be encouraged and in particular to support clinical self management. As we have seen patients do self manage but generally within an experiential rather than a holistic (or fully rational) framework. While what (knowledge) should be communicated is fairly clear in the literature, how it should be communicated is less clearly elucidated. Here patients' current practices and preferences with respect to gaining medical knowledge are explored.

**Sections 5.1.1** and **5.1.2** described some of the information and attitudes that the patient participants held in relation to the aetiology, diagnosis, treatment and prognosis of their heart failure. The way in which the diagnosis of heart failure was (or more frequently was not) communicated was also discussed in **Section 5.1.1**. To explain how patients come to assimilate all their information and attitudes would be a project in itself. However, the source of current knowledge and preferred means of communication are important for two general reasons: to enable the design of future communication around preferences; and to compare preferences with current practice.

The doctor (usually the GP) was the first port of call for medical information in the opinion of almost all the participants. Only Harry 75 expressed an active preference for the pharmacist because it saved a walk up a hill to the doctor's surgery. Jean 76 and Olive 62 would use either the doctor or the pharmacist. Ethel 83 and Lillian 78 would ask the pharmacist a question within his perceived sphere of competence, that is, medicine name changes or self-medication with over-the-counter (OTC) remedies respectively. Florence 78 said she would never use the pharmacy because there are too many to choose from. The information received verbally from doctors seems to be both trusted and perceived as definitive.

Newspapers and television weren't trusted sources of information, but to some extent books (Tony 55, Olive 62), specialist magazines (Anne 64) and the internet (Philip 65, Pete 65) were. Some patients were able to ask for (or received) advice from family members who were nurses or had health-related training (Maria 76, Tony 55, Ruth 86, Pete 65). Participants tended to express a preference for verbal over written information but the utility of both (for example, in combination) was appreciated (Harry 75, Patricia 63). This is consistent with a systematic review, which suggests patients give priority to verbal information (Raynor, Blenkinsopp et al., 2007). Only Mike 56 was critical of verbal information provided by professionals finding it very repetitive:

But I think there's a limit to what they can tell you ... when I was in hospital I got bored with them telling you, they'd come in every day telling you what to do ... and I thought "Oh! It goes in it comes out, I'm sick of hearing this."

**Yeah**

I know they're trying to help you and all that like but tell you once and that's enough you know? They were telling you every day the same thing ... you're just bored after being told the same thing every time ... and everybody tells you the same thing more or less anyway.

Mike 56

Some of what Mike 56 says here illustrates the promise and the danger of multi-disciplinary team work. He may have found it boring but at least Mike 56 recalled being given consistent messages (during his admission for MI). It should be possible for professionals to find a way to communicate to each other what a patient has heard (or wants to hear) and what still requires reinforcement (or should be avoided). A greater danger is that team members communicate "more or less" the same thing, which may generate doubt or uncertainty. We see how uncertainty prevents doctors from communicating clear heart failure diagnoses and prognoses. We should also expect uncertainty to be a barrier to patients' perceived abilities to participate in care and influence outcomes (that is, their self-efficacy expectations).

Written information was seen as particularly useful as something to refer back to if memory was poor (Philip 65, Olive 62, Rose 82), which supports the line of reasoning offered by Douglas D1<sub>s</sub> (an elderly care consultant) in **Section 5.1.1**. In line with a recent survey (Raynor, Silcock et al., 2007) participants only tended to read the PIL for

new medicines (John 67, Rose 82) or no longer bothered to read them (Patricia 63, Tony 55).

**There are also leaflets these days in with your medicines, do you read those?**

We both used to do but we stopped because of course legally they have to put everything and when you look at the list of those side-effects, you would be throwing your medication away. Although I do realise they have to put them down. But I have read just once the leaflets for each of the things we take and we are very fortunate we don't suffer any of the side-effects but I don't read the leaflets now. ((Refers to herself and partner))

Patricia 63

The information in PILs was criticised for not being personal (Ethel 83) or raising unnecessary concerns (Pete 65). A lack of personalised information for heart failure patients has also been reported elsewhere (Boyd et al., 2004). There is some evidence that, for unfamiliar medicines, patient-centred (personalised) information leads to better recall and understanding than standard information (Morrow et al., 2005). Patient-centred information is developed to match patients' physical and cognitive abilities using principles such as logical flow, large print, simple language and reinforcing icons (pictograms). Queries prompted by the PIL or in media reports (for example, newspapers: Maria 76) would be raised with the doctor for his (sic) comments. Common issues included the experience (or risk) of side-effects (Margaret 89) and the influence of co-morbidities on the safety of medicines prescribed (John 67, Mike 56).

In summary, for these patients the doctor was the most used and the most trusted source of advice. Patients were aware that other sources of information were available but they may be perceived as inappropriate, untrustworthy or not personalised. The desire for personalisation and a preference for verbal information may suggest that patients did not have (or perceive they didn't have) the skills (or the inclination) to apply general messages to their own situation. The need for personalisation suggests that patients perceived their situation as unique and that it required a particular response, which is in many ways appropriate and understandable. It may be that the validation provided by the doctor is transferable and depends partly on the consultation environment. The heart failure nurses (Sarah N1<sub>S</sub>, Julie N2<sub>S</sub>) and practice pharmacists (Vanessa P4<sub>P</sub>, Louise P5<sub>P</sub>) reported little difficulty persuading patients to take them seriously in environments similar to the GP consulting room.

## 5.2 *Chronic disease management*

The most common self management behaviours with which patients reported engagement were:

- symptom monitoring;
- rest;
- medication adherence;
- activity restriction; and
- diuretic timing adjustment.

The first three are recommended self management behaviours (cf. **Table 2.1**), the ‘status’ of the last two is uncertain. These behaviours may not be recognised or seen by professionals (still less supported by them), but medication adherence routines and diuretic timing adjustment can be fairly complex activities. Rest and activity restriction (in response to symptoms) were largely an accepted part of life for older patients. They presented more difficulties for patients of working age whose role and identity suffered enforced premature change. Medication adherence was mostly a response to authoritative medical instruction and diuretic timing responded to social pressures. At times, however, medical review was necessary or a patient’s equilibrium was disturbed: at which point formal care was called upon. The nature of this formal care is explored here for the reasons outlined in the chapter introduction, that is, to determine how straightforward the integration of more (supported) self management activities would be.

Patients describing episodes of care tended to characterise them according to the setting, the personnel involved and the actual intervention in roughly that order of priority. In the conceptual framework (**Appendix 8**), the *concept* ‘medical care’ (**Sections 5.2.1 to 5.2.3**) is defined as care provided by doctors and ‘related care’ (**Section 5.2.4**) is defined as care provided by other healthcare professionals. Within the *concept* medical care (which is the more important of the two concepts in this context) three *elements* represent settings (general practice, hospital, emergencies; **Sections 5.2.1 and 5.2.2**) and two *elements* represent issues which emerged from the interviews (conflict and responsibility; **Section 5.2.3**). Since it is the most frequent type of care and setting,

medical care in the general practice setting is discussed first. Then other types of care and setting are related to it.

### 5.2.1 General practice and clinics

As expected the most frequent medical care involved contact with the patients' own GPs or their staff. Patients also received medical care in hospitals (most often a planned out-patient visit), and in primary care clinics for warfarin management (Harry 75, Maria 76, Edward 71) and diabetes (John 67). For patients, care in different settings seemed to serve different purposes and have different characteristics. Self management is a cross-cutting activity, however, if self management were to be formally encouraged it might take some of its purposes and characteristics (in the eyes of patients) from the professional recommending it.

Contact with GPs was regularly initiated by patients to obtain an on-going supply of medication (repeat prescription). Sometimes a request for further medication was dealt with automatically and required no consultation or examination. Some patients, in the examples below (Ethel 83, Vera 84, Edward 71), gave the impression that the initial decision to prescribe is most important and prescription review activities were secondary or even unimportant.

**What sort of things have you had to go to see a doctor about?**

Nothing really, only for medication and I generally send for that you know, I just got one back through the post but when I have left it about say 3 months I go, but then they don't give me a check up they don't take blood pressure or anything, just a check up, they just give you medication again.

Ethel 83

And yes Dr ((James D4<sub>P</sub>)) makes, never hesitates you know, he makes it out for me every time I see him ... enough for three months

Vera 84

He is a good doctor my doctor. Quite honestly, I don't think. I think once you are on your tablets and that if you are just careful and watch what you are doing, you know, I don't think they can do really a lot else for you. I don't suppose ...

**... you have been for your blood pressure today haven't you?**

Yes. Well all I would go to the doctor for is just, now and again, I would go and have a check with him and get my tablets.

Edward 71

If kept in the future, self management records would be reviewed by doctors as part of the normal prescription review process. This would be additional to the blood pressure monitoring patients frequently report at the moment, and could highlight to patients the importance of review activity in maintaining clinical safety.

More frequently patients reported that before authorising repeat medication, GPs checked their blood pressure, or made other checks. GP contact was often planned and predictable. Good GPs were identified as those that first listen to the patient's problem and then take action based on the description, obvious symptoms or examination. The GPs were described as friendly, easy to talk to and concerned about the patient. This concern being expressed either in interest in the patient's story or referral for diagnosis.

He is very good my doctor. He tries stuff out. If he doesn't think it's all right he sends me to hospital to get X-rayed you see.

Clara 86

Well I think a good doctor who gets to the bottom of anything that you complaining about ... you know (searches & finds) ... and by questioning you, you know?

Vera 84

... he is straight with his answers and he doesn't mess about. Mind you, to be honest, with you, I don't think today, I don't think doctors have a lot of time and I don't mean they haven't got time for you. I honestly think that they are so busy that they don't have a lot of time to spend with people.

Edward 71

I like ((Mark D3<sub>p</sub>)) because he listens to what you have got to say.

**I was going to say why do you like him? Because he listens to you?**

He don't, when you don't walk in, say "What's up with you?", you know like some of them do? "What's up with you?" - you know what you mean? He actually listens to what you say and ((James D4<sub>p</sub>)) not too bad like is he? He sent me to hospital last time didn't he? Last time I went to see him he wasn't excited about it so he sent for ambulance and sent me straight in like. That was last time I were in, wan't it ((wasn't it))? Lungs were full of fluid like.

John 67

I told him I've got this pain in my stomach. And he sent me to the chest clinic. "Are you not listening?" I said, "It's in my stomach. Are you going to send me to the chest clinic to cure my stomach?"

Mike 56

Some of these quotes highlight patients' perceptions of the time pressures facing GPs, but it is not clear if attempting to reduce GP workload would provide an incentive to self manage. In the way that self management is currently presented to patients the focus is on autonomy rather than health service efficiency. However, patients may be prepared to accept the latter as justification if it were presented to them carefully.

In contrast to his statement above, Mike 56 said Mark D3<sub>P</sub> (a GP) was different to his other doctors because "he listened and he cured me" and also said "the others didn't even listen". This seems to imply that the act of listening is more important than the cure. A quantitative study of stated preference has also highlighted the doctor's ability to listen as the most important attribute of a time limited consultation. This was followed in order of importance by: ease of explanation, a short waiting time and amount of information (Scott & Vick, 1999). Patients, therefore, have communicative as well as instrumental reasons to see the doctor occasionally. Some patients may see encouragement to self manage as an attempt to reduce rather than enhance the quality of (valued) patient-doctor interaction.

The perceived quality of current interaction is illustrated in the quotes below. Like Maria 76 (below), Mike 56 also said Mark D3<sub>P</sub> (a GP) treated him like a friend and "Don't look down on you or nowt like that, like some of them do." Lillian 78 and Margaret 89 (below) were complimentary about different aspects of GP communication skills. However, Mike 56 (in this paragraph) and Margaret 89 (below) suggest that some GPs are better than others. An aspect of generic self management training is coaching patients to get the best from their professional carers. A growing awareness of 'expert patients' may encourage professionals to be more aware of their communication style.

**Do you find it easy to talk to the doctor? ((Mark D3<sub>P</sub>))**

Oh he's lovely, yes. He's very, very nice. He's a younger fellow, may be in his forties but I find he's like a friend, you know, yes.

Maria 76

**... what is it about your doctor now that you like?**

Well, they listen. I had a mastectomy ((personal detail removed)) and I have been having little twinges in my other breast and I mentioned this to ((James D4<sub>p</sub>)) and that was the beginning of the week, by the end of the week I had had an mammogram and seen a specialist, you know what I mean, on the ball, straight away.

Lillian 78

**What is it about him ...**

Well he'll sit down ((Mark D3<sub>p</sub>)) and he goes back in your file and he looks back ... and his, he is, he's nice. He'll talk you know, explain things to yer ... but others, one or two others, they look at yer as if you know they can't be bothered.

Margaret 89

Expanding on the theme of good relationships with doctors, Jean 76 even goes so far as to say she has “adopted” Mark D3<sub>p</sub> (her GP), that is, she treated him like a son. This was even clearer in this exchange:

**Which would you value the most do you think? ((GP or specialist))**

Well your doctor ((GP)) because he is on call sort of thing and there are 2 or 3 other doctors there that are all good, they're all like sons.

Jean 76

Philip stated that he was on “first name terms” with Mark D3<sub>p</sub>. However, Olive 62 seems relatively dissatisfied with the GP:

The ((hospital)) information service is fabulous, it really is. You don't get the same thing at your GPs, I was complaining about the GP actually to the nurse. I like the lady doctor because she speaks to me as if I'm an adult, (the men) speak to me as if I'm a two year old.

Olive 62

The concept of ‘doctor as friend’ is reported in the literature but may be problematic (Williams, 2005) (Barcia, 1993). It suggests an informal relationship based on unspoken assumptions. Friends may seek to norm their behaviour but friendships can be fragile and one is under no obligation to follow any advice given. Trends in modern medicine tend to characterise the doctor and patient as partners in a project having a business meeting rather than friends having a conversation. Businesses of course generally require agreed defined goals in order to succeed, whereas friendship is more fluid. It seems unlikely (though it is possible) that patients see the doctor as a friend in the normal sense of the word. Some patients’ approach to the doctor as friend may reflect a

memory of or an aspiration for the doctor one once saw socially in the local community. Most likely all patients value good general relationships because they help to provide continuity and reassure patients that their best interests are reflected in decision making.

One of the GPs interviewed said that he tried to be friendly (Mark D3<sub>p</sub>), but he didn't stress any particular personal relationships with patients. However, even if a doctor did consider a particular patient to be a friend *per se*, it may not be something that they would readily admit. James D4<sub>p</sub> (a GP), who was perceived by patients to be relatively reserved and less open, compared his role with that of actor:

I think it's like being an actor myself and I wouldn't dream of behaving outside of this room how I do in here really. It's not, it's like being an actor really. I think like actors bring bits of themselves to their role but basically they're acting out a role and I mean that's what we're doing. We've got lots of experience but once that door's shut it's just an act really.

**How do you think the other partners, how do you think they kind of differ from the way you might go about something?**

I think, I think they're more similar than different in lots of ways. I think there's a hidden bias in that because we all choose each other but I think we are all similar. I think we all listen to, I think we are all quite approachable. Patients won't tell you that but by and large we are, we do, I think we are, I think we're all quite knowledgeable as well and if you're approachable and knowledgeable I think they're the two keys really aren't they and if you listen to what people are saying to you?

**One of the big things that people say actually is that you know, "I like him because he listens to me". Doing something is kind of secondary to that really. It's this idea of being heard that's...**

I think in a way that's the hardest thing for us to do because we have only got 10 minutes and people don't just come in with a. I often think when I'm reflecting, I think it would be really nice (if they) just came in and said, "I want you to deal with my heart failure today and this, and this and this", but it's not like that, they start saying, "I'm breathless" and then they say it's "It's me big toe and I've just been down to the travel agents" and it's like this really, it's like a bee buzzing around in their head. If they'd just come in and say, "It's me heart failure" and then you could be in heart failure mode then but life's not like that and it never will be.

James D4<sub>p</sub> (GP)

For James D4<sub>p</sub>, therefore, listening to the patient and seeming approachable were important, but he would prefer patients to take a more direct approach to their

healthcare problems. His partner Mark D3<sub>p</sub> agreed that listening was a necessary skill, but also suggested that he might “black out” some peripheral (to a professional) social details.

My only impression from the compliments I get is that they seem to think I listen which, and that I'm fairly friendly to them, listening friendly and quite happy to, I think I encourage them to come and see me and come back rather than just send them away with treatment ... I think a lot of people with chronic diseases don't bring up all their social issues. I can't think of any, err may be I just don't, you know they say I listen, *I tend to black out*, the (kind of) problems that they want me to hear, but my experience of these chronic diseases is that they probably don't tell us a lot about their other issues. They feel that they are coming to see me to discuss their heart failure and not their social problems.

Mark D3<sub>p</sub> (GP) (*emphasis added*)

However, when patients with mental health problems attend he commented “I would certainly listen to them, because a lot of the time I know I can't do anything for them. Maybe a little bit of advice but nothing more than that.” So patients want to be heard, but for GPs listening is not such a central aspect of care, rather it is a means to an end. To the extent that self management makes patients think and act more like professionals it may be perceived as beneficial by GPs; but patients may be wary of the influence this would have on the quality of their relationships with professionals.

### **5.2.2 Hospital care and emergency care**

By contrast to general practice, hospital care was less frequent, but often planned on a (long) regular cycle of about 3 months to 2 years for various conditions. Despite the planned nature of many hospital visits, a lot of time could be spent waiting for initial diagnosis. For example, John 67 waited 2 years for an angiogram and was then told he needed immediate (the next week) bypass surgery. Marie 76 didn't wait as long but also needed bypass surgery immediately after an angiogram. Reducing this initial waiting period has been the subject of major policy initiatives (Department of Health, 2000).

Time in the hospital was also described as wasted by some patients. Mike 56 described a week in hospital following an MI as the “most boring time of my life” and thought “after two days I could have gone home.” Anne 64 similarly said “I was laid in bed

doing nothing.” Olive 62 described waiting all day to see a hospital doctor (who never came), which delayed her morning treatment (in dermatology) until the late afternoon.

Elsewhere, John 67 reported that he didn’t actually like going to the hospital, but didn’t give a specific reason. Ruth 86 and Rose 82 didn’t like the hospital or GP, and expressed reluctance to call on a doctor in most circumstances. Hospitals were also associated with bad news (often about others) and surgery, which perhaps explains why most patients were a little uncomfortable in the environment: the exceptions being Jean 76 and Olive 62 who seemed to enjoy interaction with medical staff. Vera 84 described how much she hates the hospital environment:

Because I came out three days after he’d operated on me because I was, I didn’t want to be in you know, I wanted to be home ... I hate, I hate being in hospital cos I miss my own bed to tell you the truth.

Vera 84

In contrast, Jean 76 described having “great fun” in hospital “taking the mickey out of ((mocking)) the nurses and things like that” with another in-patient. Pete 65 also described himself as having been the “joker of the ward”. Perhaps the need for humour says something about either the boredom of being an in-patient or the stressful nature of the environment. Being miserable and wanting to go home, or trying to lead humorous interaction may just be aspects of different coping strategies: avoidance and acceptance respectively (cf. **Section 2.3.5**).

Continuity and relationship building were features of general practice, but patients saw many different doctors in the hospital not just those they were familiar with. This aspect of care was not appreciated. Patients could usually identify the consultant in overall charge. If patients did talk to a consultant they respected, they tended to be very satisfied with the standard of care provided and his communication skills, for example:

... **what it is about him ((Tom D2<sub>s</sub>)) that makes you pick him out?**

He is a very understanding man. He wants to know the answers, rather like you, he needs the answers and he is very he goes in depth, but his manner is excellent, he encourages you to respond you know and he brings out the best in other words.

He knows the right questions and his person to person manner is very good.

Patricia 63

When asked for comments about this praise, Tom D2<sub>s</sub> was self effacing and also suggested that with experience it was necessary to ask patients fewer questions about their health status.

I think that's very nice; very flattering. I think actually, I think we're all like that now and I think that comes from experience. I think when you watch the registrars they're very caring and are very good but they ask lots and lots of questions whereas actually, once you've been doing it for years and years and years it becomes quite easy; you can tell within the first question or two ...

**Yes so there's a kind of tendency when you're less experienced to be kind of more procedural and ...**

Well you're more procedural and you can follow the algorithms, sometimes you get down the wrong one you have to go back again and change, whereas actually when you've, there's a limited number of responses, there's a limited number of ways that people describe heart failure symptoms ...

Tom D2<sub>s</sub> (cardiology consultant)

Patients sometimes spoke disparagingly about the consultant's sub-ordinates (see below: Ethel 83, Harry 75, John 67 and Tony 55), and it may be that the questioning procedural approach described by Tom D2<sub>s</sub> is one explanation. All the patients interviewed were of white European origin (one southern European and the others northern European) and no explicitly racist comments were made in respect of doctors (the local medical profession is racially diverse). However, John 67 expressed some frustration in his inability to understand what some professionals are telling him. This is another aspect of communication that could explain dissatisfaction with care provided by doctors in training. Note in the examples below that John's wife attempted to moderate his comments and he accepted the intervention.

... but you only see him the first time you go and the last time, in between there is about six different doctors and you can see a different one every time you go but they're all lovely and the nurses as well.

Ethel 83

I am out of breath, I am buggered. I don't know why. I went to hospital a fortnight ago and I have to see ((Tom D2<sub>s</sub>)) like. It were one of his *understudies* I saw.

Harry 75 (*Doctor's real name deleted, emphasis added*)

You never see the same fella. You know when you go see specialist? ... very, very rare do you see specialist, yer *proper* specialist. It's all or either, it's one of his registrars, or his second or his third in command or fourth in command, or a couple

that's come from West Africa and haven't a clue what they are talking about. But I've had every nation, you name it and I've had every doctor you can name.

Yugoslavs, Hungarian ((Interrupted by wife)) Poles.

*Wife: But that don't matter does it? It's just that they don't know your history.*

But I am saying you never see same fella.

John 67

Supposed to see the specialist again but only see his *underling* anyway so there's no bloody point ... at the end of the day the specialist has got so many people to see in a day that he can't spend time on you ... if he, if at the end of the day you only see his underling to say oh go and have, take, a blood sample. They've already got a bloody blood sample from me own doctor.

Tony 55 (emphasis added)

Despite these deficiencies in personal communication and relationships, hospitals were associated with extensive clinical or laboratory tests. This seemed to indicate good quality care even if it was somewhat impersonal. One or two patients particularly identified technical aspects of hospital care that were superior to general practice.

Oh that's a marvellous clinic ... well they did do everything, they took blood tests and X-rays and really went all through you, a marvellous person, so patient and actually he didn't tell me then what was matter with me, he didn't say you have heart trouble or owt like that you had to pick it up as you go along.

Ethel 83

**Not an exact science sometimes? ((GP monitoring of medical condition))**

Well not really, a mean what can you do with a stethoscope? It's only a piece of tubing, if you are really bad you would go to ((hospital)) wouldn't you?

John 67

I find that I can talk to the doctors at the ((hospital)) better probably because they are seeing patients that want to know.

Olive 62 (see also her comment in **Section 5.2.1** above)

**And what's nice about her? ((Consultant cardiologist))**

Well she'll explain things to you and ask you, you know "How are you?" and "Are you any difficulty breathing?" And you know, "Are you thinking alright, are you sleeping alright?" ... things like that. Yes she's very good and (of course she prescribes tablets).

Margaret 89

Patients seemed willing to trade off some aspects of continuity for the high level of technical care provided in the hospital setting. They also provided evidence that hospital consultants are at the top of the medical hierarchy. This is perhaps best explained by the conjunction of communication and technical skills, which is further illustrated here:

**Why would you go to your GP ((for information)) rather than anybody else?**

This is in the medical context isn't it? Well they are the experts aren't they? Unless they refer you on to specialists ... it is never very wise to listen to other people ... I had that and you end up either frightened to death or thinking 'strange person' ... the best people to go to are the ones that have or can acquire the answers.

Patricia 63

I go there about every 6 weeks to the renal clinic, that's the bit what I call the big clinic ((renal)), that's the important one to me because Dr Z ((renal consultant)) done all he can for me, everything I can sit and talk to him like you could an old fashioned doctor ... If Dr Z said to walk on the road I would do. I know that what he is telling me is Gospel and it's for want of a better expression.

Lillian 78 (doctor's real name deleted)

The use of emergency care (ambulance service and A&E) is of particular interest in the context of heart failure, because one objective of self management is to reduce emergency admission rates. Emergency care was described less commonly than other types of medical care, but some patients had experienced frequent admissions. For example, Harry 75 reported 8 or 9 admissions in a 10 month period. Dislike of hospitals in general clearly offers some scope to encourage self management, perhaps just to avoid the "drunks" in A&E (Ethel 83).

In summary, hospitals are associated with good quality care, especially that provided directly by consultants. People lacked confidence in their own potential to make good decisions (cf. **Section 7.2.2**) and expressed awareness of primary care's diagnostic limitations. For patients, medical care had communicative and technical aspects. They saw themselves (largely) as able to communicate well and engage in relationship building with professionals when given the opportunity. However, technical aspects of care were perceived primarily as the doctor's domain (especially that of the hospital consultant), something that one accepts (or are subjected to) rather than engages with or questions. To the extent that clinical self management is perceived as a complex technical task, patients' attitudes present a barrier to implementation.

### 5.2.3 Conflict and responsibility

Encouragement to self management has the potential to interact with two *elements* of the medical care *concept* that were independent of setting: conflict (or perhaps *tension* would be more accurate in hindsight) and responsibility. Low-level conflict (incompatibility of views) could be associated with diagnosis or treatment and involve doctors and patients. For example, patients reported feeling upset if further tests did not seem congruent with the symptoms they had just described. The conflict here is between doctor and patients and is caused by the different interpretation of symptoms in relation to possible causes. Patients also reported diagnostic conflict between doctors, usually in secondary care, who could not agree if the patients' primary symptoms were related to heart or lung disease (cf. **Section 5.1.1**). Therapeutic conflict arose once diagnosis had been agreed (or at least general treatment started) and consecutively seen doctors altered doses or specific medicines.

But I kept going in hospital after that and every time you went in you saw a different doctor, and he would stop you on some medication and put you on something else and you know. And it were doing no good and then I went in and saw this Dr X ((consultant pharmacologist))...

**And the heart consultant, what do you think of him.**

Well I have only seen him once ((Tom D2<sub>s</sub>)) well twice ... as I say I've seen all his associates and every time I have gone in I have seen a different doctor. That's what I mean if you went in and saw the same doctor, they'd know what they were doing, what tablets they were giving you and if they weren't doing you no good, they could change them. These I have been on now, these tablets, I have been on these for a while now they seem to be working alright.

Harry 75 (*Doctor's real name deleted, medication now settled after consultation with Dr X above in the patient's opinion*)

**What's good and bad about the different treatments and the different people that you see?**

It's all right. Down there ((the primary care clinic)) I just walk in and take your blood, that's neither nowt nor ((sumat)) like ((something or nothing)). Getting through to specialist were a bit, took a long while ... but that particular time I were under Dr Y ((respiratory physician)) for my chest as well wan't ((wasn't)) it? And they were both blaming each other. I'd had my bypass done but they were both blaming each other. One were saying it were me lungs and one were saying it were me heart.

John 67

From a professional perspective the same incidents are not so much about conflict as control or responsibility. For a given set of symptoms one of a GP's jobs is to exclude more serious but (perhaps) less likely causes, and diseases affecting different (biological) systems can have similar symptoms. For both these reasons the required examination or tests may not seem to match the symptoms describe. However, the GP may not see the need to fully explain the apparent discrepancy, believing they are acting responsibly.

In a rare case of patient reported conflict between sectors, Lillian 78 was told some injections prescribed by the hospital should now be prescribed by the GP because "they were too expensive". More commonly, for patients such conflicts and disagreements as there were built up and could grow in significance over time. Potentially (in comparison to just doing what one is told) clinical self management develops another front on which conflict could develop. By putting patients in control the possibility that control may be disputed at some future point arises. Indeed since some patients could prove to have inadequate clinical self management skills an increase in disputes may be inevitable. This interference with relationship building is unlikely to be welcomed by patients or professionals, particularly those in primary care professionals who need to maintain good long term relationships or risk losing their customers.

#### **5.2.4 Related care**

Related care is used here as a descriptor for healthcare provided by nurses, pharmacists and the professions allied to medicine; it is a counterpart to medical care provided by physicians and surgeons. Whereas an objective of self management is to decrease demand for medical care (in both primary and secondary care settings), there is no particular desire to reduce the demand for related care. In fact some related care professionals (especially community pharmacists) are seeking more clinical patient contact (Department of Health, 2008a).

There are policy initiatives to push care from the secondary to the primary setting (for example, to 'polyclinics') and from more to less expensively trained professionals (for example, to non-medical prescribers). Clinical self management is a logical extension of

this activity, and patients in need of self management support may be encouraged to ask non-medical professionals first. Patients' current use, experiences and expectations of related care may have an impact on such aspects of self management implementation. Apart from doctors the following professionals were mentioned by patients:

- community pharmacists (not hospital);
- practice nurses and specialist nurses (in local clinics and hospitals);
- chiropodists and physiotherapists.

Local clinics provided a substitute for some out-patient hospital appointments, for example, warfarin monitoring.

All patients were asked if they made use of any alternative or complementary healthcare providers, which none did, but two (Ethel 83, Philip 65) had taken cod liver oil. The focus of self-management in heart failure is specifically on the adjustment of a drug (usually furosemide) in response to weight changes. Apart from doctors, therefore, pharmacists and nurses are those most competent to deal with patient queries and most likely to be asked questions by patients in this respect. Additionally, the dispensing pharmacist has the opportunity (in theory at least) to intervene or provide information every time a medicine is re-supplied. Since patients have a choice about which pharmacy they use, they were generally asked how this choice was made. Feedback on the role of nurses did not need to be actively sought.

One-third of the patients used the small pharmacy located within surgery premises, which was described by one as "a little cubby hole" (Florence 78). The reason given for this choice was always the convenience of the location, rather than (for example) speed of service (another known influencing factor) or the standard of care (a professional aspiration). The reasons given for other pharmacy choices were closeness to home, the availability of a prescription delivery service or the approachability of the pharmacist, for example, in answering questions or providing supplies in an emergency. Questions patients asked pharmacists were of two sorts: queries regarding the medicines supplied (for example, quantity or brand); and confirmation of information on the label or in the patient information leaflet. Doctors were usually assumed to have made rational decisions regarding diagnosis and the choice of therapy.

Nurses were encountered in clinics (for example, primary care warfarin clinic and secondary care heart failure clinic) where they gave advice or took blood samples for laboratory tests, and during hospital stays where they were described as providing general care. Patients seemed to be generally satisfied with nursing care although one patient (Olive 62) commented on the time pressure staff worked under and hurried explanations that were offered (in the context of an in-patient dermatology stay). It seemed clear from patients' explanations about what pharmacists and nurses did that doctors were seen as the prime decision makers. Thus pharmacists dealt with minor queries about medicines and (in hospitals at least) "nurses did all the work" (Mike 56). However, the actions of prescribing, referral and (hospital) discharge were the responsibility of the doctor. The patients' approaches to and described experiences of care were, therefore, fairly traditional.

Where this leaves related care professionals' role in self management is fairly uncertain. Primary care nurses are already acting in clinical roles once the preserve of secondary care and/or doctors. Patients saw these roles, didn't appear to have any complaints about them and further change may be willingly accepted, for example, having a nurse as an initial contact for self management queries. Community pharmacists are in a position to provide accessible healthcare advice without an appointment. However, patients' had limited perceptions of their wider clinical competence.

### **5.2.5 Diagnostic and laboratory tests**

Diagnostic and laboratory tests serve two distinct purposes. Firstly, they are used to establish or confirm a diagnosis, which then influences the broad treatment plan. Secondly, they are used to monitor the effectiveness of treatment and to ensure the on-going safety of particular medicines. Clinical self management engages the patient in a simple test (body weight) on a daily basis. Patients' views about current testing procedures, recording and usefulness are a likely influence on the perception of self management.

It was clear from patients' comments on medical care (especially in the hospital setting) that diagnostic and laboratory tests were an aspect of care that patients experienced and

valued. In the context of heart failure management, periodic blood tests (U&Es: urea and electrolytes) are particularly important because diuretics and ACEIs can both have an adverse effect on renal function. Blood pressure measurement was the test most frequently mentioned and seemed to be a fairly routine part of medical care. Blood and “fluid” tests were the next most frequently reported and patients also described a variety of scans, for example, plain X-rays, CT and DEXA.

Patients described the role these tests played in both initial diagnosis and on-going management. A certain amount of testing was expected around the point of diagnosis, for example, Ethel 83 expressed surprise that a medicine had been started before some tests had been completed.

Actually he didn't give me any tests or anything, he just put me on thyroid tablets.

Ethel 83

Patient didn't express any awareness of medicines being used by doctors as a diagnostic tool or therapeutic trial: with the exception of Olive 62 who reported being on a “slow acting inhaler” for a month as “a trial really”. They did describe waiting for tests results to confirm a diagnosis or inform decision making, as the short quotes below illustrate.

Well he says he hasn't got all the blood tests back yet. So he can't really make a decision ... you can tell a lot from blood now like you know?

Mike 56

But I went for the test in the June previous that's when they found out about the heart.

Lillian 78

Mike's quote (above) suggests that tests sometimes take on an almost mystical quality. Patients gave the impression that professionals were reluctant to confirm diagnosis or embark on a general course of action without appropriate test results, which is to be expected and may be compared favourably with traditional ‘experiential’ diagnosis following clinical examination only.

Ethel 83 commented that the hospital was good at doing a complete set of tests at each out-patient visit (weight, blood pressure, blood tests), but she had to “remind” her “own doctor” (the GP) to send for them. A comprehensive battery of tests in hospital had also

been experienced by Maria 76, Lillian 78 and Olive 62; it was a considered a distinguishing feature of specialist care.

And err they gave me a real good test at the ((hospital)) ... the only thing that was found was the thickening of the valve of the heart, one of the valves the aortic ...  
Olive 62

They did all sorts of tests even at that time ((in A&E)). I went in at 8 o'clock and six hours later I was up on the ward.  
Pete 65

Olive 62 and Pete 65 (above) demonstrated an unusually high degree of technical understanding. More commonly patients had a poor understanding of tests or were confused by their scheduling (Ethel 83, Harry 75, Tony 55), for example:

For some reason. And I've got to do fluid once every two months, err blood once every two months.  
Tony 55

The most common action taken as the result of a test was changing a warfarin dose following a blood test (for example: Maria 76, Harry 75). John 67 had stopped taking an ACEI as a result of a test and been restarted on a lower dose:

They actually phoned me up from ((the hospital)), I stopped takin it just before Christmas one year, I stopped takin it cause it were damaging my kidneys, when I had a blood test. And when they put me back on it I questioned it, a ses ((I said)), but it's a lower dose, so it seems to be, I feel alright like.  
John 67 (*Hospital name removed*)

Lillian 78 was also aware of being monitored for signs of any further damage to her kidneys, as was Pete 65:

And now I'm going every three months for blood tests for, to check on (the amount of damage me liver's having) because of these medicines.  
Pete 65

In the context of possible self management, Philip 65 wondered if a blood test would be required after taking an extra dose of a medicine:

You have a blood test just after that extra dose ... and it's harmful so they knock it down ... it's like driving a car ... go an X number of revs over the red line just to get out of a dangerous situation (or problem) ... but you do it regularly; you'll muck the engine up.  
Philip 65

Anne 64 described being in hospital having tests, but not being given any information about her diagnosis. Ethel 83 pronounced herself “confused” because tests that the hospital doctor said were necessary, were not in fact performed regularly. Mike 56 described having X-rays taken but not getting feedback.

They took photos and never seemed to say nowt to me you know?

Mike 56

It seems, therefore, that patients had a strong sense of the general importance of diagnostic and laboratory tests. However, the need for specific tests may not have been explained particularly well, they may just be one of a ‘battery’ required initially and periodically. Patients concerns about tests did not revolve around their intrusive or uncomfortable nature. Rather patients were concerned if either test results weren’t linked to some communication or action, or expected tests weren’t performed in line with their schedule. This suggests that with clear explanation the tests required in support of clinical self management would not be a barrier to implementation. Patients may even derive some satisfaction from an ability to interpret a simple test and take action on their own behalf. However, this does stray into technical territory that patients may prefer to leave to professionals.

### **5.2.6 Titration of doses**

Clinical self management would engage patients in changing diuretic doses in response to short term weight fluctuation. Patients’ attitudes towards this activity may be influenced by changes they experience in doses of their regular medication. If they experience dose changes with a clear rationale, then this may leave patients with a positive attitude. However, if medication is stable in the medium to long term or changes are poorly explained, then they may have a negative attitude. Similarly professionals may be more or less comfortable with the idea of (potentially) frequent dose changes based on their experience of current practice. These issues are explored in this section.

Titration is now used by many healthcare professionals as the preferred term for optimising doses of medicines. Optimisation involves the maximisation of clinical effects (which have been demonstrated in clinical trials) and the minimisation of

adverse effects (which are experienced by the individual patient). The rationale for dose adjustment (up and down titration) is, therefore, quite complex and involves an element of clinical judgement. Crucially titration is not a one off process but involves on-going commitment to monitoring both good and bad effects. Patients in general seemed to dislike change or had a relatively poor understanding of its rationale.

And they all try to change your tablets. They think they are doing you a favour by changing your tablets, don't they? And it doesn't always look like that, that way like.  
John 67

**...do you think that would be a good thing? ((Changing own dose of a medicine according to written instructions))**

No, no he wouldn't tell you to do that, he had gone into it because it tells you how you mustn't overdose you see, but the one I take is 40 mg which he says is fairly high like.  
Ethel 83

In the above quotes, we see that John 67 has experienced medication change but views it negatively, even though he accepted that professionals had good intentions. John 67 it seems would not choose change and Ethel 83 would actively resist it: citing professional authority in support of her views. For some these negative feelings were reinforced by the adverse consequences of medication change. Tony 55 described the consequences of dose reduction in quite dramatic terms:

And it all started off, all of a, when they changed the, when they changed tablets, take one dose less than what you are doing, the whole lot flared up again ... so at the moment I'm taking the maximum dose of them ... it's the only thing that keeps me. Now and again I can cut my blood tablets down a bit.  
Tony 55

This illustrates both adverse consequences of professionally instigated change and also changing doses without professional supervision. Therefore, an individual's attitude towards change may vary from medication to medication, just as everyday adherence does. There is a relationship between adherence (supported by both routine and trust in professional authority) and a desire not to make short term dose alterations (cf. Ethel 83 above). Anne 64, however, described the on-going change in her doses in a neutral matter of fact way: just another element of care that "you get used to".

Patients' comments on dose changes usually related to warfarin or the experience of adverse effects with ACEI. For example, patients taking warfarin generally understood that changes in dose were related to a test that (somehow) measured the thickness of the blood. However, no patient referred to the test in any more specific terms than making the blood "too thick" or "too thin", that is, they did not mention the concept of a target range for the test, which is clinically important. Below Harry 75 describes the experience of his ACEI dose being increased, with a focus on the mechanics of supply rather than the need for change.

... they've altered me tablets on there you see, where a were taking half a heart tablet, the last time I was in they put me on a full one, and Lisinopril they put me on two, where I used to take one. But when I got my prescription last time, they have only give me enough for 14 days now instead of 28.

Harry 75

So for patients, the practical consequences of dose changes rather than the rationale for change may be more significant and also better understood. The rationale for change is better understood when variation in medication is in response to adverse events. John 67 described an ACEI dose reduction because of adverse effects. Maria 76 had stopped taking one ACEI because it caused an "irritable cough" (which is less serious but more obvious than the kidney damage John 67 describes below) and was prescribed an alternative ACEI.

It damaged me kidneys. They actually phoned me up from ((the hospital)), I stopped takin it just before Christmas one year. I stopped takin it cos it were damaging my kidneys, when I had a blood test. And when they put me back on it I questioned it, a ses ((I said)), but it's a lower dose ... I feel alright like.

John 67

In summary, for patients 'titration' was simply manifested as a change in dose, which usually had negative associations:

- established everyday routines were upset;
- side-effects often seemed to precipitate the need for change;
- blood was *too* thin or *too* thick; or
- changes were enforced not chosen and the rationale was not communicated.

It is possible that change is disliked because it forces people to question the unspoken assumptions of everyday life, which can provoke uncomfortable feelings (Garfinkel, 1964). The EPP encourages people to be more involved in treatment decisions, but

doesn't offer clinical advice. Jane E1 (an EPP administrator) described how patients on the generic training course sometimes have issues with the number of medicines they take and their side effects. Part of the training encourages patients to work with professionals to develop a care package that they are happy with. However, this 'proactive' approach was not apparent in patient interviews.

We don't get involved in the clinical management, that's for them to sort out with their healthcare providers. It has happened that people have turned up to courses with their bag full of medication dumped out on the table. Like "Look at all these" you know and I say "Oh you have to take a lot" and we just ask them to put them away, it's not appropriate to be dealing with that sort of thing. If they are unhappy about their symptoms, part of the action planning and the session around communicating with your healthcare provider is to be able to help them go back to them with a written list if necessary. "I'm not happy with doing that, that and that. I'm not happy taking that because of those side effects. That tablet gives me those side effects which is worse than those" and you know, so we encourage them to look at the effects themselves, we encourage them to bat it back to their healthcare team and say, you know, and be more proactive really.

Jane E1 (EPP Administrator)

Professionals compared titration of ACEIs in chronic heart failure (which has proven long term benefits) unfavourably with other medicines and diseases because the symptoms and effects were less obvious. For example, titration of diuretics in acute heart failure reduces shortness of breath and dramatically increases urine output. Even so patients may require time to become comfortable with changes and think about taking some responsibility. This is made more complex by the need for heart failure patients to take a number of other drugs, including beta-blockers, an increasing dose of which may make them feel physically worse. Douglas D1<sub>S</sub> (an elderly care consultant) compared ACEI titration with dose alteration in Parkinson's disease and diuretic dose adjustment. His perception was that change is easier when effects are obvious.

I think with Parkinson's Disease the symptoms are clinically quite obvious and the patient can actually see the benefit of the drugs that, you know severe Parkinson's, severe bradykinesia they can't get out of the chair, so if you give them a drug to increase, they may be able to become more mobile and they can tell when the drug is working and then they can, so that they can, both if the drug's working and also they can tell if they're getting side-effects, that they're having hallucinations, they can say well I took my pill at twelve o'clock, and then I was seeing people going through wall a few hours later, so it's a more sort of obvious thing and they can see the tremor may be getting a bit better. Whereas heart failure, particularly among

the elderly who are not terribly mobile, they may not be particularly short of breath, they may or may not have oedema so they may be taking all these pills and they may not see the particular benefit of it. Yes if they go into hospital with acute heart failure, yes they feel much better but when they're sort of chronic coming up to clinic they may not associate, we may start them on pills which may not make them feel any better, such as ACE inhibitors or angiotensin receptor blockers which probably increase the, improve the prognosis of heart failure but it may not make them symptomatically any better, so they may not associate these pills with having any benefits. The same way as with diuretics make them pass water and get rid of the oedema, they can see that but they can't see the (internal changes) with the ACE and ARBs.

Douglas D1<sub>S</sub> (Elderly care consultant)

Tom D2<sub>S</sub> (a cardiology consultant) seemed to encourage (below) some informal clinical self management in more symptomatic patients he considered suitable. He was aware of both the risks and benefits of diuretic dose adjustment and flagged up GP responsibility for ACEI titration. Tom D2<sub>S</sub> seemed to communicate adjustment instructions verbally (which patients do like), although this may just be a pattern of his speech. This would tend to exclude patients who lack verbal reasoning skills, and we see above (**Section 5.1.1**) that even patients with good health knowledge can fail to grasp the finer details.

Yes, and it is something I kind of encourage but to a limited extent and I encourage it with the kind of bad heart failure patients so the patients who have little in the way of symptoms, have left ventricular dysfunction, are on medication and you kind of vaguely keep an eye on them; but I often discharge them to their GP now. The ones that I think benefit from self-medication are the ones who are fluid overloaded and are on big doses of things so you know they're usually on at least 80 milligrams of frusemide equivalent, often 80 milligrams bd and with that they'll normally be on an ACE inhibitors, spironolactone, beta blockers and all that kind of stuff. So I think it's our responsibility to prescribe all these things. It's our and the GPs responsibility to try and titrate up the doses to the maximum, but I think the one thing that we do encourage them to do is to adjust the frusemide dose and I do say to them, "Actually you know, you're, you know this is walking a tight rope you know, that you're fine just now but there's a balance here and on one the hand you have too much fluid on board and you get breathless and your ankles swell up and on the other hand you go the other way and you get de-hydrated and you feel lousy and your blood pressure's low and your kidneys start not working and you have to kind of judge that as best you can and stay balanced and stay in the middle of the tight rope so you know if you're ankles start to swell up then I think you should increase the dose of frusemide and take an extra two tablets a day for

three days and then go back to what you're on. If it goes the other way; if you start, if you're not passing much urine and if your skin's dry and you're thirsty all the time, then you should cut out the frusemide for two days and then re-start the treatment", so I do encourage that and then I say, "And if things aren't better in about 2 or three days you need to come and see us" and I think, I think that works; I have the impression that people come in and say that well they've done that; and it's OK and it reduces the frequency of hospital admission but I think that's probably the only treatment adjustment line I encourage.

Tom D2<sub>s</sub> (Cardiology consultant)

If patients are resistant to necessary change or more patients are to be involved in active medicines management, then better (verbal and written) information should be provided. This process may be best started by a nurse skilled in communication but may be continued by a pharmacist with more technical knowledge of drug use. Sarah N1<sub>s</sub> described the comprehensive information and support provided by the Acute Trust heart failure clinic.

... they're referred to us through either the cardiology wards on both sites or through cardiology out-patients. OK? They have to have had an echo for us to see them and that is obviously because you are telling someone that they've got a chronic disease with a poor prognosis, you need a definitive echo to be able to tell them that. We see them on the ward if we get the referral through the ward and we tell them about the diagnosis. We talk about what it means to them, what it means to their symptoms, we include their family, if they wish. We will always try for there to be a next of kin there if possible because there's a lot of information given at the first session. We give them written and verbal advice on self-monitoring, what to do, when to seek a healthcare professional's advice. We look at their drugs and we look at their renal function. We bring them back into heart failure nurse clinics usually within three weeks of discharge because the peak period for discharge is usually within two to three weeks after they've gone home for them to be readmitted, with symptoms of heart failure. We ring them at home a week after discharge to see how they are getting on and they get our service phone number to ring us for advice in office hours. We also have a database where we collect all the information, audit things like drug titration and all the patients that we've got on that obviously we can look at their drugs and their symptoms at any point.

Sarah N1<sub>s</sub> (Heart failure nurse)

In Sarah's practice, she chose to tackle the problem of communicating bad diagnostic and prognostic news head on. She recognised the difficulties inherent for both her and her patients but claimed to see the long term benefits of therapeutic honesty.

And often the fact that they're asymptomatic with the diagnosis they'll still be on the medications. They might not necessarily need diuretics but they'll still be on ACE inhibitors, beta-blockers, rate controlling drugs. It is very hard and sometimes you feel like you are breaking an awful lot of eggs to make an omelette. And I've had patients that have reacted psychologically quite badly to their diagnosis but, and you wonder sometimes whether you've done the right thing, but I have to say that in my experience, in just the 8 months I've been doing it, is riding it out with the person. I would say that they nearly always will benefit from knowing the truth and it helps them to make changes that are going to benefit them ultimately in the long term. Like quitting smoking, like trying to eat a healthier diet, and changing all of these things early before they become symptomatic can actually improve their long term prognosis getting them on the right medication, so yeah it is really, really difficult and there are a lot of problems associated with it and in some ways for me as a heart failure nurse it's a lot easier to sit and tell someone with oedema and breathlessness how to manage it and that they've got heart failure because it's almost a relief to some people to know what's happening. So it's a lot easier to do that than it is to tell someone sitting there that can walk, that can jog sort of a few miles and you know has never had to worry about their health in their life, but I think that ultimately they do benefit from that ...

Sarah N1<sub>S</sub> (Heart failure nurse)

Except for those patients referred to specialist services (like Sarah's), it is far from clear where the main responsibility for dose titration should lie. In his quote below, Tom D2<sub>S</sub> (cardiology consultant) describes a clear shift from chronic disease management in secondary to primary care. He said that at one time he would personally titrate doses of statins and ACEIs, but now trusts GPs to select a statin of their choice (for example) and get on with the job.

It's very clear that there's a move towards chronic disease management in Primary Care and there needs help or the tools and all the rest of it to do it and you know, and Primary Care is getting much, much better about all these kinds of things. You know, when I came here 10, 11, 12 years ago we had to titrate up doses of statins and ACE inhibitors. But that's all, I don't do that anymore, I just say "Put them on a statin of your choice" I know they'll monitor things, which is great, and I guess the chronic heart failure is one of the next things that you know we'll see patients when they're acutely unwell (in their condition). But I actually, the longer term maintenance management will be done in Primary Care level which as much help from pharmacy, from practice nurses, from whoever.

Tom D2<sub>S</sub> (Cardiology consultant)

However, Louise P5<sub>P</sub> (a practice pharmacist) complained about vague instructions in discharge letters. Luke D5<sub>S</sub> (a respiratory consultant) said clearly that however much he wrote to GPs the only way to do effective titration was to call patients back to his own clinic. Julie N2<sub>S</sub> (a heart failure nurse) noted that the guidelines and protocols for chest pain were older and less “wishy washy”, which may make them easier to comply with. However, David P3<sub>S</sub> (a hospital pharmacist) thought that heart failure guidelines were perfectly clear. This range of experience and opinions points to a very real problem achieving the best level of standard care for patients, even before enhancements such as clinical self management are considered.

For patients with benign disease...I mean ACE inhibitor titration is a fine example, you can write umpteen letters to the GP asking them to call the patient back, do a renal function and titrate their ACE inhibitors but it never seems to happen and the only way it happens seems to be if I actually bring them back to my clinic periodically and do it and I think it's a real issue and I have no solution for that.  
Luke D5<sub>S</sub> (Respiratory consultant)

I think they probably are. I think there are very strict protocols and guidelines to follow with chest pain which have been around for much longer and the whole breathlessness thing of heart failure is very, I think it's difficult anyway and it's wishy washy and it's very difficult to be objective and often the patients are very difficult to assess if you don't know them as well.  
Julie N2<sub>S</sub> (Heart failure nurse)

Protocols, should be fairly straight forward in terms of if we're talking about a drug titration process. It's fairly straightforward, we know, we've worked to a PGD ((patient group direction)) within the hospital and that's been approved and used for several years and so whatever we develop will be based on that.  
David P3<sub>S</sub> (Hospital pharmacist)

Whether or not protocols exist or are easy to follow it seems that primary care professionals perceived more reasons not to change what has already been prescribed. Mark D3<sub>P</sub> perceived moral problems with the number of medications and tests that he found himself recommending:

Going back to the hypertension, there's one analogy that some people do readily accept that we are giving them tablets that aren't going to make them feel any better, but it seems very hard, it feels like we are pushing medication onto people and more and more medication that don't affect their day-to-day living and it's hard to do that, particularly with people who pay for prescriptions, you feel really sort of

stretched to tell them they are going to have to take another tablet. Heart failure isn't quite as bad as things like diabetes, you keep adding and adding more medication, trying to tell them "Yes it probably will make you live longer but not feel any better". That's quite hard, particularly with the ACE inhibitors and then you've got to say you need to have blood tests quite frequently as well and taking more of your time and a lot of heart failures with chronic renal disease we are doing blood tests every week almost it feels like.

Mark D3<sub>p</sub> (GP)

Jenny N5<sub>p</sub> (a modern matron) found herself in the position of checking the medication and tests that GPs have in fact ordered. She doubted her own knowledge and wondered how best to communicate concerns both to patients and fellow professionals.

One thing that I get in a fuddle with - because I don't always share that confidence in the prescribing, some of it is my lack of knowledge, some of it's the medical ( ) lack of knowledge and things around it - is things lack monitoring and things like that. So I go along to people and you just think, well nobody's actually you know, you're on this whopping dose of spironolactone and nobody's checked anything for ever. Why is that? And I, you don't want to say, you don't want to frighten the patient. You say "Well I need to go and check what we need to do about making sure that this is alright" and then you run back and think well why hasn't this been - is it me that's not knowing good practice these days, is it just something I've dragged up from my past? And then you have to broach this "Excuse me I'm going to stick a needle in this person because of this, this and this" and then I'm going to "Where is your system to keep them within the limits?" ( ) that they are looked after from that angle. And you know, "I'm not going to go every 3 months" and "If this woman's U&Es are up the spout I'm not going to" you know "It will be you that needs to do this" but how do we link them in to prevent?

Jenny N5<sub>p</sub> (Modern matron)

The range of professional approaches to dose optimisation and disease monitoring may come as something of a surprise to patients. They may assume that there is a correct course of action for their situation, and trust professionals to follow it. However, patients did recognise different attributes of care in different settings (cf. **Sections 5.2.1** and **5.2.2**). Quite apart from any role in clinical self management (daily weights and diuretic dose changes) there seems to be a potential role for patients as guardians of their own general disease management. GPs may fear additional dose changes and diagnostic tests. If they knew patients had been properly informed about the rationale for change, then a greater fear may be failure to optimise care.

### **5.3 Chapter summary**

The fundamental problems inherent in the creation of healthcare described in this chapter are communication and mutual understanding. Garfinkel (1964) cites Schutz's idea that in order to go about day-to-day life one must assume that others make the same assumptions as you about everyday objects. Usually when people talk there are gaps that are filled by common assumptions, and to question these gaps by asking people what they really mean risks offence. Generally, the patient participants made similar assumptions to each other, even if their behaviour and outlook were manifestly different. Some of the difficulties in heart failure management arise because unspoken assumptions about the condition were actually very different. One may expect this to be when comparing patients and professionals, and this could be made explicit during a successful consultation. However, the extent to which assumptions varied among professionals is somewhat surprising, and has little opportunity to come to the surface.

Ideal heart failure management, if maximising clinical outcomes is the goal, might look something like the Acute Trust heart failure clinic. A diagnosis is confirmed before referral to the clinic and in the initial sessions time is taken to explain the nature of the disease and its consequences. The patient's concerns (and those of family members if necessary) are listened to and a personal management plan agreed. Monitoring is routine and medicine doses are optimised wherever possible. However, the exact opposite model of care is more prevalent: no clear diagnosis, no explanation, no personalisation, infrequent monitoring and inadequate doses.

The reasons for this are not ignorance but good intentions. Particularly when the patient is old, aspects of the ideal model may seem pointless and unnecessarily intrusive to the professionals. However, this means that patients are denied choice about how they cope with their own health problems. It would be appropriate in many (but not all) cases to involve patients as active partners in disease management. They have the capability and willingness to understand more, and the more they understand the easier it would be to optimise care.

## 6 Self regulation and professional regulation

Clinical self management is about patients monitoring and responding to changes in signs or symptoms. This chapter begins with a description of related activities that patients already (informally) engage in (**Section 6.1**), and continues with patients' views about new aspects of (formal) self management that were presented to them (**Section 6.2**). In **Section 6.3**, professional views about increasing patients' self management activity are described and contrasted with the patient views already expressed. Finally, in **Section 6.4**, the most profound issues and dilemmas highlighted by contrasting views are discussed in turn.

People's health status often varies unpredictably and they may be able to cope with some variations better than others. People are expected to cope with minor ailments (for example, coughs and colds) and slight exacerbations of chronic conditions, perhaps taking advice from informal carers or community pharmacists. However, serious accidents, severe exacerbations or major new diagnoses usually require intensive professional support. It seems likely then that different models of healthcare will suit different people at different times for different medical conditions. The process of determining an appropriate model of healthcare in particular circumstances may be implicit or explicit. Decision making may be led by the patient or a professional. Thus, the overall pattern of healthcare for an individual may be complex, including both traditional and modern elements: **Chapters 5 and 6** demonstrate this. Note, for example, Harry 75 who exhibited both low and high adherence to current medication and reported that professionals took a relaxed attitude towards his lifestyle (his GP notes stated that he "declined" smoking cessation advice from the heart failure nurse). In contrast, Patricia 63 reported that she once had low medication adherence, but must now take all her medications carefully and consider the potential impact of any planned activities. It was also common for patients taking diuretics to modify dose timing whether their professional carers were aware of this self management or not.

Government policy (cf. **Section 1.4.2**) suggests that a movement towards more self care (including self management of long term conditions) would achieve important objectives, chiefly improving patient satisfaction with care and the efficiency of the

healthcare system. However, this has to be negotiated through practise and implemented at ‘street level’ (Lipsky, 1980). This chapter directly explores the barriers to achieving these objectives in the context of (clinical and generic) self management of heart failure. The factors that hinder or facilitate the development of self management in these circumstances provide direct and indirect evidence concerning:

- the congruence of patient/professional values and Government policy;
- the benefits that may be achieved in practice; and
- the probability that any new proposal will become normal practice.

I have called the response to change itself, or the suggestion of change, ‘regulation’. Self regulation, therefore, concerns the problems patients face, the actions that they take and their response to feedback. In the context of chronic disease the main ‘problem’ for patients is minimising the effects that symptoms have on the activities of daily living and maximising feelings of well being. Professional regulation in this context is considered to be conceptually similar. However, since healthcare professionals are self-interested agents of both patients and the state, their ‘problems’ are somewhat harder to characterise. Broadly, professional practice involves some compromise between:

- maximising the health status of patients;
- treating patients with respect and dignity (for example, giving choices);
- minimising use of organisational resources; and
- maximising professionals’ personal resources: time and income.

The individual compromises reached by professionals may depend (respectively and among other things) on:

- the patient group served;
- the context of practice;
- financial constraints in healthcare organisations; and
- personal professional motivation.

We might expect patient dissatisfaction with the current standard of healthcare (process) or achieved health status (outcomes) to provide an incentive to self manage. **Chapter 5** demonstrates that, generally, satisfaction with the standard of healthcare was good. However, there were exceptions to this such as: Tony 55, who was dissatisfied with many elements of his current healthcare; Ethel 83 and Olive 62 who expressed

dissatisfaction with some aspects of their current primary healthcare; and Patricia 63 and Mike 56 who expressed dissatisfaction with some elements of their previous secondary healthcare. Patient satisfaction was generally linked to a high degree of trust: particularly that exhibited in GPs and hospital consultants.

In this chapter, patients first give details their health status in terms of physical and mental symptoms (**Section 6.1**). Symptoms provide the most tangible incentive to improve healthcare whether by optimising professional or self management. Symptoms indicate that healthcare is sub-optimal and their alleviation is the short to medium term objective of change. Attitudes towards the key elements of clinical and generic self management (the *a priori* focus of this policy orientated study) are then explored (**Section 6.2**), which are:

- willingness to monitor and record symptoms;
- willingness to change diuretic doses in response to symptoms; and
- willingness to participate in group discussion with other patients.

A lack of physical or mental capacity to participate in clinical self management was not planned for but was identified and is highlighted. The professional agenda is integrated into this chapter in two ways (**Section 6.3**). Firstly, by professionals' direct comments on incidents and ideas described by patients. Secondly, by identifying themes and concepts that emerged from professionals' reflections on practice development.

Any move towards self management requires an effective therapeutic alliance between patients and their professional carers. At the end of the chapter there is a discussion about both the general issues influencing such effectiveness and specific dilemmas (or choices) that the key actors will face (**Section 6.4**).

## **6.1 Symptoms and coping strategies**

The impact physical symptoms had on patients' household and occasional activities is discussed in **Section 4.4.2**; the most common restrictions were centred on lifting (usually shopping) and walking. Restrictions could be caused by a single symptom (for example, shortness of breath) or a combination (for example, pain and lethargy). The frequency and range of individual patient symptoms are summarised in **Table 6.1**, with the exception of anxiety and depression (cf. **Section 6.1.6**). It was usual for patients to report multiple symptoms (up to 6 in the case of Olive 62) and only two patients reported shortness of breath alone (Ethel 83 and Jean 76).

In **Table 6.2**, the common symptoms (central column) are linked on the one hand to physiological impairment (causes) and on the other to social handicap (consequences) (WHO classification cf. Badley (1993)). For patients, we might expect symptoms that have the most social impact to be reported as most troublesome. Professionals may be (justifiably) more focused on symptoms whose cause they can modify. However, for patients symptoms can cause distress when there is no activity to perform, and indeed may be more noticeable when activity levels are low, for example, pain when resting. Symptoms may also allow activity but only with a degree of physical discomfort or anxiety, which restricts capacity for social interaction.

The way that someone copes with symptoms (to reduce frequency, severity and impact) reveals information about their approach to healthcare and life in general. In the sections below the way that patients coped with each of the most common and troublesome symptoms is discussed in turn. The starting points in each case are patients' experiences of health, rather than any particular disease or diagnostic category. It is particularly important not to impose a medical framework, because patients have so much diagnostic uncertainty.

**Table 6.1:** Frequency and range of symptoms experience by patients

<i>No.</i>	<i>Pseudonym</i>	<i>Shortness of breath</i>	<i>Ankle swelling</i>	<i>Pain</i>	<i>Lethargy</i>	<i>Forgetful</i>	<i>Others</i>
1	Ethel 83	✓					
2	Maria 76	✓		✓		✓	Deaf Insomnia
3	Edward 71	✓	✓				Insomnia
4	Florence 78	✓	✓				Continnence Vertigo
5	Clara 86	✓		✓			Deaf
6	Patricia 63	✓			✓		
7	Jean 76	✓					
8	Lillian 78	✓	✓		✓		
9	John 67	✓	✓	✓			
10	Harry 75	✓	✓	✓			Weight loss
11	Mike 56	✓		✓	✓		
12	Philip 65	✓	✓		✓	✓	Deaf
13	Tony 55	✓	✓	✓		✓	
14	Ruth 86	✓					Insomnia
15	Olive 62	✓		✓	✓	✓	Cough Itch
16	Anne 64			✓			Cough
17	Doris 88	✓			✓		
18	Rose 82	✓			✓	✓	
19	Margaret 89	✓	✓		✓		Vertigo Blind
20	Pete 65	✓				✓	
21	Vera 84			✓		✓	

**Table 6.2:** Symptoms - their causes and consequences

<i>Impairment (physiological)</i>	<i>Disability (activity)</i>	<i>Handicap (social)</i>
Respiration	Breathing	Endurance
Memory	Forgetfulness	Independence
Hearing	Listening	Communication
Circulation	Ankle swelling	Movement
Balance	Vertigo	Climbing or reaching
Circulation	Lethargy	General functioning
Neurological	Pain	Varies with severity

### 6.1.1 Shortness of breath

When talking about their health, the most common symptom patients said they experienced was shortness of breath and the most common (and obvious) response to breathlessness was rest. However, shortness of breath without exertion could also be a problem. Ethel's quote below is typical: she described shortness of breath related to walking and general household tasks; also she didn't understand why walking "on a level" should cause problems at all.

**If you noticed you were short of breath or your ankles were swollen, what do you think you would do?**

Well I am short of breath, all the time, well I am alright now but say if I got up and started polishing that sideboard, I would be short of breath then and if I get up in the night just to walk that small distance to the toilet and get back into bed I don't know why because it's all on a level, I am breathless then.

Ethel 83

Inability to complete tasks for oneself was the main functional impact of shortness of breath. The most common response to shortness of breath was simply to rest (for example, "go lay down" Edward 71). This supports an academic opinion that rest is intuitive and requires little thought (Riegel et al., 2004) (cf. **Section 2.2.3** and **Table 2.1**).

If rest didn't improve symptom control, then a doctor might be called. It is obvious from Jean's quote below that she was highly satisfied with the care provided by her GPs.

Note the transfer of responsibility as first the GP and then an ambulance were called, Ethel was told “you’ll be alright, don’t worry” perhaps to maintain her sense of optimism during a difficult situation. She now tries to be careful so she doesn’t need oxygen again.

They have been wonderful, they have been really good. In fact I had to ring the doctor from here and I couldn’t get my breath and he sent an ambulance for me and I said I didn’t need it. He said “I could tell from the way you were talking to me that you needed help”, but he said “You will be alright, don’t worry about it.” They put me on oxygen now that did me the world of good. But now I find I have got to be careful, I have got to take deep breaths and try and keep off it but sometimes I wish it was on pipe that I could just you know have a whiff. Pity they don’t make cigarettes like that.

Jean 76

Whether or not greater self management could have prevented Jean’s emergency call on this particular day is unknown, however, this is just the sort of incident that personal responsibility for dose titration is designed to avoid. Patients were typically vague about why they were short of breath (for example, Jean 76 and Clara 86) and expected the GP to know what to do.

Most patients were not able to just “work out” what the causes of their problems were, and gaps in knowledge point to limited patient education by professionals. If improving patient knowledge is desirable, then professionals may need to initiate the process. The nature of the gaps identified in this study is profound, suggesting that many patients would not know what questions to ask or when an answer is likely to be found. Explanations for shortness of breath (and also memory problems) were frequently linked by patients to ageing rather than heart failure (or cardiovascular disease in general). In this example, Ethel 83 linked breath limited activity, rest as therapy and age as an explanation:

**Would you ever notice that you were more short of breath or ...**

Yes, yes. I would if I go up any steps I am very short of breath or as I say, just polishing, I am out of breath I have to sit down and have half an hour like and then I can start on another little job. I mean I think that’s age as much as anything. Everything wears out, even cars wear out don’t they with age, you can’t expect to keep going for ever can you, not perfect.

Ethel 83

Olive 62 said lung problems were the cause of her breathing difficulties (which was likely to be the case), but doctors had not been able to give her a precise diagnosis. She needed a number of inhalers, including one for emergency use, and had home oxygen. Her breathing was also affected by warm weather and hay fever. Tony 55 was having trouble understanding both the cause of his breathlessness and the medical response to it, which was unusual:

I'm still having trouble breathing some four years on, three or four years on, and they still don't know what's wrong. They told me there's a tear in the heart but that shouldn't affect the breathing the way it does.

Tony 55

It seemed that in general, patients did not mind not knowing precisely what was wrong with them. However, Tony 55 illustrated that some patients can become uncomfortable when their doctors don't seem to know either. He further complained that it can take some time to recover from breathlessness *and* that doctors never see him at his worst:

If I go the toilet well you don't want to know about that. It takes five minutes to start putting the breathing back together.

The thing is you, see you go in the doctor's surgery, well you've seen me when I walked through, I puff and pant, like a ( ). Two or three minutes later, or thirty seconds later, I'm back to normal.

Tony 55

Some patients both didn't know and didn't want to know what was wrong with them. For example, Ruth had episodes of breathlessness at rest but also said:

Just cos I don't get out of breath ((at a particular time)) I think I'm alright. Me daughter plays pot with me cos I tell her there's nowt wrong with me.

Ruth 86

She claimed not to have been told what causes her breathlessness and didn't actively push professionals for an explanation but thought perhaps she should. Despite such apathy she was happy to take instructions from the doctor. This presents a rather mixed picture of someone partly in denial of health ill but nevertheless accepting the treatment offered. This is consistent with a strategy to maximise clinical outcome (by following the doctor's instructions) whilst minimising cognitive input (by not thinking about the causes of ill health). This must be underpinned by trust in the prescriber (one of Ruth's relatives worked with her consultant) and/or a desire to minimise confrontation with a

concerned family: who will perhaps accept their relative's reluctance to seek help providing regular medication is taken.

It becomes harder to avoid the cause or minimise the seriousness of symptoms if they are progressive, such as those experienced by some patients, for example:

**Does it tend to be the same or is it up and down sort of thing?**

It has always been an up and down thing until very recently when it has become uniformly horrible. I know I am in a bad way now.

Patricia 63

**Right what sort of things have changed?**

Well getting my breathing more, it is getting a bit worse now. I haven't far to go before I am out of breath. If I just go to the centre here ... I have got to stop.

Clara 86

An objective of self management would be to slow the progression of disease, however, patients didn't generally view disease progression as modifiable. Patients did expect surgery to improve symptoms, for example, a bypass graft (Maria 76, Jean 76, John 67, Philip 65) or fitting of a pacemaker (Philip 65, Doris 88).

**Do you notice any changes in shortness of breath day-to-day?**

Since the pacemaker was fitted it's been better

Philip 65

Philip's response implies that he made the connection between heart (pacemaker) and shortness of breath. Mike (56) expressed surprised that smoking cessation hadn't led to even fewer symptoms, he could walk further but was still out of breath. This exhibits Mike's failure to understand his condition as long term and to some extent irreversible.

Shortness of breath is a defining symptom of heart failure and almost all the patients (**Table 6.1**) described some experience of it. However, patients rarely made the less than obvious link to heart problems, which is unsurprising because levels of diagnostic knowledge were low (**Section 5.1.1** and **Table 5.2**). To help patients make this link, which is a step towards clinical self management, professionals would have to be more open about diagnosis. If nothing else some patients may experience less anxiety if they understood that distressing symptoms did have a real cause, rather than being left with

the (uncorrected) impression that age itself is inevitably associated with serious functional decline. Understanding the underlying causes of breathlessness may also help patients to plan more appropriate activities and respond effectively to exacerbations.

### 6.1.2 Pain

The second most common symptom was pain, which tended to be (on-going) muscle or (occasional) chest pain. Pain was generally considered to be a “serious” symptom, more so than shortness of breath. For example, Ethel 83 says that her heart problems must be “slight” because pain isn’t a feature of them:

**No so would you know the names of any heart problems you had at all?**

No, it must be slight I suppose, you know I have had no, touch wood, I don’t have pain but you see my husband had it for years and I knew what to expect with him he had it very bad.

Ethel 83

Despite a perception of seriousness, the response to pain (unlike shortness of breath) was sometimes to “work it through” (Tony 55) rather than rest. This demonstrates that is possible to carry on with many activities while suffering a degree of pain, and that in patients’ experience activity could lead to pain reduction, for example:

And the pain I’ve had with this sciatica on my legs, oh it’s absolute agony it’s been. Just moving, just turning over in bed (I’m OK in bed where it hurts) you know. But when I’ve got up during the day it’s worked it a bit away but it’s been quite easy this last two days

Vera 84

Indeed, evidence based treatments for back pain (Silcock, Moffett, Edmondson, Waddell, & Burton, 2007) and arthritis (Christmas & Andersen, 2000) recommend that people remain as active as possible.

Waiting or rest was also a common strategy, particular in response to acute cardiac pain as Harry 75 describes below. However, his approach could easily lead to the late diagnosis and treatment of a heart attack. So it would be better if Harry had some clear guidelines for dealing with angina brought on by activity, which might include rest and using a glyceryl trinitrate spray, but probably wouldn’t include going to bed in pain (Joint Formulary Committee, 2008c).

**Say if you do feel particularly badly on a particular day or you feel that ...**

Well some days I do, I do feel a bit down and I keep getting a lot of pain in me top of me arm here and in chest like, angina. And I've been going to ring up yer know ((the doctor)) and then a thought oh no, I got into bed about 11 o'clock and I have been alright following morning yer know?

Harry 75

Musculoskeletal pain is a symptom that may be more noticeable and troublesome during inactivity or when trying to sleep. Vera 84 described a simple change to her sleeping arrangements, which demonstrates self management:

Me toes have, me toes have always been inclined to be a bit numb you know but I have recently very strong, but this past two days I've moved into the back bedroom ... a different bed you know and strange that. It's eased the pain in me legs you know. Nothing, but I just feel that's it's a different bed ...

Vera 84

It's not clear how people decide whether rest or activity is an appropriate response to particular types of pains. Professional guidance might vary (ideally) according to the cause of the pain (at rest or during activity), the location of the pain (in heart or legs) and the duration of the pain (seconds, minutes or hours). Mike 56 expressed confusion about the safe administration of his painkillers, which may have left him with some unnecessary pain because of under-dosing.

Yeah, he give me a great big box like that ((of painkillers)), I've got to take up to eight a day ... I've taken four today. And this is, I won't take any more because I'm not sure when I'm taking pills, cause I don't know whether they'll mix with each other ... I suppose they should do, otherwise he wouldn't let me take em would he?

Mike 56

For pain, therefore, patients demonstrated self management behaviour related to activity and medicines taking. However, this didn't seem to involve any logical principles of pain management or use any patient (or condition) specific guidelines. They applied what seemed to be common sense and tried to avoid calling for help. These self management behaviours could potentially be safer and more effective if patients' health knowledge was improved and simple decision making tools were provided.

### 6.1.3 Ankle swelling

Ankle swelling is another classic symptom of heart failure, but not so disabling as shortness of breath. Unlike shortness of breath and pain, which often responded (in the short term) to ‘passive’ treatment (rest, working through), ankle swelling was more often linked with medical attention and the need to take diuretics. Sufferers tended to be older, with the exception of Tony 55. Lillian 78 described how the importance of the symptom was missed by her old GP:

And another doctor in the clinic I went to on the Friday with my ankles swollen, oh he said it's the warm weather. I was in hospital on the Tuesday at the ((hospital name)) for 19 days with my heart. So needless to say, I changed doctors, and touch wood I am ((now)) getting first class attention.

**So how long ago was it that you were in hospital after your ankles swelled?**

Oh that would be 3 or 5 years since I should think before I had my knees done, and we were in ((seaside town)) and I couldn't walk and talk. If I wanted to talk I had to stand still. So if I didn't talk, I could walk.

Lillian 78

In the first half of the quote above, Lillian states the practical consequences of poor treatment, which were in this case an extended hospital admission and the breakdown of trust in her GP. That she would move GP for this reason demonstrates independence and self management. The second half of her quote (indicating severe shortness of breath) should have been (together with ankle swelling) highly suggestive of heart failure decompensation. Had Lillian 78 been more aware of her diagnosis perhaps she would have been in a position to demand better initial treatment? However, because she has changed GPs her list of formal diagnoses (what she might have known) at the time of the above incident is unclear. Her current knowledge was still limited (**Table 5.2**), but she did trust her new GP.

Ethel 83 described another way that patients without sufficient health knowledge can be misled by their carers. In **Section 5.1.2** I reported that she was instructed by letter not to take her diuretics on the day of travel to a seaside convalescent home. Following such a journey she described not being able to “put my legs up” like at home and that her ankles “really came up”. This led to a consultant referral on her return. Medication changes had also helped to ease the ankle swelling of Harry 75. However, Florence 78

found herself caught between the need for diuretics to reduce swelling and dread of their effect on continence (which dominated most of her interview).

**Have you been taking these tablets and things for long.**

A long time, yeah. I think I said to ((Name of GP)) what about these water tablets, don't, will I ever come off them, and he just said "No" you know?

*Daughter: Well I used to be on water tablets in hospital, they took me off them Mam, because it got too much.*

I couldn't do with that, coming off it.

Florence 78

Some patients found that activity helped to relieve swelling. For example, Edward 71 noted that "I mean first thing on a morning *obviously* they are swollen but within half an hour it is down and okay" (emphasis added). Philip 65 stated "The walking makes it easier. If I don't walk my ankles puff up. I have elastic stockings on at the moment." He was the only person to mention support hosiery, which can relieve swelling in the ankles caused by the inability of veins to carry blood (against gravity) back to the core circulation. In untreated heart failure this would simply leave relatively more fluid to pool elsewhere. Philip 65 was being treated for heart failure and his GP said that the hosiery (which is usually prescribed) was no longer needed. Philip found it "more comfortable" to carry on using hosiery, which provides an example of self management. Tony 55 found that walking could make his ankle swelling worse ("like a rock" rather than "in like a balloon"), he seemed to have difficulty maintaining a helpful balance of rest and activity.

Providing better patient education and involving patients in the monitoring of short term weight fluctuation would allow patients to make more informed choices about how to manage ankle swelling and should enhance patient safety. With current levels of education, monitoring and early management there is a danger that patients would delay professional contact and/or maintain higher diuretic doses for too long.

#### **6.1.4 Lethargy**

Lack of energy (lethargy) was also reported by patients, which makes sense in heart failure if enough oxygenated blood is not circulated effectively. Of course, patients' ability to make sense of the symptom in these terms is restricted by their lack of health

knowledge. For example, Mike 56 reported feeling tired but not understanding why because he gets enough sleep.

Patients with better knowledge (cf. **Table 5.2**) were able to make a link between their heart problems and lack of energy. For example, at first Philip 65 considered ageing to be responsible for his tiredness but he now made the link to heart disease:

I never got tired ever. Even when I was working, and it was quite a physical job at the time ... but I never got tired ... but since the heart attack ... so *obviously* the heart's not been functioning like it should do.

Philip 65 (emphasis added)

Doris 88 and her family also knew that lack of energy was directly related to “leaking heart valves” and that a pacemaker was helping to manage the condition. Less directly than Philip 65 and Doris 88, Rose 82 suggested that she “gets tired (a) little bit more” and therefore her heart problem “can’t be very bad”. Patricia 63, however, found lack of energy the worse thing about her illness and her activity was restricted on a recent holiday, only rest improved her symptoms.

There is probably little clinical self management can do to improve patients’ energy levels and patients who suffered from lack of energy tended to understand (in basic terms) how and why this was linked to heart problems. An exception to this is Mike 56, who as noted previously has not really adopted a chronic model for the explanation of his condition(s). For Mike 56, and patients like him, better understanding may lead to more realistic expectations of health status and as a consequence improved satisfaction with the professional care he receives.

### **6.1.5 Loss of memory (forgetfulness)**

Deterioration of cognitive function in heart failure has been previously noted but not widely investigated (Almeida & Flicker, 2001). Memory loss, was reported frequently by patients, and has been reported in another sample of heart failure patients as one part of a general pattern of cognitive decline (Vogels, Oosterman et al., 2007). The causes of cognitive decline in heart failure aren’t completely clear (Debette et al., 2007) but a relationship has been confirmed in clinical studies (Vogels, Scheltens, Schroeder-Tanka, & Weinstein, 2007).

Unlike lethargy, no patients attributed their loss of memory to heart problems (nor did any professional suggest such a link). Pete 65 did make a possible connection between memory loss and (non-cardiac) disease progression, but he was relatively young and his symptoms were relatively severe. For Rose 82 loss of memory was the worst effect of *ageing* and the reason why she preferred information to be written down. Maria 76 and Olive 62 also invoked memory problems as a reason to have written medical information, for example:

The stage I'm at, at the moment, I would rather it ((information)) be given to me face to face but the stage I'm at, at the moment, well I'm not remembering (everything) I have to have something written down...

Olive 62

In the context of medication adherence, both Maria 76 and Rose 82 used compliance aids (MCAs) to help them remember to take tablets, for example:

Just to remind me that's all. I look and see if I've taken them or not.

**Yes. Oh that's a good idea.**

Cos your memory gets old as well. Never mind your heart.

Rose 82

This is a highly practical response, both Maria 76 and Rose 82 imply that since the cause of memory problems is age nothing could be done to actually improve this element of cognitive performance. Vera 84 implies the same thing when trying to recall a relative's name: "It's awful when you're getting to *this stage*" (emphasis added). Philip 65 also said "As you're getting older my memory's not as, not as lucid as it used to be." However, Tony 55 admitted to long-standing memory failings: "I always have trouble with names. I can't even remember half the family's names."

In summary, memory problems were frequent, usually reported in the context of medical information or medicines adherence, and attributed almost exclusively to the ageing process. This interpretation of the symptom may be more or less correct in some cases, and yet not the whole story. Patients with memory loss were often keen to take practical measures to enhance adherence behaviour, which shows respect for the advice they have been given. Since memory is such an important part of identity, professionals could consider sharing more clinical interpretations of the symptom.

### 6.1.6 Mental health

Loss of memory is summarised with physical symptoms in **Table 6.1** and discussed above in that context because in practice it is usually considered to be a neurological problem rather than a psychiatric one. The context in which patients reported memory loss reinforces the perception of it as a simple unchangeable failing, rather than a variable alteration of mood. Patients' memory was described as bad at their particular "stage" of life or disease, not bad "at times". Loss of memory can be frustrating and, particularly when more severe, have an impact on mood or identity. However, all patients were asked specifically if their initial diagnosis, symptoms or limitations of daily living made them feel "worried" (that is, anxious) or "down" (that is, depressed). I do not claim that such feelings can be easily distinguished. Sometimes patients also volunteered thoughts and feelings about their mood.

Some self reported symptoms of poor mental health were expected since: mild neuroses are a common part of the human condition (Cross, 2009), neuroticism is one of the major personality traits (cf. **Section 2.2.4**) and prevalence studies demonstrate neuroses in older people (Saunders et al., 1993) (Nilsson et al., 1997). However, those suffering from more severe symptoms would be excluded by the study participation criteria or perhaps unwilling to volunteer as research participants. The importance of mental health in chronic disease (including heart failure) is evident from the literature (Jiang et al., 2007) and supported by this quote from the local EPP administrator:

We do actually run a one session on depression, depression management, within the expert patient programme itself because we find pretty much, these are just ((her own)) statistics, but I'd say 9 out of 10 people will flag up depression, not necessarily clinical, but at least reactive, so we often have many people who suffer from clinical depression with long term illnesses.

Jane E1 (EPP Administrator)

Anxiety-like symptoms were most often associated with diagnosis, hospital tests and the first instance of heart problems. For some these issues clearly stirred memories of past illness in their immediate families. John 67 and Lillian 78 used a family history of heart disease as a way to modify or contextualise their worries. John 67 began by saying "well it worries you *obviously*" (emphasis added), then he continued "*but* I mean my mother had problems" (emphasis added) as if there was an expectation of similar

problems. Lillian 78 presented a similar *post hoc* rationalisation, the idea that problems run in the family served to dissipate her worries:

**When you first found out you had problems with your heart and I know it's a bit vague the way you found out, how did it make you feel, were you worried at all?**

Well I was worried in as much that my father died when he was ((age)) with coronary thrombosis, just collapsed and died. He went to see his doctor at 6 o'clock, now we are going back to ((year)) now, he saw doctor at 6 o'clock and he was dead at 9 o'clock. Where now a days they would have had him in hospital and known how to treat him. Daddy died with coronary thrombosis. My sister, ((detail deleted)), she had a heart attack teens of years ago so I just thought, oh well it runs in the family. It didn't worry me, I haven't changed my lifestyle at all, I know my limitations, and I do sleep a lot that's because of anaemia.

Lillian 78 (emphasis added, detail deleted to protect identity)

Mike 56 understood that smoking was "hurting" him, but was expecting and more worried about the possibility of cancer. Lung cancer, which Mike 56 mentions, does often have a particularly poor prognosis, but he suggests no understanding (here or elsewhere) that his current heart problems may have a terminal outcome.

**How did it make you feel generally having a heart attack. Was it a shock or...**

Well as I say I didn't know I was having one at the time. It was a shock when I found out but not so much a shock. I knew the cigarettes were hurting me ... but you know I thought well, I heard that you could get heart attack, but more lung cancer ... and when they took photos of me in hospital I was a bit frightened I thought will they find any lung cancer in me or owt like that?

Mike 56

Harry 75, clearly was expecting to die sometime soon, he was worried about what new investigations may uncover but at the same time discounted the impact of potential findings. He said his prayers and claimed to take each day as it came.

**... were you able to understand what they told you?**

Oh yeah well that were last week when I were waiting for that whatyercallit: endoscopy. She were an amazing doctor, it's a lot of stress and a lot of worry. I am frightened honest, yer know, but as I say yer've to live life to full. I don't think about it, I say me prayers at night and morning, and thank God for givin me another day, a mean every day's a bonus. A mean you get people saying no it's raining again, I am not bothered it can be snowing, as long as I am here.

Harry 75: 77

Patricia 63 had experienced weeks of confusing symptoms prior to her diagnosis, and she described positively finally finding out what the problem was.

**So it was all quite confusing at the time ((of diagnosis))?**

It certainly was and it was very upsetting because I really was ill wasn't I? ((to husband)) ...not able to do anything at all, and it was ... oddly, it was good to know what the problem was because you tend to think of yourself as a bit of a hypochondriac when these things are going on and nobody says what's the matter.

Patricia 63

All of these quotes about worry around the time of diagnosis suggest it is important for patients to have some way to explain their symptoms and manage their expectations: whatever they may be. Family history or obvious risk factors provide seemingly straightforward explanations. However, there were clear gaps in patient understanding, suggesting professionals made limited attempts to help patients make relationships between their risk factors, diagnosis and (particularly) prognosis.

Worry or anxiety was usually described as a response to events that resolved when explanations were identified, created or found. This suggests that the information required to support clinical self management may have a positive impact on mental health after any initial reaction has settled. However, Jean 76 described how after getting on so well at first anxiety has become a more predominant (and continuous) feature of her life. Jean 76 herself explained some of these feelings in relation to a building accident in her flat when windows were smashed late at night.

I am nervous when I go out now, crossing the road and things never bothered me. But I am sort of double checking all the time, you know or I would rather go with somebody else with me. I think I got on so well after my operation and in fact I went to the, down at the swimming pool they have a what do you call it, a gymnasium, and I started going there two days a week and it was doing me good. I mean I wasn't over doing anything obviously, I am 76 now, that's old, but I got so used to it and I felt so well I didn't realise how well it made you but I told my family, the younger ones, I said "For God's sake go to a gym and work things off" I said "you'll feel much better." "Oh my mothers telling us what..." I mean I never would have thought of it that way but it did do me good but now I can't do it.

**Has it actually made you feel sort of down or anxious itself the being ill?**

I get anxious about all sorts of things now. I listen to a tape that is peaceful now and again and things like that but I find sometimes the least I can do I just forget everything and pick a book up and lose myself in the book.

Jean 76

This demonstrates that resolution may be temporary or liable to change for unexpected reasons. Professionals should continue to engage in a degree of social conversation to monitor mood fluctuations and identify potential influences. Self managing day-to-day should not lead patients to be professionally abandoned week-to-week or month-to-month.

Some major life events will be an obvious cause of stress at least initially (for example, retirement and accidents). Less obvious events and problems could also lead to anxiety often in the context of housing, transport and finance, for example:

So I owe about £160 and it's all worry to me, all stress.

**And that's making you feel worse?**

Yeah. I mean I've heard nowt from Council, so it's stress and worry that makes yer, oh it sends you out of your mind at times but you have got to live with it.

Harry 75

It's marvellous ((the Access Bus)). There's not many people who know about it. I wish they did .... I'm frightened they'll take it off there's only four of us going on it.

Rose 82

Day-to-day worries could also be 'anxiety by proxy', with patients (particularly women, for example Ethel 83 and Maria 76)) saying they were more worried about friends or family with health problems than they were about themselves. Professionals will always lack the time and resources to identify such varied events and help patients deal with problems constructively. Professionals can act as a signpost for other services and can promote general strategies for dealing with unhelpful negative feelings, indeed this forms an important part of generic self management training.

Depressive symptoms were described as periodic, affected patients at "times" and often associated with activities of daily living rather than specific events. Some patients (Edward 71, Mike 56 and Harry 75) suggested that these occasional feelings were normal (or at least less abnormal than worry or anxiety) and they coped by carrying on with whatever activity physical (or financial) resources allowed, for example:

**So how did you first find out that it was your heart that was the problem, how did you feel?**

Oh

**Very flat?**

I still do at times but it's, you haven't to think about it have you?

**Right. Just to get on?**

Carry on (as) normal.

Harry 75

For men in particular life at home without the distraction of work could be relatively dull, Mike 56 described shopping for his mother as the "highlight" of his day.

Jean 76 described a confident and open discussion with her GP about these occasional feelings, which were related (partly) to loneliness. There is a clear element of banter in Jean's *recollection* or *remembering*. There is also an element of contradiction in between Jean's "bright self" and the nervousness she described above.

I know it's stupid. Actually I just said the wrong thing because I walked into the doctors a fortnight ago for my tablets and I was depressed and I was miserable and I don't know what it was for, and he said "Oh what's wrong with you today you're not your bright self." I said "Oh you know all of these tablets" I said "will you put them in the bin?" And he says "Now you don't mean that" I said "Yes I do because I am just sick and tired of taking them all." He says "You need a holiday." I says "Where are you taking me?" He says "You're alright." It's just odd times, I suppose being on your own you get like that as well.

Jean 76

Some women described household activities that added interest to the daily routine. However, Ruth 86 was becoming frustrated that she could no longer cope with the heat of the oven while baking. Rose 82 described being less active and it seems less settled since her husband died, no doubt grief plays a part, but caring also provided her with a role or something to do:

Actually I think that kept me going ((looking after sick husband)). Now I sit around more because I haven't got anything to focus on ... (I make myself get up and) go out cos sometimes I think oh I can't be bothered having a go but I have a friend (and) got to go.

Rose 82: 63

Most patients seemed to have some regular contact with friends and family, or a supportive daily routine. It certainly seems possible that self management training could help patients to deal both with 'events' as they arise (and cause anxiety) and a day-to-day 'role' (that would ameliorate depressive symptoms). However, self management

training should be used to open up and encourage new avenues of support, not necessarily close down old ones.

### **6.1.7 Summary of symptoms and coping**

Patients experienced a range and severity of symptoms that seemed fairly typical considering their age and morbidity. The general coping strategy that emerged for physical symptoms was:

- avoid symptoms if possible by limiting activity;
- minimise impact of symptoms on activity by splitting up tasks (shortness of breath) or working through (pain);
- call for help if a period of rest doesn't resolve symptoms.

At some point or other, symptoms had encouraged all these patients to seek medical attention. Part of their general response, therefore, was to submit (to varying degrees) to the medical regimen prescribed as described in **Chapter 5**. We see in this current chapter that their response to remaining symptoms may be influenced by causality assessment. Most patients' assessments of causality (whatever the symptom) were somewhat vague. A unifying theme was the impact of age, that is, older patients expect to get less healthy and accept disease progression. Responses, when considered necessary, were typically restricted to simple common sense measures like rest. Self management philosophies draw on a more radical notion that disease progression is modifiable and encourage more active measures to maintain or improve health. There is clear potential not only for clinical self management to improve the experience of physical symptoms but also for generic self management to help patients deal constructively with a range of everyday mental health symptoms. Since, mental health symptoms (unlike physical symptoms) did not have fixed interpretations (for example, age) it may be that (at least initially) patients would see them as more susceptible to a change in response or coping strategies.

## **6.2 *Patients' views about self management***

All patients exhibited some degree of self management in a general non-technical sense, that is, dealing with everyday physical symptoms by taking rest or simple medication.

However, the main purpose of this project was to investigate attitudes towards the (clinical) self management of chronic heart failure by symptom monitoring and diuretic dose adjustment. In addition, the EPP, which teaches generic self management skills, involves patients in peer group work and support. To gauge interest in more formal self management, attitudes to these three central components were discussed with each patient. Only Harry 75 had any real experience of structured heart failure management via the nurse-led service. For other patients the concepts had to be introduced to them in an appropriate context. Unlike other aspects of the interviews patients are not recalling events they have experienced or explaining attitudes they have developed, rather they are giving an initial impression of their attitude towards a different style of care.

In this thesis, attitudes to self management are explored in context and related to patients' experiences of care. However, attitudes towards the components of self management described above could also be considered (*a priori*) as specific manifestations of three of the 'big five' character traits in psychology (**Section 2.2.4**). Daily monitoring and recording of symptoms requires a degree of 'conscientiousness'. For patients used to traditional relationships with healthcare professionals, willingness to participate in dose adjustment requires 'openness' to new ideas. Among other personal characteristics, successful participation in group work requires a degree of 'extraversion' (Barrick et al., 1998) (Thoms et al., 1998), that is, a willingness to seek inspiration from and be influenced by the opinion of others. 'Neuroticism' has already been considered above in **Section 6.1.6** about mental health. Potentially those who are 'disagreeable' are among those who fail to volunteer for research studies. Thoms et al (1998) demonstrated that self efficacy was significantly correlated with neuroticism (negative), extraversion, agreeableness and conscientiousness (all positive). It seems likely then that, full participation in self management (supported by self efficacy) would require desirable character traits on almost all of the dimensions psychologists consider important, which is difficult to envisage as common.

The character traits are themselves influenced by people's prior experiences (nature and nurture) in the very broadest sense and would be a blunt analytical tool in qualitative research. However, in clinical practice it is possible that an assessment tool (for self management suitability) that took into account broad personality characteristics would

be more appropriate than simple stereotypes based on age, gender and race. Professionals are generally trained not to make assumptions about patients' preferences, however, given the pressure of work it is likely that many do (at least occasionally).

### 6.2.1 Symptom recording

The simplest step towards self management is the monitoring and recording of signs or symptoms. This normally means weight (a *sign* unless it can be perceived by the patient) since short term fluctuations are linked to fluid retention and it can be objectively measured in the home. However, patients could also record incidences of shortness of breath and their degree of ankle swelling. Julie N2<sub>s</sub> (a heart failure nurse) described the importance of weight monitoring and how its very simplicity may lead (medical) professionals to overlook it.

Yes, I think lots of people don't realise the importance of weight and I think the medical side of things, doctors have always been, they do very much look at other clinical signs rather than their weight, very much into their medical skills, clinical skills type things rather than something just very, very basic like weight.

Julie N2<sub>s</sub> (heart failure nurse)

Douglas D1<sub>s</sub> (an elderly care consultant) agreed that such monitoring and recording “*would* be useful” (emphasis added), implying that it is not current or usual practice in his clinic. This interpretation is consistent with Douglas's description of patient care in **Chapter 6**, where he describes patients not understanding as much or being as involved in care as they might be.

**One of the aspects of self management for example might be keeping diaries of symptoms or weights.**

That would be useful, particularly weight, also symptoms would be useful and particularly either we've altered treatment or they've altered treatment for some reason to see whether it makes any difference.

Douglas D1<sub>s</sub>

The monitoring and recording of weight or symptoms was introduced to patients as a potential daily activity. For weight monitoring household scales would not necessarily need to be calibrated so long as they were stable and accurately showed fluctuations. Patients had experience of weight monitoring of course but not generally its systematic recording, with the exception of Harry 75 and John 67. Harry 75 didn't know if the

record he had once kept was ever used and John 67 was sure his record had made “no difference” to his care.

**So is your weight something that you make a note of each day?**

Well she said I had to do it, I were doing it every day and then she said do it twice a day, every 2 days, this ((name of heart failure nurse)) at heart thing. I think that's why they are doin this escapology ((endoscopy)) thing. ((Patient was worried about recent weight loss and waiting for investigation))

**Have you found it useful to have a record like this?**

I don't know, she just wanted it doing so I did it. But it's handy, a mean when you go in hospital and show them that.

**Are you aware if the doctors have ever used this information and done anything with it?**

I don't know.

Harry 75

**How would you feel about actually making a note of how short of breath you were or say how badly swollen your ankles were on a particular day, so you had like a diary, would you...**

*Wife: He's done that. Haven't you? Through lung man?*

I've done that yeah. I've have done that through lung man ((respiratory consultant)) aye, I have done that 2 or 3 tests I have had I have done that. But you have taken them in, and I don't (think they do) a right lot about it.

**Did you find it easy to do to keep the diary?**

It wasn't hard, it was writing it all down like. To be honest I don't think it would make any difference. Whether it would help them or not I don't know, I don't really know.

**But it didn't help you very much?**

It didn't help me at all writing it down. I mean it doesn't make any difference to me, to them whether I am out of breath or not really.

John 67

Since Harry 75 and John 67 expressed such fundamental negative comments about professional use of the symptom record, this issue was explored in the professional interviews and is presented here before further consideration of patient views. I asked Luke D5<sub>s</sub> (a respiratory consultant) about John's experience of symptom recording, but note that Luke D5<sub>s</sub> was not actually John's consultant and is not commenting from direct experience of this patient.

For asthma we do ((use symptom diaries)) but it's interesting what you said. Is the patient doing the symptom diary? And I'd have asked who they are doing it for? Because you gave me the impression that the patient was doing it for their doctor.

**In a way yes.**

Rather than for themselves?

**Yes.**

Now the asthmatics, we do get them to keep a sort of symptom diary. They keep peak-flow records, which are a blowing test morning and evening ... now those patients are keeping those peak-flows, now some people will just keep doing their peak-flow record permanently and will bring it to clinic and they'll give it to me and I will probably spend no more than ten seconds looking at it because it's actually graphical and as I open it I can actually see a months worth in one line, across two pages ... I don't actually need to spend a lot of time looking at the diary to get the information I need. To the patient that may look like a cursory look.

**Yes, yes I see.**

But the main purpose of the diary is for them, not for me really.

**So I guess if you're going to keep a symptom diary it should be something that you're able to use to adjust what you do for you on a routine basis?**

Or when to call for help.

**Or when to call for help and I guess we could say that it might be good practice if a professional was looking at a symptom diary for them to say, "I notice it's fairly flat; that's good" or "I notice it's up and down".**

Yes, and I'm probably guilty of not doing that but I would agree with the sentiment.

Luke D5<sub>S</sub> (respiratory consultant)

Luke D5<sub>S</sub> described clinical self management as a routine activity for his asthma patients and said that a written personalised plan is used to guide the patient. The plan was designed to help patients keep themselves symptom free on a day-to-day basis, and this provides a direct incentive to participate. With regard to professional oversight, effective assessment of the record can be fairly brief. It would be understandably discouraging if a patient was asked to keep a record and after taking the trouble to do so it offered no perceived benefit to them or their carers.

Luke's view of brief professional assessment looks charitable in light of Sarah's comment (below) that as a heart failure nurse she sometimes wonders why she bothers to encourage good record keeping. Sarah N1<sub>S</sub> tried to make accurate and complete notes in the patient held cardiac record book supplied to some patients by the Acute Trust,

however, there appears to be a lack of inter-professional communication or an absence of agreement about good clinical practice.

They all get one ((a cardiac record book)), it's a list of their medications, what they are on and why they take them. It's got a load of information on sort of blood pressure monitoring and things like that in it and it's got somewhere for the healthcare professional to write in, you know, their blood pressure, their pulse, their cholesterol. There's also a section at the back to write their weight in. It is useful but only if the patient takes it to all their out-patient's appointments and every healthcare professional involved, if they make changes it modifies the record. I've given patients the record and I see them in three months time and they've may be had four or five clinic, various clinic appointments apart from mine and they say "Oh love, it's only you that fills it in".

Sarah N1<sub>S</sub> (heart failure nurse)

Given their place at the heart of current management and in the estimation of patients (cf. **Chapter 6**), the engagement of GPs would be critical to encourage patients to reliably monitor and record symptoms. Mark D3<sub>P</sub> (a GP) described difficulty getting patients to keep weight records even when he would find it useful and highlighted the case of just one patient who was halfway to clinical self management. He also admitted that more attention could be paid to patient created records when they have been requested.

I think I do explain that the reason why they are monitoring their weight, that is fluid retention and there will be a little bit of variation but it still doesn't seem to make any difference to them. They just don't seem keen to do it. It did help, I (did) have one fellow who unfortunately died about a year or so ago and he was very good, he would come in with his little chart, so it is, I think some of them can do it, and he would show a dramatic increase in weight but he would come and tell me about it and not increase his medication.

**Sometimes people report that they've been asked to do it and when they've gone back no-one's looked at their records ...**

There is probably an element of that as well, that we don't pay enough attention to the effort they are putting in. Say for things like diabetes, they come in a show us their sugar records. "Oh yes, it's very nice, thanks". It's the (HbA<sub>1c</sub>) we are interested in and they get fairly unhappy when we ignore their efforts.

Mark D3<sub>P</sub> (GP)

Douglas D1<sub>S</sub> (an elderly care consultant) also agreed that professionals should make an effort to look at patient record keeping that has been requested, like Mark D3<sub>P</sub> he placed this agreement in the context of diabetes care.

Despite such practical problems, all patients who were able to said they were willing to monitor and record weight or symptoms if asked. Some patients made the association with a diary (Ethel 83, Patricia 63, Tony 55), and Tony 55 was keen to point out that he would not record personal information.

**How do you feel about writing down each day sort of keeping a note of how you are and things like that?**

Well it doesn't differ that much so far like. I mean if I were really poorly I would put it down in my diary like, very bad day or owt like that, but otherwise I would just accept it. I am not too bad compared to others.

Ethel 83

**If you were asked to keep a record, I am not really suggesting that you should, would you mind, would that be alright?**

Not in the least, I keep a diary ( ) for social events, but no wouldn't mind.

Patricia 63

I dislike keeping diaries cos I always consider what I do's private and private's the way it should be and the way it should stay. If they asked me to do it I do it as long as it's specifically for the those things ((Shortness of breath, swollen ankles))

Tony 55

Ethel's favourable comparison of her own health compared to others is consistent with her comments elsewhere. Tony claimed to be quite private but was very open in the interview disclosing personal information that was unrelated to the topic. He was one of the few patients (cf. **Section 6.2.3**) to express any real preference for group activities.

In clinical self management short term weight fluctuations are monitored, but Harry 75, Maria 76 and Patricia 63 expressed specific concerns about losing weight, for example:

**How do you feel about recording may be or at least keeping an eye on your weight and shortness of breath?**

This is something we do once a week isn't it, we have a pair of good scales and that's how I have been able to realise that I have lost over a stone in a few months. I couldn't give you a blow by blow, I lost so many ounces or pounds, but certainly from 10 stone 7 at the beginning of last year, and I was weighed at the hospital yesterday, 9 stone 5. And I haven't dieted, I haven't been exercising, so presumably that's one of the results of the deterioration.

Patricia 63

Comments about weight loss remind us that weight change isn't specific to heart failure. It was appropriate, in interview, for patients to make their own associations with weight monitoring. However, in practice it would be important to clearly define and explain the reason for monitoring. Even if ideas appear to be very basic, widely different interpretations are possible and could have significant clinical consequences. For older patients, in particular, systematic weight monitoring may help in the early detection of other medical problems, for example, those related to thyroid function or cancer.

Unusually, Philip 65 was familiar with the concept of daily weight variation and its consequences in heart failure, as illustrated here:

**Yes. Does your weight change very much do you know?**

It will vary over the day probably. In a morning it's about nine seven may be on a night it's nine thirteen.

**Right**

You just get this variation; it's like the legs puffy ... on a night, in the morning they're not

**Yes. Do you write down your weight and...**

No, I check on the scales ... but if I reckon about 5lb doesn't matter ... if it varies a lot then (I get ready to make adjustments on the medication) ... I don't think 5lb is a big variation over a day but then again I might be wrong what do you say?

Philip 65

To make this monitoring useful, Philip requires some guidance about the level of daily variation that would be considered significant. His general understanding was good, yet his ability to make specific clinical interpretations was poor. He is capable of self management but his doctors (who he told about large fluctuations) did not seem to want to optimise his current behaviours. Incidentally, 5 pounds of weight variation equates to more than 2 litres of fluid, which does seem to be quite large.

A typical attitude towards such record keeping was that would be "no trouble" or the patient was "not bothered" by it if they "had to" and it "may help", for example:

If they wanted a record (keeping of it) I'd do it.

Rose 82

Well I'd give it a go. I wouldn't say no outright. I don't believe in saying no outright.

You've got to consider every aspect.

Anne 64

This *disinterest* or neutrality on the issue of weight monitoring would make for easy adoption of the practice, but encouraging action on the basis of monitoring may then uncover resistance. Patricia 63 thought that becoming “too obsessed” was a potential danger; she was well aware of her health status but doesn’t want its assessment to dominate normal life.

**Do you think that’s the sort of thing that’s helpful in keeping an eye on your health if you like?**

I wouldn’t, I use the word again hypochondriac, I think it is very easy to become obsessed by the whole thing and it is better not to. If you use your common sense just approach it, I think what we tend to do is think in this situation these are the symptoms, what will the doctor want to know and that helps you to observe the important things without being, as I said, obsessed by it.

Patricia 63

Only Jean 76 actively seemed to think monitoring was a good idea, seeing it as an aid to communication with professionals, rather than an opportunity for independent action.

**How would you feel about making a note each day about your things, how you are feeling and how short of breath you are, keeping a record?**

I never thought about that. I could write it in my file couldn’t I?

**Do you think that would be a good thing, do you think that would be helpful or would it be something you would be happy to do?**

Yes it wouldn’t bother me. Yes it’s a good idea that because if I don’t do it and I try to remember one day last week when I couldn’t do, I would have some sort of design or some letter or something I could put in.

**So that would be something you would find easy to do?**

It’s much better if you can do that for yourself because it helps your doctor and it helps anybody else as well. You can say to somebody well I go through that, I do that.

Jean 76

Four patients lacked either physical or cognitive ability to both monitor and record weight without help: Florence 78, Doris 88, Margaret 89 and Pete 65. This is the only criteria that would have excluded any patients from this component of self management. Florence 78 appeared willing but at the time of the interview she was almost chair bound and probably underestimated the practical difficulties.

Florence 78, Doris 88 and Pete 65 formed the small group for whom self management seemed generally inappropriate. Margaret 89 (who was blind) would need special

equipment to participate, for example, talking scales. Based on symptom monitoring the patients split into just two main groups ‘those that can’t’ and ‘those that would’, but some did have more reservations than others.

In summary, it appears that weight and/or symptom monitoring would be easily achieved for the majority of patients. A small group probably would but could not carry out this most basic clinical self management activity. The information generated by patients could be useful both for the self management of heart failure and general clinical monitoring. There is little conflict between weight monitoring and the general model of care implied by patients’ wider comments. However, patients’ neutrality about the issue of weight monitoring, suggests that greater effort would be required to actually use the records generated to influence (patient) action without further professional contact. In addition, explicitly consulting patient generated records should become a more recognised and consistent part of good professional practice.

### **6.2.2 Dose changes**

Attitudes towards diuretic dose changes were more complex than those towards symptom monitoring: they lay on a continuum from active dislike to willing participation. Patients were asked to imagine that their doctor had given them a clear set of instructions to follow that involved taking an extra diuretic tablet (perhaps for a day or two) if their weight increased by more than a certain amount or if symptoms changed in a particular way. Specialist carers believed this type of intervention would be helpful. Sarah N1<sub>S</sub> (a heart failure nurse) described the basic procedures, which allow for telephone contact with a professional prior to decision making.

So there are certain criteria they have to fulfil. If they fulfil that criteria and they are happy to weigh themselves we will give them information, basically it says to weigh themselves every day at the same time. ... If they gain 2lbs in 24 hours, not to worry but to be aware of it. If the next day they weigh themselves and they have gained again then they either ring the heart failure nurse or the GP. Either, but not to leave it, contact someone. We tell them to increase the dose of the diuretic they are on ... take an extra one for three days, carry on weighing themselves and what we’d expect to see is their weight coming back down again, loss of the fluid and then back onto the dose they were on before.

Sarah N1<sub>S</sub> (heart failure nurse)

As these procedures are currently implemented for patients referred to Sarah's service, at first fairly frequent and active professional support can be given but this is withdrawn when the patient is more confident. Sarah N1<sub>S</sub> continued:

Depending on the patient we would ring them to check they were OK, they would ring us to tell us that everything is OK, or if they were particularly independent and confident they would just do that themselves anyway and say well "I don't need you to tell me to do that, I know to do it myself" which is fine and it's getting them to accept that it's fine to do it yourself but we are there for advice if you need it.

Sarah N1<sub>S</sub> (heart failure nurse)

However, there are risks involved if patients gain too much weight too quickly and delay professional contact:

Also telling them that if they did take an extra diuretic and things got worse then they'd definitely need to contact someone because we need to sort it out quickly, so catch them before they become too overloaded. When we see them initially, I will always tell them myself why it is bad to become too overloaded because to them what's the difference between 4lbs of fluid and 8lbs of fluid, so it's explaining well actually that's two litres of fluid and it harder to get rid of that much fluid than it is a little bit of fluid.

Sarah N1<sub>S</sub>

Specialist professionals also wanted patients to operate within the boundaries of the protocols provided. Some patients already operated within the spirit of professional instruction rather than to the letter (cf. **Section 5.1.2**) but the margins of safety around current treatment recommendations are generally quite wide. Involvement in clinical self management could narrow these margins and patients would need to be aware of this. Julie N2<sub>S</sub> (a heart failure nurse) described the problem of the "intelligent" patient that wanted to do "too much":

Yes and I would say actually some of our most intelligent patients are probably the most difficult. They will ring you, I guess they do contact you but they are almost wanting to do too much. They've read a bit about this, that and the other and some people want to manage things themselves and manipulating things all the time and they don't realise the impact of that.

Julie N2<sub>S</sub> (heart failure nurse)

Generalists who saw the benefits of dose changes in principle had doubts about the practice. Both Vanessa P4<sub>P</sub> and Louise P5<sub>P</sub> (who are practice pharmacists) related the ability to safely self manage to patient education and saw the benefit of avoiding

unnecessary professional contact. However, Vanessa P4<sub>p</sub> wondered how conscientious patients would be:

Yes, I think on the face of it sounds like it's a good idea like I suppose asthmatics taking peak flows isn't every day but we know in practice they don't do that and they wait till their asthma gets out of control before they present to the practice ... so I think for patients who are well educated on their disease and you can tell what sort of patients it will work for, I think that's a good idea, but getting somebody to weigh themselves every day, I don't know if they'll do it.

Vanessa P4<sub>p</sub> (practice pharmacist)

Mark D3<sub>p</sub> (a GP) seemed to recognise both the potential resistance to change implied by patient neutrality towards symptom monitoring and his own position of authority in relation to patients. However, it is important that professionals advising self managers are also willing to stay in touch (cf. **Section 6.1.6**). It would be understandable (and perhaps appropriate) if professionals new to self management of heart failure emphasised patient safety over patient autonomy.

I think they would do, I think a lot of them may be concerned that by altering the treatment that they are going against our wishes and that even if we, even with, unless they actually had written instructions saying you can increase your frusemide. Even with that some of them are still frightened of doing it. They would much rather speak to us and discuss it with us before they did it, which they certainly can do, then that's not really self management. It is self management, they are spotting their symptoms, but there is still the input from us.

Mark D3<sub>p</sub> (GP)

Mark's colleague James D4<sub>p</sub> (a GP) reported the sort of diuretic dose changing instructions his patients were likely to receive currently.

**So you might actually yourself suggest to somebody to take more diuretics in a kind of, not so structured as the hospital. You might give somebody some advice about...**

Yes you might. It tends to be the other way round, really, they often come out of hospital on quite big doses of diuretics and you sort of say to them, "We'll reduce them, if you get more fluid then just increase them again."

James D4<sub>p</sub> (GP)

He emphasised the need to reduce doses, which have been temporarily increased, after the sort of hospital admission that clinical self management tries to avoid.

Some patients were able to relate potential diuretic dose changes to their experience of warfarin dose adjustment or emergency medication such as sub-lingual glyceryl trinitrate (GTN) for angina or asthma relieving inhalers. Such experience was normally neutral or positive. Based on attitude towards dose changing patients split into three main groups:

- active rejecters;
- doctor trusters;
- logical adopters.

Four patients actively rejected the concept of dose adjustment: Ethel 83, Clara 86, Harry 75 and Vera 84. Ethel 83, Clara 86 and Vera 84 shared high levels of medication adherence behaviour, relatively poor heart failure knowledge, age and gender. Harry's presence in this group is somewhat unusual given (apart from age and gender) his positive experience of the heart failure clinic, relatively good heart failure knowledge (cf. **Table 5.2**) and self management practice (he stopped taking some stomach medication). However, he was currently settled in a stable effective regimen after numerous changes to his medication. He was also intent on "living life to the full" after being given a clear (limiting) prognosis.

**Do you think it would be useful and you would have to make your own decision about what to do based on those ((instructions from doctor))?**

No. I'd sooner leave it as it is.

Harry 75

Clara 86 and Vera 84 had similar attitudes to each other feeling that dose changing was the doctor's responsibility. They were resistant to any alternative on the basis that they lacked medical knowledge, which is probably a fair assessment, but they also lacked a desire to find out more, for example:

I don't know it's up to him you see, it's up to him.

**So you do what he says. If he wanted you to make some decisions yourself without him, do you think you would be comfortable with that or not?**

I would rather do what he tells me

**So you are happy to do what the doctor tells you. That's fine. Why would you not want to be more involved yourself, why is it you like to...**

You don't know if you are doing right or wrong do you? I wouldn't take anything. I do what doctor tells me because you don't know if you are doing right do you?

Clara 86

Ethel 83 went further suggesting prohibition rather than undesirability. She explained that the doctor would not issue dose changing instructions and the manufacturer's leaflet warned against it.

No, no he wouldn't tell you to do that, he had gone into it because it tells you how you mustn't overdose you see, but the one I take is 40 mg which he says is fairly high like.

**So you are happy enough taking the tablets but you don't think you would want to be responsible for changing the dose yourself and thinking I need more this today.**

Oh no, it warns you not to do that anyway on the leaflet.

Ethel 83

A more common (but more passive) response to the suggestion of dose changing was to trust the doctor to give the right instructions. That is, if the doctor said that changing doses according to these guidelines was appropriate, then it must be the right thing for me and I will do it (perhaps unwillingly). This attitude (or one similar) was shared by: Edward 71, John 67, Mike 56, Philip 65, Ruth 86, Olive 62, Rose 82 and Margaret 89. This group includes four of the seven male patients interviewed. All of these patients reported high levels of medication adherence behaviour. Only Philip 65, Olive 62 and Rose 82 had relatively high levels of health knowledge. The basic attitude of 'doctor trusters' was influenced or modified by three factors:

- a comparative assessment of patient and professional knowledge;
- trust in the doctor to suggest appropriate interventions; and
- confidence in one's own abilities to manage dose changes.

The first two factors were expressed in similar ways to the 'active rejecters' Clara 86 and Vera 84 above, but 'doctor trusters' expressed more confidence in their ability to follow new (but clear) instructions from the doctor.

John 67, illustrated all three of these factors and some experience of dose changing. He trusted doctors as professionals who knew what they were doing, but when pushed (and reflecting on experience of other dose changes) he suggested that he would follow a new set of procedures.

**Say you had instructions that said you know if you have got particularly short of breath you were to take an extra tablet?**

Oh yeah yeah well they tell me that in any case, they tell me that in any case. He ses to me if a get pain take extra pain killers or...the standard treatment he doesn't because you don't expect to take any more than you need to, but it is mainly pain killers what I take extra that's all and me sprays like. I take that on my own bat because you can't expect them to tell you when to take um, you have got to use your own brains about that.

**So you feel fairly happy taking some extra things when you need them.**

Oh yeah, yeah, well you've got confidence, I think it's more like confidence when you take um you feel oh well its (going to make me) feel better, yer know what I mean, whether it's mind over matter I don't know.

John 67

Responding to a similar question, Edward 71 and Rose 82 again illustrated belief in the doctor's superior knowledge, but enough trust to do whatever the doctor suggested. Unlike John 67, they did not attempt to rationalise dose changing behaviour, for example:

**Imagine you had some instructions that said if your ankle is particularly badly swollen, to take an extra one of your tablets ... would you like that?**

Yes I would do that.

**You would do that?**

Oh yes.

**And would there be anything bad about it?**

No, well how do you mean?

**Well I mean some people might think it was a bit uncertain say, you wouldn't have to take it every day but only when your ankle was particularly bad.**

No I would do that ( ) if he said that you know obviously.

**And you would feel happy to do that?**

Yes oh yes.

Edward 71

For Mike 56 the doctor had done enough in the past to prove that any instructions he gives are worth following.

Oh if I was told to take two, I'd take two like you know.

**Right.**

I do as I'm told, and that's it.

**So you'd feel happy about doing as you were told?**

Oh yeah, yeah

**If you'd got clear instructions?**

Yeah. See, he's proved to me that he can look after me so I've got all faith in him.

Mike 56

Olive 62, one of the younger patients with better health knowledge, focused particularly on her own confidence. She attempts to rationalise dose changing by reflecting on a past experience and in that context expresses doubt about her self management actions.

If I had instructions, I would take it. ... ((Brian D6<sub>S</sub>)) said to me ... at the heart clinic when I was in. Come off the amiodarone he said, and I was only taking two digoxins a day then ... he said, if you, I (know) how to take my pulse now, and if my pulse rate goes up, then my heart rate goes up, doesn't it. He said, if that goes up, he said, take another digoxin, you don't have to go to your doctor. So OK that was fine ... but I often think to myself, did I do it unnecessarily or not ... You know, I'm never too sure of myself because I'm not experienced enough to ... really be able to say so I'd answer it with that, you know because, yeah I do as they say but make me wonder in my own mind

**You'd have that little bit of uncertainty as well?**

Oh, you know, if I'd done the right thing

Olive 62: 185

Olive's consultant at this time seemed a little hesitant when asked if this was the kind of advice he may have actually given.

I may have done. I don't often give advice about digoxin that way but some people I might. So that's possible.

Brian D6<sub>S</sub> (cardiology consultant)

However, in interpreting what Olive 62 says it is her willingness to try something new despite remaining doubts that is more important than the factually accurate recall of events, which is (a little) disputed.

Philip 65 was equally willing to try short term dose changes that may stabilise his condition, but expressed doubt about his lack of detailed medical knowledge and the possibility of ending up in a "right pickle". This echoes concerns expressed by Julie N2<sub>S</sub> (a heart failure nurse) above and so Philip's caution may be considered desirable.

Caution was absent in Tony's comments below. Tony 55 falls somewhat outside the three groups considered in this section, but he is perhaps the first 'logical adopter'. He felt that dose adjustment was something he did well already (without instructions) and to a better standard than doctors. He had relatively low levels of reported medication adherence and relatively high levels of health knowledge.

Ahh, basically I keep my breathing under control and he knows I do ... but as I say if I need to take the extra tablet I take the red tablet and move it forward ... but that's all I'll do ... there's nowt he can tell me about that, that I don't already know ... basically I know what my tablets are for, how to use them ... and how to make them work.

**Yes. And you feel you're doing that already as best as you can?**

I can't see it making any difference anyway

**Yes. Well that's useful.**

It's just a matter of finding out what works for me ... I learnt along time ago to do that

Tony 55

Tony's potential over-confidence presents a real danger, but he is already self managing in a completely unknown (to his professional carers) and unregulated way. An honest discussion with his GP about how his medicines are used, a check on the safety of modifications to his current regimen and provision of some clear professional guidance may be very helpful.

Finally, the main group of 'logical adopters' were willing to adjust doses and able to see the personal benefit (to some extent) of doing so, rather than just taking it on trust that doctors' recommendations were sound. This group comprised: Maria 76, Jean 76, Lillian 78, Patricia 63 and Anne 64. All of whom had high levels of medication adherence, but only Patricia 63 and Anne 64 had relatively high levels of health knowledge. Of these, Lillian's response was most doubtful and was based fundamentally on trust in a particular doctor. She knew from personal experience what the trigger for and effects of an additional diuretic tablet might be, but didn't think being in control of this would be something intrinsically desirable.

**What about if it was something like if your ankles are swollen, take an extra water tablet?**

I've done that as well.

**...I am trying to find out what people would think about it...**

If ((Doctor X – trusted consultant)) said to walk on the road I would do. I know that what he is telling me is Gospel and it's for want of a better expression. But I know he is only doing things for the better to be a help so I don't think I have any difficulty with that to be told to do something, I think I would do it to the letter.

**So if the doctor said it was a good idea.**

I'd accept it

**...do you think actually being involved would make you feel better in itself or not?**

I don't think it would. I don't think so.

Lillian 78

Maria 76 and Jean 76 simply thought instructions for changing doses when they experience symptoms would be helpful. Jean 76 made one of the few expressions of genuine desire for more control over disease management saying "Your body is yours and you are what you make it." Unlike Tony 55 (above) this was not linked to any real dissatisfaction with current care. Patricia's approval for dose changing instructions was the most fulsome:

I think it would be entirely good because it is what's the word I am looking for, it's re-assurance, you have something to go to and relate to your symptoms without being in the least a hypochondriac, there are the instructions, there are the explanations, relate them to your symptoms and you know what you then have to do, I think that is very re-assuring.

**Sometimes it might be take more tablets, sometimes it might be call the doctor, I guess.**

Yes well I have never had to call him except for the flu but I would know when and I would know when not to.

Patricia 63

However, Patricia 63 also expressed concerns backed up by an understanding of the mechanism of drug action:

I think I would take one ((tablet)) and I would appreciate that if he said I needed the second one, I would, I would also appreciate that if I had to take two a day I would be stuck here for every day and that would need a lot of thinking about but on the other hand, if that's for your health's sake, it is drawing fluid away from where it doesn't belong, I think what I would do is listen to his advice, take the two and then days when we wanted to go out I would just fall back on the one and wait till that wore off.

Patricia 63

Like almost all the other patients Patricia 63 trusted her doctors and required access to reassurance from them, despite willingness to take more personal disease management responsibility. This may be influenced by her negative experience of previous low medication adherence (cf. **Section 5.1.2**).

Overall, the most critical factor supporting willingness to change doses was trust in the doctor to recommend effective action. It also helped if patients had some future focus and an awareness of symptoms that may be modified; housebound elderly patients are reported elsewhere to resist future planning (Carrese, Mullaney, Faden, & Finucane, 2002). Patient support was limited primarily by lack of medical knowledge, and also by lack of confidence in their own abilities. A desire for more personal control over disease management was rarely expressed. For most active involvement in dose changes would just be an extension of good adherence with more conventional medical care, rather than a radical departure into new territory. In many ways trusting the doctor (whatever his instructions) is the default option. Arguably the 'active rejecters' had a better attitude towards self management, even if they wouldn't participate in one particular form of it and were not open to change. A lot of effort could be made to implement self management for those classified here as 'doctor trusters', but who actually turn out to be more resistant to change than they first admitted.

### **6.2.3 Peer group work**

Symptom recording and dose changing are key components of clinical self management and their safe implementation requires improvements in patients' medical knowledge. In the most likely scenario, education would be provided by specialist heart failure professionals one-to-one as an add-on to conventional specialist care. This occurred in the Acute Trust heart failure clinic and was expanding into primary care. However, COPD specialist care locally already made use of group work (in a primary care setting), Julie N<sub>2</sub>s (a heart failure nurse) said the use of group work was under consideration for heart failure patients and generic self management training (EPP) is organised around peer group work led by a lay facilitator. Therefore, views about group work have the potential to influence self management implementation and should be assessed carefully. Group work offers an efficient use of trainer resources, however, its greatest potential benefit is the sharing of ideas and experiences between participants.

Group work was initially presented to patients not specifically as training but more generally as an opportunity to meet with and learn from others with similar health problems, that is, the patients' peers. It was usually emphasised that there were likely to

be a number of other people with similar health problems to them, and patients were asked if they thought they could benefit from listening to the experience of others. Patients were able to relate this to their prior experience of rehabilitation programmes, discussions with other residents in sheltered housing and talking to friends (for example, in public houses). Patients' experiences of these interactions were quite variable and attitudes towards peer group work were consequently complex. Based on these attitudes patients split into three groups, which are called here: 'privates', 'social members' and 'social leaders'.

Unwillingness to participate in peer group discussion dominated for 14 of the 21 patients (the 'privates'). There were a number of reasons given for this including:

- not wanting to focus on being ill;
- a perception that everyone would say the same thing; and
- a desire to maintain privacy.

Vera 84 and Rose 82 illustrated a desire not to think about illness and to carry on with their normal activities. For them it seems group work might interfere with their preferred coping mechanism. Incidentally, Vera 84 was less troubled by heart failure symptoms, whereas Rose 82 was clearly quite ill and had swollen ankles at the time of the interview.

No, I'm not in to that. ((Discussion with others))

**Could I ask what it is about it...**

I don't like being poorly ... no, I don't like talking about it.

Vera 84

I don't want to dwell on it. ((Her illness)) ... I can cope if I don't dwell on it.

**So you wouldn't find it useful to talk to other people?**

No. I don't like to talk about it.

Rose 82

In slight contrast to Rose's flat denial of current symptoms, Mike 56 accepted that he was ill but preferred to think of himself as "cured" following a brief hospital admission for a heart attack and having given up smoking (cf. **Section 5.1.1**).

Tom D2<sub>s</sub> (a cardiology consultant) indicated that Mike's attitude was quite common and may be influenced by the intensive nature of modern in-patient care.

... we get all these letters coming from the rehab nurses to say err "Mr So and So was offered rehab in group therapy and said he doesn't want to" you know which is quite surprising actually. You would think that most of them would take everything that was going in terms of advice and group therapy. But actually a large number of them there's denial after the event err because they just want to get back to normal and get back to work and they don't want to admit that anything has happened. And it's one of, it's one of the down sides of the way that we're err dealing with lots of things now, that if you, if you had a heart attack 10 years ago you'd be admitted for 10 days and if you're admitted for 10 days actually you can't really deny it's happened, you're in a hospital bed for 10 days, you're on tablets and you know it sinks in that you've had it. We now see a lot of people with unstable angina where we admit them one day, we do some complex angioplasty the next day and they're home in 48 hours and they have much more trouble coming to terms with it all. You know, because they've had such a short admission and they're a bit confused about what's happening.

Tom D2<sub>s</sub> (cardiology consultant)

Thinking that everyone will say the same thing, or something you've heard before, questions the basic utility of group work. This is illustrated here by Edward 71:

Well I don't know really, I mean I think personally I rely on my doctor, what he says, I mean after all talking to people fair enough they are only discussing the same thing, that they've got what you've got so.

**And you don't think it would be helpful to meet and discuss...**

No I don't think so. Might be wrong but I don't think so.

Edward 71

A desire for privacy (or simple to focus only on one's own worries) was the most common reason given for unwillingness to participate in group work. This was illustrated straightforwardly by Ruth 86 and Patricia 63 (below). However, Patricia's objections are more thoughtful and considered than Ruth's or others above.

No I don't think so. I think I'm all right on me own.

**Right. Is it just the fact that you prefer to be, to keep it to yourself?**

Yes. Keep to me self.

Ruth 86

Oh I would hate it, I am not a group person. I will talk to ((Husband)), ((Husband)) has quite a lot of knowledge really after everything he went through. The GPs are

always available and always willing to discuss anything of concern. I am not a group animal. I really don't want to be. I know it helps a lot of people and they find it of very great value, I am not one of them.

Patricia 63

Clara 86 offered the additional excuse that she lacked energy in the afternoon, which seemed to be the case at the time of the interview. It is not possible to comment on her actual capacity to benefit from improved disease management, but Clara 86 seemed resigned to her current health state.

I can't be bothered no. I am alright as I am love.

Clara 86

In another variation on the theme of privacy, Ethel 83 declared that she did sometimes listen to others talk about their problems, but she had no interest in discussing her own health. However, Ethel 83 had been engaged in some group work and would like more interaction with others if it revolved around more social activities.

I don't talk much about mine ((health)) but you have to sit and listen to other people talking about theirs, they go on forever sometimes. It's all part of life.

**Do you think it helps people to talk about it?**

Oh it does, yes, if they need to I don't, I am a quiet person I don't need to talk a lot about all my problems.

Ethel 83

For Ethel 83, Clara 86 and Vera 84 their negative attitude towards group work based on health issues is consistent with their rejection of dose changing in **Section 6.2.2**. Ethel's positive approach to social (rather than medical) group work may relate to her communal living in sheltered housing.

Sarah N1<sub>s</sub> (a heart failure nurse) reflected on the personal nature of some patients' issues as a reason why group work may be unattractive.

Right. I think a lot of the issues are very personal. Some things that I hear in my position are very, very personal and very, they might not even disclose what they tell me to their nearest and dearest, so that might be one of the reasons why I'm speculating why perhaps they wouldn't want to go to a group because your discussion would be very superficial.

Sarah N1<sub>s</sub> (heart failure nurse)

Certainly, one of my interviews ended when a wife was trying to prompt her husband (the interviewee) to disclose more than he was comfortable with about how his disease had affected their relationship. There was so much antagonism towards group work with peers that I also started to ask patients if they would attend group sessions to hear an 'expert' speak. Harry 75 and John 67 indicated that they would have some interest in expert talks, despite not wanting the worries of peers to add to their own.

**...would you like to go and hear more about your heart from experts?**

Oh I wouldn't mind that, I don't need a dietician, I don't want to listen to a dietician.

Well I am not dieting am I? I'm trying to put weight on.

**...is there anything that you think would be a valuable talk?**

Well I mean I go see ((Heart failure nurse)) at ((hospital)), I mean she talks to you about health things and that, she gave us that book ((of patient information for cardiovascular patients)).

Harry 75

**Would you be interested in say if there were I don't know talks from experts and things like that say a dietician?**

I might go listen, I wouldn't go taking notice of a dietician because it is a waste of time to be honest. I mean if stuff they bought were any good if it tasted alright people would take it, it tastes bloody awful. I mean it does, it does, it tastes horrible. I mean it doesn't taste like what it's supposed to taste like, if they made it taste right you would have no problems in dieting. But if I had chance to listen to an heart man talk. My brother goes to see them and he told me about somethings what they said and I mentioned to my specialist and he says wont such a thing. I found out why, because he goes to ((Name of other consultant)).

**So you would be interested in sort of a talk by a specialist?**

Oh heart specialist, definitely yeah. Oh aye yeah.

John 67

Lillian 78 had a more neutral attitude to peer group work, so long as it didn't make her feel worse. Like Ethel 83, she lived in a sheltered flat and had lots of opportunities (which she took) to talk to other residents. Lillian 78 would welcome further advice about diet.

As long as they don't make me feel worse I wouldn't mind. It is just I don't suppose really there would be any harm in it.

**Do you think there would be any good in it ...**

No, no, no. Because I am happy with myself and I don't think I could ((garbled)) I don't think so that is my own idea but I don't think I am gaining anything by that.

**...would you like to go to talks where you could get more information say about diet or exercise?**

Diet definitely. I have to do something about it. I will have to go on bread and water or something. I have never weighed so much, never, and when I see myself sideways on, I'm (needing) bigger and bigger clothes, I get so despondent.

Lillian 78

Mike 56, however, expressed reservations even about expert talks, reckoning that he had already heard the same message too many times while in hospital.

I just found it so boring you know. You drugged up that much, you don't know your there half the time you know. ((Whilst an in-patient))

**... would you go to talks that were like from doctors ... what about that?**

I don't think I'd go, no.

**Right. Same reason?**

Well it's, yeah, I hope it'll never happen again with all these pills I'm taking and not smoking you know ... but I think there's a limit to what they can tell you ... you know. When I was in hospital I got bored with them telling you, they'd come in every day telling you what to do ... and I thought oh it goes in it comes out, I'm sick of hearing this ... I know they're trying to help you and all that like but tell you once and that's enough you know. They were telling you every day the same thing.

Mike 56

Sally C1 (a clinical psychologist) was asked to comment on people's stated preference for privacy and found it understandable. She accepted the coping mechanism this demonstrated as valid, and thought patients should have choice about what they reveal to others. She also raised a further concern that patients at different stages of the disease may frighten each other, which partly reflects patients' concerns that group interaction may make them feel worse.

It is difficult because I feel with health conditions I think again people should have a choice about how much they share and how much they don't of course. ... One of the difficulties which we've discussed about having a group, with this particular group of people is because people have different stages of the illness. If you've got a group of people who are quite asymptomatic with some people who are say at a different stage of illness. Is that going to be frightening? How do you manage that?

Sally C1

The 'social members' were Margaret 89 who thought that the company might be nice and Olive 62 who had already found friends in disease based support groups.

Just finally then what about meeting other people with similar health problems to yourself. Do you think that would be helpful?

Oh, I, I do actually ... I go to the Leeds Group of the National Osteoporosis Society.

**Right**

I haven't been for a time because the health problems have stopped me, I've been appointments here, there and everywhere but I'm trying to start to go to Breathe Easy which is the British Lung Foundation which is at ((Name of area)).

Olive 62

Olive 62 had few local family connections, which may partly explain her greater willingness to participate. Her quote also illustrates that people who are interested in group work may well be involved in more than one group, that is, there are "group people". For example, Olive 62 herself and also a person she mentioned who wrote the newsletter for both societies she was interested in. Margaret 89 was slightly more prosaic than Olive 62 and saw group work simply as a chance to find more company and discuss more social issues.

Well it'd be company, it would be a break (if nothing else)

... **what sort of things do you think it might be interesting to find out about?**

Well to see what they do and what activities they did and...

**Yes**

And things like that you know, and if they go away and. They might know places where you can go and things like that.

Margaret 89

Margaret 89 had local family support in abundance but found residents in her sheltered housing rather dull. She would require help with transport to a venue because she was blind.

Modern matrons, Dawn N4<sub>p</sub> and Jenny N5<sub>p</sub> recognised two distinct groups those that are 'clubbable' and those that want to remain self-sufficient, for example:

Yeah, I find generally that people want to be very independent and err stay as independent and self-sufficient ... as possible and it's a certain sort of person that wants to engage with other about illnesses, a lot of people don't want to make their illness part of a social ... situation. Which is almost what, probably what, the expert patient group is asking you to do. It's like making a club out of the fact that you've got diabetes or heart disease. And some people actually want to shut the fact out that they've got this disease, they manage it themselves, they take these drugs,

they limit their activity in certain ways so that they don't over do it. And that way they manage it OK.

Dawn N4<sub>p</sub> (modern matron)

A paradox being that group work is intended to make people more independent. Dawn and Jenny's characterisation fits with the response to symptoms and coping strategies described above by patients. David P3<sub>s</sub> (a hospital pharmacist) contributed to group work sessions. He noted both the "filtered" nature of his audience and that individual attendees responded quite differently to the content.

The group sessions that I do are really quite successful but we've got firstly, we've got a filtered audience in that they've agreed to come to the group sessions and I would imagine a proportion of the patients that are asked say "No groups aren't for me I'd rather have something at home individually or follow a different programme" so the patients that I see are obviously the patients who have agreed to do this but the dynamics of the group are usually, work very well ... it usually always stimulates questions and there's may be a pocket of people who want to ask lots of things about their own things ... some people will come and sit in the group and listen ... I think the majority of people do get something from the education but as I say these are the people who are group people and they've agreed to do the group work.

David P3<sub>s</sub> (hospital pharmacist)

On reflection perhaps the proposition of group work was not well put to patients by me and is not well explained in practice. The EPP does bring people together to share experiences, but in the context of a highly structured skills training programme. Patients did tend to be more positive when offered something more tangible than listening to others. Certainly, this was the view of Luke D5<sub>s</sub> (a respiratory consultant) who had experience of running and contributing to group work for patients with COPD.

Well we really broach self management for the majority of patients, we do ... pulmonary rehabilitation within the community ... we get typically about fifteen to thirty patients there for the educational session. And they've all done an hour of exercise either before or after the education. And I do the session on exacerbation management with them so I'll spend the best part of an hour. And we'll talk about what exacerbations are, how to recognise the symptoms and during that you realise very quickly the people who are happy just knowing that this is a sign that my chest is deteriorating, I need to get help. Other people are saying that I can never get an appointment with my GP and you say, "Well how could we tackle that?" and they start talking and I think patients, this issue of confidence and trust, the patients trusting themselves. There's often an issue that yes, "You say that's

fine but my GP will never ever trust me to do it"; so they're worried that the GP won't trust them and the biggest hurdle is with them trusting themselves to make this decision correctly.

Luke D5<sub>s</sub> (respiratory consultant)

Luke's comments in this context about confidence and trust are compatible with 'doctor trusters' explanations about their potential involvement in dose changing in **Section 6.2.2**. However, here Luke D5<sub>s</sub> suggests that "I trust the doctor" may be complemented by "but the doctor doesn't trust me". The course Luke D5<sub>s</sub> was involved with clearly seemed to tackle what this analysis shows to be an important triad of issues from the patient perspective: trust, confidence and knowledge.

We do sixteen sessions and I'm usually coming in at about session eight or nine so they've already got used to some of the other weeks and they're taught by pharmacists on their drugs; they're taught by dietetics on what to eat; they're taught by nurses; they're taught by physios on control of breathing so they've had a different expert and certainly the approach I take ... I will ask them some simple questions at the beginning and get people to do things and by the end of it they're talking freely but there's a lot of work going in to make that but my aim during that session is not necessarily to promote self management, it's for these patients to know what an exacerbation is and what the options are for managing themselves.

Luke D5<sub>s</sub>

In the sessions Luke D5<sub>s</sub> described above didactic content gave way to the discursive as the sessions progressed, and over time patients that wanted to take more personal responsibility for their care were gradually identified. However, the best way for patients and their GPs to become less dependent on each other but still maintain a good working relationship (which is essential) is unresolved.

The 'social leaders' expressed much more confidence about group involvement. Jean 76, Philip 65 and Tony 55 thought they had little to gain from group work but would participate for the benefit of others, for example:

If somebody was stuck and needed someone to talk to I am always willing to listen or even suggest what they ought to do, I have done that with people. Not particularly heart patients but some of the old dears in here.

Jean 76

Of all the patients interviewed Jean 76 talked most about interacting positively with professionals and seeking out contact. However, she saw the opportunity to give advice

rather than listen or develop the potential of others. Tony's attitude was similar but he had tended to find his own path, rather than being influenced by professional views.

Not for me it wouldn't do (me) any good but it might do them some good.

**Right. How do you think it might help them?**

Well because what I've learnt while I've been putting up with this.

Tony 55

Unlike Jean 76 and Tony 55, Philip 65 demonstrated some development focus and a more subtle concern that reliance on groups may be disempowering.

And what's good for one person may not necessarily be good for another one even if they are people with a similar problem.

**Yes. Do you think that you would gain anything from a support group?**

No, because I'm content with my life. I'm not saying I wouldn't meet with other people if I was asked ... I would help tell people, as I've spoken with you

**Yes. So you'd be interested in helping others to cope perhaps when they first...**

As a discussion group, yes.

Philip 65

Tony 55 also identified the danger of group work that stops after a short time with no follow up.

**... so you're relying on that sort of informal help aren't you from...**

Yeah cos you don't get no other. It's like when I did the arthritis thing. They said "Oh were going to send you on a course and show you how to cope with it." Yes that's great, fantastic, five weeks one day a week. And sod you, you can bugger off now. I haven't seen the arthritis specialist for five years.

**Was that course helpful at all?**

Not really because basically what it was, was. They put you in this (wheel), put it in the pool and see how you cope in the pool. We'll show how to use, do things up and down but what they don't tell you is that every time you move your leg up and down there's no bloody fluid between the kneecaps and it's, the phrase agonising doesn't come into.

Tony 55

What Tony 55 described sounds like a professional-led arthritis management course; in an EPP type (lay-led) course he would have been encouraged to set and achieve his own targets. This may have been more productive in his situation.

There is very little in terms of age, gender, prior medical experience or domestic circumstances that seemed to link or distinguish those ‘social members’ and ‘social leaders’ most tolerant of group work. However, Olive 62, Philip 65 and Jean 76 did share former occupations as civil servants or ‘white collar’ local council workers, and Tony 55 was a former leader in a voluntary organisation. So these four have experience of environments in which group work is encouraged and members of teams have opportunities to contribute to collective activity. Margaret 89 did not share this experience with the others in these groups, but was interested primarily in the social rather than the medical aspects of group work.

Julie N2<sub>s</sub> (a heart failure nurse) described tentative plans to arrange disease specific group work for heart failure patients. It seems that the professionals have identified the issue of encouraging attendance in the first place and the psychological upset attendance may cause. However, Julie N2<sub>s</sub> did not mention the need to have strategies to moderate the influence of ‘social leaders’. Perhaps, in the presence of appointed group leaders or facilitators ‘social leaders’ would not be so vocal. However, those interviewed for this study were confident individuals, able to communicate relatively well with professionals. Training to facilitate group work generally includes tactics to constructively use all types of participant input, which could be helpful.

We don't do any group work at the moment. I've always had quite a bit of difficulty in how we would deal with that in terms of putting somebody with very mild heart failure in the same room as somebody with very severe heart failure and the psychological impact that could have ... we've got a very good psychologist at the moment and we are just looking at ... some form of exercise programme would be our ultimate goal but in the interim arrange some sort of patient forum so that patients could get together and meet each other and use that as some sort of support group ...

**And where has the desire to do that come from, is it from you thinking and reflecting on the service or is it the patient demand or...**

Yes, I don't think it's patient demand. Some patients have asked about support groups but very rarely actually. We do occasionally put people through the rehab exercise programme, the better, the more well patients and that's very well received but really the idea's come from us and a feeling that we would like to put some of the people in the same room because it is so difficult for patients to meet other people with that diagnosis.

Julie N2<sub>s</sub> (heart failure nurse)

'Privates' were usually sociable in the normal everyday context but typically reported wanting to keep their personal details confidential or being somewhat bored by the health problems of others. For some there was a specific reluctance to engage in activities that were disease based rather than more generally social or cultural. For 'social members' another opportunity to get "out and about" seemed worthwhile. In my opinion, 'social leaders' are a great concern. Singularly, they may see their role as advice giving rather than facilitating, thus reducing the participation options of others. Together, leaders may clash with each other and divert the group from its objectives. Groups should strive for free-flowing discussions that unskilled leaders may hinder (Toseland and Rivas, 2005). Although complex, patients' views on group work were more forthright than their rather neutral views on symptom monitoring and easier to discern than their (often) ambiguous views on dose changing.

In summary, peer group work is the element of self management to which there was the greatest resistance. There was little demonstration of passive acceptance (as seen for dose changing) people either rejected the activity or accepted it purposefully. Those rejecting the activity probably have the greatest capacity to benefit from it, if it can be presented in a constructive and unthreatening way. Those that accepted the activity included both those who were already comfortable in group situation and those who wanted to "advise" rather than develop others. The overt purpose of group work may be to share knowledge about self management. However, EPP type courses are underpinned by a notion to encourage self-efficacy. This psychological construct does relate to the issues of trust and confidence identified as barriers to dose changing. Courses to encourage clinical (rather than generic) self management would need to find an open and constructive way to achieve something similar.

#### **6.2.4 Summary of willingness to participate**

All patients would agree to monitor and record symptoms if it was considered a helpful activity by their professional carers. However, some patients could not do this easily for physical reasons. Dose changing was rejected by a few, passively accepted by most and welcomed by some. Symptom monitoring and dose changing do fit with existing models of care, and patients' attitudes towards them can be linked to disease

management more generally. Group work divided patient opinion most strongly and attitudes towards it appear unrelated to previous patterns of care. The patient groups outlined above for dose changing and group work can be made to settle into a single set of groups but not without anomalies. There isn't a simple relationship between willingness to change doses and participation in group discussion. Unsuitability for self management (Florence 78, Doris 88 and Pete 65) was an *ex post* judgement made by me. Overall two-thirds of the patients could and would participate in the components of self management presented to them to some degree.

Only one patient (Jean 76) was equally keen on all three components. Perhaps, Jean is more or less typical of today's 'expert patient' who is a former white collar worker with some experience of public life. Jane E1 (an EPP administrator) described the type of person attending local EPP courses.

They're mainly public sector or voluntary or charitable based workers that have come on it. You know, the realities of being with a long term condition employed by a small company ... is still "You won't get the job" and that's my personal perspective. Most people with long term health conditions know better than to try and work for a small company because of the time off sick. Discrimination, the fact there isn't any backfill for the team when you're off ... that could partly explain why.  
Jane E1 (EPP Administrator)

Jane E1 was uncertain why the demographic profile of EPP attendees was skewed and offered one possible reason why. This analysis offers another, which is also structural but doesn't involve active discrimination against people with long term conditions. If health reforms are to proceed as current policy demands tomorrow's expert patients will need to include 'blue collar' workers with little social experience outside the workplace and family. Many such patients (in this sample) placed enough trust in doctors (that is, consultants and GPs) to be guided by their influence either passively or for positive reasons. A minority would actively resist changes to the *status quo*.

With regard to dose changes those labelled here 'active rejecters', 'doctors trusters' and 'logical adopters' are similar to those labelled (respectively) 'rejecters', 'passive accepters' and 'active accepters' in the context of medication adherence (Pound 2005). However, (medication) adherence behaviour does not seem to be predictive of

willingness to self-manage. The typology is contextual, not a straight forward (or universal) description of a character trait. In so far as character is indicated by these typologies medication adherence probably relates more to conscientious; and willingness to self manage (since it was an unfamiliar concept) more to openness.

Participation in group work adds a dimension to the analysis not often considered in health services research, which tends to focus either on (a) the doctor-patient relationship (micro level) or (b) public health (macro level). As traditional means of healthcare delivery (one to one, patient to professional) change and develop (into self care, remote consultation, group therapy) this dimension is likely to grow in significance.

### **6.3 Professional views about self management**

Interviews with professionals identified a range of self management conceptions and some opportunities for patients to engage in chronic disease self management (both clinical and generic). The EPP was the main generic opportunity. It was in its national pilot/evaluation phase at the time of the professional interviews and on the (apparent) verge of 'mainstreaming' into normal practice. Heart failure patients with sufficiently advanced disease could be offered self management as part of the Acute Trust heart failure management service, and there were well advanced plans to extend a similar service into primary care. In addition there was a COPD management service well established in primary care. The COPD service is relevant both as a general example and because of the particular confusion patients demonstrated between heart/lung symptoms.

#### **6.3.1 Meaning of self management to professionals**

All the health professionals were asked directly if they had heard of self management and what they thought it meant, with the exception of: those directly involved in the EPP (the administrator, Jane E1 and the tutor, Felicity E2); and the specialist heart failure nurses (Sarah N1<sub>s</sub> and Julie N2<sub>s</sub>). These four would certainly have heard of the concept because they used it daily. It was thought, but probably should not have been

assumed, that the former would describe self management in terms of generic coping skills and the latter would describe it in terms of diuretic dose adjustment. Sarah N1<sub>S</sub> and Julie N2<sub>S</sub> offered definitions consistent with my assumption in the course of their interviews, for example:

I guess it's depending on the patient but yes to self manage themselves in terms of weight, self monitoring the symptoms and then also to self manage the diuretic therapy and also taking control of their other sort of medical therapy as well, making sure they are on the right doses and the right tablets.

Julie N2<sub>S</sub> (heart failure nurse)

Most of the professionals (including four with connections to the nurse-led service: Tom D2<sub>S</sub>, Brian D6<sub>S</sub>, David P3<sub>S</sub> and Sally C1) described self management as some sort of dose adjustment in response to changes in symptoms, with the intention of heading off exacerbations and avoiding hospital admissions. Two professionals (Nicola N3<sub>P</sub> and Tom D2<sub>S</sub>) included in their response a (different) 'mini-protocol' for diuretic dose adjustment. Nicola N3<sub>P</sub> was a development nurse working to extend the nurse-led heart failure service into primary care. Sarah N1<sub>S</sub> also gave a mini-protocol (cf. **Section 6.2.2**), which was different again (from both Tom's and Nicola's) in its detail concerning short term weight gain and associated diuretic dose adjustment.

Luke D5<sub>S</sub> (a respiratory consultant) thought that most patients self-managed "to some level" and described as "more advanced" the process of monitoring and starting an intervention "without involving a healthcare professional". Patients' experiences of chronic disease behaviour and management (cf. **Chapter 5**) supports his view.

Yes, I think every patient with a chronic disease self-manages to some level, even if it's simply, when do I go and see my doctor; that's self-management. But I guess most of the time we are talking about something a bit more advanced than that in terms of the patient monitoring their symptoms; trusting their assessment of their symptoms and then starting some, usually medical, therapeutic intervention without involving a healthcare professional. And then, the part that I think is important, monitoring their own response to that treatment so that they then involve a healthcare professional if things are not improving.

Luke D5<sub>S</sub> (respiratory consultant)

Luke's definition appears to be sophisticated in that it is both holistic and incorporates a final feedback loop; this may be explained by his prior involvement in the self

management of COPD. In contrast, four of the professionals' responses included some indicator of doubt or equivocation, but these may just be 'figures of speech': "I guess" (Sally C1, Jenny N5<sub>P</sub>), "I presume" (Mark D3<sub>P</sub>) and "I suppose" (Susan P2<sub>C</sub>). Four other responses included disclaimers about the limits of their knowledge: not hearing much (James D4<sub>P</sub>), "not really" (Vanessa P4<sub>P</sub>), "from a distance...nothing local" (Louise P5<sub>P</sub>) and nothing in "great detail" (Geetha P1<sub>C</sub>). With the exception of Sally C1 (a clinical psychologist), all these doubts and uncertainties were expressed in the responses of primary (or community) care professionals, none of whom were developing specialist heart failure services as part of their role.

Dawn N4<sub>P</sub> and Jenny N5<sub>P</sub> (modern matrons) described both generic (understanding, information, confidence) and clinical (dose changing) aspects of self management. As modern matrons working in primary care it was their job to spend time with patients working out why they were intensive users of healthcare services. Douglas D1<sub>S</sub> (an elderly care consultant) and Geetha P1<sub>C</sub> (a community pharmacist) described greater patient knowledge and interest in care without involvement in medication dose adjustment. In many ways Douglas D1<sub>S</sub> and Geetha P1<sub>C</sub> (along with the two GPs) had the most traditional roles: as an 'old school' style consultant and a 'dispensing chemist'. Their view of what self management is or should be probably accords with the expectation of the average patient. Susan P2<sub>C</sub> (a pharmacy area manager) placed self management in the context of medicine de-regulation and the ability to buy cholesterol lowering drugs over-the-counter (OTC) in pharmacies. This is consistent with her role developing business in a chain of pharmacy shops.

In summary, definitions of self management provided were largely consistent with professional roles. Specialists in the field of self management and/or heart failure tended to express more certainty in their definitions. Generalists understood what self management meant in the context of heart failure but tended to be more uncertain and vague. Community pharmacists grasp of self management as part of clinical practice was weak. This reflects the realities of their working environment, in which clinical developments have tended to limited and practice change is a slow process.

The variation in professional conception of self management highlights three important issues:

- specialists want to expand self management but need generalists to implement or at least promote schemes on a large scale;
- inconsistent messages about the patients' expected roles in care may lead to patient confusion or apathy; and
- clinical self management (dose adjustment) and generic self management (goal setting or decision sharing) may be seen as independent activities.

Naturally, the meanings ascribed to self management were strongly associated with the type of self management activity that each professional encouraged (or was involved in developing) and the type of patient self management was considered suitable for (cf. **Section 6.3.4**). The most frequent reason given for encouraging self management was to reduce secondary care admissions. The current state of self management practice is described in the following sections.

### **6.3.2 Generic self management**

Only Susan P2<sub>C</sub> expressed a consumerist view of self management, in the context of buying a medicine for long term use after taking a private test to identify cardiac risk. This involves independence (as far as possible) from professional input and paying for one's own care. Generic self management was seen mainly as a way to enhance professional care or deal with those issues that conventional medicine has limited time (or effective treatment) for; for example, improving communication skills and dealing with low mood.

Jane E1 (an EPP administrator) described how patients must volunteer for rather than be referred to the EPP. She described the aims of the EPP in terms of benefits to both the health service (for example, reducing admissions) and patients, for example, allowing them to: initiate a discussion about side-effects with their GP; "break free" from a cycle of low mood; or raise awareness about local health service provision.

The EPP seems to draw on Seligman's insight (1975) that the persistent inability of one's own actions to make a difference to outcomes leads to a 'learned helplessness'. Once learned it is very hard to encourage people to actively help themselves even when their actions could actually make a difference. In Seligman's classic (but somewhat cruel) animal experiments dogs that have been trained to be helpless are literally dragged out of harm's way until they re-learn that change can make a difference (Seligman, 1975). Rather less dramatically the EPP teaches people to set a meaningful but achievable goal, which is reached in small progressive steps. In patient accounts we see some examples of help seeking behaviour (in response to symptoms) that would not have occurred without family pressure (cf. **Section 6.1**).

Many of the problems encountered in the local organisation of the EPP involved lack of awareness, particular among professionals who might recommend the programme to suitable patients. Jane E1 (an EPP administrator) described the "buy in" that she was seeking from professionals.

What we need them to see is that we're not, this is an assistance, we are not focussing on anything clinical, we are not telling people to stop taking their medications, we are not going against any of their medical advice, we are just giving them a set of skills to help them self-manage their condition better and give them the confidence actually.

Jane E1 (EPP administrator)

She expresses concern here not to impinge on, but rather to assist, the roles of healthcare professionals. This assurance would no doubt be welcomed by professionals lacking confidence in their roles and patients who have confidence in their professional carers. Jane E1, it seems, is right to identify the support of professionals as a crucial step in promoting self management. Nevertheless, the patient interviews suggested that mainstreaming EPP would be difficult mainly because of antipathy towards group work.

The overall aim, what we are hoping to get towards, it might not happen in 2005 it might be something that is happening nearer 2006, is to be running courses back to back so as soon as one six week course finishes, another one starts up and then even after that to be able to run simultaneous courses but in different parts of the patch.

Jane E1 (EPP administrator)

Jane E1 confirmed that the EPP appealed to those already involved in group activities and described “buy in” from an elderly action group previously mentioned by Ethel 83.

Yes, I think part of it with ((this part of)) Leeds specifically is we have got wonderful buy in from an organisation called ((Locality name)) Elderly Action and they are very enthusiastic and word has got around, people have done the course, so we actually get probably about 70% of people attending each course are getting referred probably through word of mouth by ((Locality Name)) Elderly Action, so the nature of it being a long term condition that affects the elderly, that’s possibly why in my opinion, I don’t think it’s necessarily the same for the whole of Leeds.  
Jane E1 (EPP administrator)

Note, however, that Ethel 83 described the benefits of this same action group as being social and wanted to go on more supported trips with friends, she did not mention seeing EPP publicity, which suggests penetration of the self management message was far from complete.

**I was just wondering whether you notice, when you get people together for the expert patients, whether kind of social more social than healthcare needs come out?**

I think very much it’s half and half actually. I think a lot of people with long term health conditions feel isolated and I personally that’s how I came into contact with the expert person patient programme, I went on a course over a year ago, I’ve got a long term health condition and that feeling of being a freak. Like you’re sat at home you know, people ask how you are and shall I bother telling them and actually we’re all in the room and all of us had different conditions, yeah. Quite a few of us might have had had similar aches and pains in certain joints, but we all have that feeling of being a bit like alienated I suppose.

Jane E1 (EPP administrator)

I don’t know the nature of Jane E1’s long term condition, because she was not interviewed as a patient and she did not volunteer the information. However, generally the explanation she gave seems to make sense as the reflection of a fairly young person (which she was) with a long term condition that sets her apart from contemporaries. Similar thoughts and feelings (“being a freak” or “alienation”) were not expressed at all by (older) patient participants. The opposite is true in fact as chronic disease and progressive deterioration are “accepted” and people expressed the view that others were worse off. One does hear ideas of difference from contemporaries echoed in the voices of those male patient participants whose working life had been disrupted by disease (Edward 71, John 67, Mike 56). The proportion of EPP participants referred by the

elderly action group warrants some explanation, which is probably unrelated to Jane's personal experience of ill health. Likely options include:

- simple publicity and recommendation (as Jane E1 suggests);
- group people are attracted to Elderly Action and EPP;
- Elderly Action 'primes' people for further group activity.

With respect to the second of these, Jane E1 (an EPP administrator) identified the attraction of EPP to "group people".

**... people who'd previously been involved in ... community things or in group action were ... more keen and more likely to want to get involved.**

Yes we see that too definitely. Not just with tutors but even people who attend the course. I mean some people have no experience but you do find in every course there will be a couple of people who are very active locally or in a specialist health condition support group or charity, something like that, yeah you do find them already, got that bent to them.

Jane E1 (EPP administrator)

The extent to which Elderly Action primes the unexposed for further group activity is difficult to explore in the data collected for this study. However, Felicity E2 (an EPP tutor/facilitator) described putting EPP 'graduates' in touch with patient groups like Breathe Easy (also referred to by Olive 62), or those for myalgia and MS. So it seems that group involvement is at least capable of capturing the imagination of those previously disinclined towards membership. However, Felicity's experience seems to be that EPP was mainly serving those already engaged.

The people we've had on the course so far have been quite motivated because they've actually seen it advertised in the newspaper, they've actually picked up the phone and they've actually wanted to do something about it, so ... there's high motivation there. They're interested in what it is, they're interested in whether it can help them and they are the sort of person that obviously wants to help themselves but I think we've been very fortunate to have motivated people and of the people that have come, some have been very actively involved in support groups of their own and have come really as an add-on to that and picked up the extra information and actually presented it at their own local support groups as well.

Felicity E2 (EPP tutor)

I also asked her how she thought EPP participation could be encouraged in those not inclined towards groups.

I would love to see those people in this course; I'm not sure that the course would work as well for those people because it's very structured and very rigid. I think ... they'd be far more complicated, they'd be less motivated. I think their attitude would be more negative to this kind of approach. They would perhaps see it as being a bit more dictatorship, you know a bit more dictatorial really. But I would love to see those people and I would love to work with a group of those people to see how it works but I think they would need more time, more discussion and there may be far more issues around the resistance but I'd love to see them on it.

Felicity E2 (EPP tutor)

If Felicity is correct, then research on the effectiveness of the pilot EPP courses has limited relevance for a more typical patient population. Similar concerns were expressed by Dawn N4<sub>p</sub> (a modern matron) in **Section 6.2.3**. Felicity E2 wasn't a typical patient since she actively sought out the EPP course with the intention of becoming a "facilitator", and she had already "gone ... way beyond any of the content of the course" in prior development activities. For her, the EPP worked by giving people "confidence" to discuss care, ask for advice and become more "independent". She said:

I personally feel that some GPs do feel very threatened by it. They don't like a patient to be too knowledgeable and in a way it changes their relationship. We feel the relationship should be equal but a lot of healthcare professionals feel that they're superior.

Felicity E2

Confidence in this sense is about ones' capabilities and self-efficacy, and Bandura's theory of self-efficacy underpins much of the EPP (Bandura, 1997). In another sense patients have confidence (place "trust") in their doctors' abilities to make the right decision for them, which is a route to dependence rather than independence. Patients' lack of confidence was identified in **Section 6.2.2**. The importance of dependence and independence are further discussed in **Section 6.4.5**.

One issue (mentioned by Jane E1 and Felicity E2) may be that the highly structured EPP course is licensed to the NHS under very strict conditions. There is no 'taster' or 'EPP lite' (as it were) and the dominant medical culture (in clinical practice rather than at professional conferences) is only slowly moving towards active promotion of patient involvement in decision making. Crucially EPP develops generic self management skills not condition specific clinical knowledge.

How EPP and clinical self management best fit together is debatable. They seem to be complementary activities, one is not necessarily a pre-requisite for the other, and they are not mutually exclusive. Nicola N3<sub>p</sub> (a development nurse), who is helping to develop clinical management in primary care states:

I mean what we would expect or how that would fit in with the service is that we would expect patients to actually attend the programmes that we provide and then to go on and do the expert patient because they have got the knowledge of their own disease and then they get the generic the generic things afterwards I wouldn't send somebody straight to a expert group.

Nicola N3<sub>p</sub> (development nurse)

There is a hint in this quote that Nicola sensed danger (or at least ineffectiveness) if patients tried to apply self management without a full understanding of their clinical condition. I suspect this overstates the risk and fails to recognise the emphasis placed within the EPP on non-clinical goal setting.

Dawn N4<sub>p</sub> and Jenny N5<sub>p</sub> (modern matrons) would like to refer into the EPP, but they would of course have to encourage their patients to self refer.

Yeah like referring to the expert patients programme or something like that, which is what we hope to do with people that we worked with so that they could bring some of their knowledge into an arena where they can talk to others and sell it, like a self help group really.

Dawn N4<sub>p</sub>

And you get the thought process thing going on so you get your confidence (built up) "Maybe I can do this, I didn't think I could." So you'd still need to get the clinical knowledge bit, but that ability within them to think it is possible, so you lose that (pattern) of dependent patients hopefully.

Jenny N5<sub>p</sub>

The need or demand for EPP is potentially very large. When checked in March 2008, 9 generic EPP courses were planned to take place in Leeds between April and December 2008, as well as three for "supporting parents" (of children with long term conditions). A job advert (expiry date 20 March 2008) stated (Expert Patients Programme, 2008):

We ((the EPP CIC)) have ambitious plans to increase our capacity from 12,000 courses to 100,000 ((nationally)) by 2012 and to widen our reach to help more people.

However, EPP courses themselves have been delivered by volunteers (paid expenses) and Felicity E2 (an EPP tutor) wondered if this was sustainable:

I personally feel as if I'm doing a job that I'm just not paid for it and I sort of like feel, at the moment that's fine because I am getting the satisfaction of doing it ... I don't think the programme can run long term on that because you'll get people who'll come, and the idea is actually people who come on the course to get them out to be tutors. And so there's a continual, very costly, because you then have to take somebody, you have to train them which is quite a lot. And then they may deliver a few courses and then they're going to lose interest because it's a bigger, much bigger, commitment.

Felicity E2 (EPP tutor)

At the time these interviews took place, generic self management was clearly an option for the patient interviewees and they should have been part of the target population for the EPP. However, their direct carers seemed to lack interest in and/or awareness of the opportunities. The EPP facilitators seemed well aware that although strictly speaking people volunteer for their course, professional “buy in” and support from patient interest groups were crucial to effective dissemination. Doubts remain about the effectiveness of the programme for those initially disinterested or detached.

### **6.3.3 Clinical self management**

There was no sense in the interviews that clinical professionals (that is, not Jane E1 and Felicity E2) were either recommending the EPP, or aware that any of their patients had completed the programme. The potential importance of EPP to clinical practice was clearly recognised by Nicola N3<sub>P</sub>, Dawn N4<sub>P</sub> and Jenny N5<sub>P</sub>, as is evident in their quotes above (**Sections 6.2.3 and 6.3.2**). Most clinical professionals were doing nothing (or very little) to actively encourage generic or clinical self management. Where clinical self management was promoted it could be formal or informal. Informally, it could have involved requests to monitor symptoms and/or change doses for a fairly short period of time; these instructions were likely to be verbal only.

Formal clinical self management involved referral to a specialist service and/or provision of a written protocol. Note, however, that the professionals who mentioned a specific protocol (cf. **Section 6.3.1**) did not agree on the fine details, only the general process. A COPD specialist service was active and established in primary care. The heart failure specialist service was restricted to secondary care, disagreement about

protocols expressed in this study suggest that wider roll out could be problematic. David P3<sub>S</sub> (a hospital pharmacist) was confident that existing protocols could be adapted for primary care, but may have referred more to ACEIs than to diuretics (cf. **Section 5.2.6**).

Protocols, should be fairly straight forward in terms of, if we're talking about a drug titration process. It's fairly straightforward, we know, we've worked to a PGD ((Patient Group Direction)) within the hospital and that's been approved and used for several years and so whatever we develop will be based on that.

David P3<sub>S</sub> (hospital pharmacist)

I expected Tom D3<sub>S</sub> (a cardiology consultant) to have a fairly formal approach to self management. He said:

You know nurses tend to do these things much better than doctors, according to protocol, but mine is a fairly informal thing, just take two extra frusemide for three days or stop them for three days.

Tom D2<sub>S</sub> (cardiology consultant)

This view about the superiority of nurses was shared by Douglas D1<sub>S</sub> (an elderly care consultant) who stated:

I think they ((heart failure nurses)) could be a very useful role in managing patients, particularly things like, nurses are better at routine ensuring adherence to protocols. I think if we're going to get the maximum benefit from drugs we should titrate up ACE inhibitors and the ARBs to the doses that were used in trials ...

Doctors tend to think "Oh there on that, it won't do him any harm, we'll just leave him on the lower dose" which may be ineffective, so it's best to titrate them up to effective doses. I think the heart failure nurses are probably better at that than doctors.

Douglas D1<sub>S</sub> (elderly care consultant)

Brian D6<sub>S</sub> (a cardiology consultant) described the benefits of a more structured approach to clinical self management:

Yes. I do occasionally tell people, you know, clearly if their weight is going up or they are more short of breath, if they have some (understanding) they can take an extra frusemide tablet or whatever it happens to be, but now we have clearer guidelines to be able do that on a more regular basis.

Brian D6<sub>S</sub> (cardiology consultant)

The professionals involved in it seem to believe the quality of service offered by the Acute Trust heart failure service was good. Clearly they had the time and willingness to discuss diagnosis, prognosis and treatment in some depth. The referred (note not

‘volunteering’) patients usually had moderate to severe symptoms and a recent in-patient stay. Symptom severity, in particular its speedy reduction, may help to convince patients that diuretic dose adjustment has merits as Sarah N1<sub>S</sub> explained:

If over a period of time somebody gets to realise, as much as they might be stubborn and not ever want to take different meds, if over a period of time you can get someone to realise that diuretic therapy could change on a weekly basis and you are not going to see your doctor every week and you might see a different doctor every week, you can almost certainly, because it controls the symptoms so radically, that you can be breathless one day on 40 mg of frusemide and OK two days later on 80, you can convince an awful lot of people. It might take time but you can convince an awful lot of people, even if they are not happy to do it themselves, that diuretic manipulation is really, really necessary.

Sarah N1<sub>S</sub> (heart failure nurse)

The time available for patients was clearly important and Sarah N1<sub>S</sub> described elsewhere how the patients’ attitudes and questioning would change over time, as trust developed and their most significant issues slowly emerged. The main problem identified for the service was capacity for primary care expansion.

We’re going to run into the same problems that we have in secondary care in that the number of staff limits the number of patients that you can see. It’s a fantastic service but you’re only seeing a small percentage of the actual patients that you would like to be able to see or who would benefit from, so the intention is to set up this service in primary care (in one) locality and then expand it by using possibly GP practice nurses, community pharmacists in order to widen the number of patients that we’re able to see.

David P3<sub>S</sub> (hospital pharmacist)

The issue of capacity was linked to some concern about the perceived quality of care for heart failure outside the hospital.

I think it’s OK for that proportion of patients that have a heart failure nurse looking after them, but obviously we only see the tip of the iceberg in terms of the cardiology bed base and I think also I do find that I don’t know if the GPs are nervous or just aren’t aware of the heart failure treatment side of things, but often patients will see GPs and very little has been done or there does seem to be a disparity between what we are seeing in somebody seeing their GP with chest pain compared to somebody seeing their GP with breathlessness relating to heart failure.

Julie N2<sub>S</sub> (heart failure nurse)

It should be noted that patients themselves were more tolerant of breathlessness as a symptom (**Section 6.1.1**). Pain was seen a serious symptom and continuing pain would not be suffered without questioning (**Section 6.1.2**). So GPs may experience more pressure to resolve chest pain than shortness of breath. Plans to improve this care did not revolve around better training or awareness raising for existing primary care professionals, but rather providing more specialists to whom patients have easier access.

We are hoping we might be able to appoint perhaps another ten heart failure specialist nurses throughout Leeds and would be more community based rather than hospital based, which the current heart failure specialist nurses are, so yes it's quite a lot of change there.

Brian D6<sub>s</sub> (cardiology consultant)

The modern matrons were the only primary care professionals interviewed who were impatient for change.

When you look at what provision around the respiratory team, the model's there, you've got a model that works, and again it's growing and changing and their very new and expanding and I think the demands on them is probably, they knew it would be a lot, but it's growing faster than they thought. But you've got a model that works and building in, sort of building capacity in the system for knowledge, for people like practice staff, you can build your knowledge base as well as providing your specialist input and then they've got pulmonary rehab and this that and the other going on. So you've got a model that works sort of hub and spoke thing so all that's thought through.

Jenny N5<sub>p</sub> (modern matron)

Patients' direct carers had more interest in, and support for, clinical self management than generic self management. This is not surprising since clinical self management embodies a medical model of care, which happens to be practised by the patient. This is in line with a modern trend towards consumers providing services for themselves that once required professional input. Outside the health sector we see this in internet banking, online holiday booking and shopping at Ikea; the experience of which may in time increase patients' confidence to provide their own healthcare. Consumer provided services are increasingly common and the sense of control they provide may be popular. However, they tend to exclude large sectors of the population who lack functional literacy or IT skills. In the health sector we see online health advice and the ability to order a range of diagnostic tests by post. The driving force behind customer engagement in production is economic, specifically to reduce production costs for the supplier.

Outside health customers may experience added value as improved choice and lower prices. Within health customer disadvantages are more apparent: the need to be much better informed; the risk of taking more responsibility; the difficulty of getting advice when needed; and time diverted from other (social) activities.

#### **6.3.4 Suitability of patients for self management**

After explaining to each professional how clinical self management had been described to the patients (chiefly as symptom monitoring and dose adjustment), they were asked to describe how they would assess its suitability for their patients. The only consistency in the responses was the absence of hard and fast rules. Responses clustered around four general issues:

- Cognitive capacity – can they self manage?
- Willingness – do they want to self manage and to what extent?
- Co-morbidity and case complexity – is it safe to self manage?
- Clinical assessment of severity – do they need to self manage?

The intersection of these issues (which concern, respectively: capability, autonomy, risks and benefits) suggests a prevailing wisdom that the sub-set of patients suitable for full clinical self management may be quite small yet varied. However, note that heart failure specialists consider the general level of unmet need to be high and their service capacity to be limited. Julie N2<sub>S</sub> (a heart failure nurse) commented on the percentage of her patients that adopt various levels of self management.

**Is it nearly everyone who is self managing or is there some sort of split?**

I guess I would probably cut the patients down into: self managers that will manage everything ... and perhaps that's a very small proportion really, may be only just 20%; and then another portion that are very good at monitoring their symptoms and you would trust to seek advice early, may be another 30%. I would say probably a total of 60% or 70% do something.

**...and presumably a kind of small chunk at the bottom who?**

Won't do anything. Yes, they won't do anything and they either won't want to bother you, or anybody, or they will just, it appears to have gone in one ear and out of the other sort of thing for whatever reason.

Julie N2<sub>S</sub> (heart failure nurse)

Remember that patients in the service will have had at least one heart failure related admission and may have (periodically) severe symptoms. The reasons Julie N2<sub>s</sub> gave for non-participation seem to relate to willingness or capacity, her patients were (or have been) quite ill but she did not mention disease severity or complexity as limiting factors. Clearly, some level of capacity is important and general capacity may be expected to decline with time, so assessment should be done on a ‘rolling’ basis. In fact, some professionals worried that self managing patients could decline without it coming to their attention. Douglas D1<sub>s</sub> (an elderly care consultant) suggested that either the patient *or* a carer should have capacity. However, he wanted to retain some measure of control or independent check on outcomes:

The sort of patients that might be suitable is either the very sharp mentally or they’ve got a spouse who is on the ball or they’ve got an involved child, son or daughter, who can sort of help them to do that. The only sort of slight worry is that they might be sort of lulled into a false sense of security ... I think if they’re getting regular blood tests I would be happier.

Douglas D1<sub>s</sub> (elderly care consultant)

Doubt or uncertainty is expressed throughout this quote using the phrase “sort of” frequently, he emphasised his concern in another place saying: “I worry about patients self managing themselves and just quietly deteriorating.” He expressed concern both for patient safety and that a traditional professional role was still useful. He would have cared for many patients who were (for various reasons) frail or vulnerable. Some patients described problems with memory, which are not necessarily related to capacity as such and may even be a function of heart failure (cf. **Section 6.1.5**). Self management involves the recording of symptoms and written guidelines, which should support remembering and may balance some of the risks that Douglas D1<sub>s</sub> worried about.

It is important not to confuse capacity with health literacy, which is a separate but related issue. Health literacy is a learned skill, which mediates action for the archetypal ‘informed patient’.

I think you have people who take an interest and yes they still want advice from professionals as such but they are prepared to make decisions for themselves as well and you know want to be involved. They are the ones that read all the patient information leaflets and will come in prepared almost.

Louise P5<sub>p</sub> (practice pharmacist)

It is possible to explain the actions required for clinical self management to a person with limited health literacy, and for those actions to be carried out appropriately. Julie N2<sub>S</sub> (a heart failure nurse) noted that some more literate patients were actually the most difficult to deal with, since they wanted to deviate from protocols (cf. **Section 6.2.2**). Conversely, it may be easy to give people with limited literacy practical steps to follow:

I think sometimes you get some people that are a bit more astute and I think the psychological impact is that bit greater and that affects their ability to work with the heart failure symptoms so it does have an impact and I think a lot of it is about how you explain things ... somebody might not be able to read but if you can talk to them about the fact that their slippers are too tight, you know basic things, about their slippers getting too tight or getting them to look at their weight chart and then may be if they do go down the pub and have a couple of pints then just look at your weight chart the next day.

Julie N2<sub>S</sub> (heart failure nurse)

There are some obvious potential links between capacity, willingness and age. *A priori* one would expect younger people to be both more willing and more able to self manage than older people. While reference was made to age it was generally accepted that old age as such did not rule out self management, for example:

You can't define it with ages but I suppose age comes into it to a certain degree. Maybe not your real elderly patients who are on multiple other medications for other things as well.

Louise P5<sub>P</sub> (practice pharmacist)

Sarah N1<sub>S</sub> (a heart failure nurse) thought “younger people much more eager to manipulate their own medicines.” Her colleague Julie N2<sub>S</sub> tended to agree about the influence of age, and also supported the comment Douglas D1<sub>S</sub> (an elderly care consultant) made above about carer capacity.

**So we've got this 20% of people that cope really well or are suitable to do the full self management bit, do they tend to be a certain type of patient or again is (it) a very individual thing?**

It's generally people that have very supportive partners around or families. I don't think it relates to sex at all, male or female, and they are (a) slightly younger end of the spectrum, 60 or 65 year old; and the younger patients are, the very much younger patients in their 30s sort of thing, are generally very good as well.

Julie N2<sub>S</sub> (heart failure nurse)

Two pharmacists raised concerns directly linking age with capacity, which might be considered a little paternalistic. Geetha P1<sub>C</sub> (a community pharmacist) was one of the

few professionals interviewed who didn't have routine private consultations with patients. From personal experience of a similar (busy demand-led) environment I know that certain working assumptions and stereotypes can be necessary at times to cope with the workload. Vanessa P4<sub>P</sub> (a practice pharmacist) whose role should take pressure off GPs, also worried that self management might stimulate demand for professional time.

**So you think they might be kind of some resistance to that kind of thing?**

The fact that you are going to get more elderly population who often can't remember to do it, yes, I don't think all patients will do that and I guess if their weight goes up and up and up do they think "I need to make an urgent appointment" "I need a visit", does that put pressure on the GP surgery?

Vanessa P4<sub>P</sub>

Mental capacity is an issue because a certain amount of knowledge or understanding (however transmitted) is required of self managers. Sometimes the need for education was presented as a problem for the teacher (professional) rather than the student (patient), for example, Julie N2<sub>S</sub> (a heart failure nurse) mentioned how message delivery needs to be altered to suit different types of patient. Brian D6<sub>S</sub> (a cardiology consultant) clearly identified the educators' skills as crucial, then linked this to the patients' capacity and willingness.

Right, okay. So appropriate patients, well they need to be educated first of all, so they need to know about their condition and education is far better delivered by a specialist nurse than by a doctor who doesn't do it very well, so they need to understand their disease. They need to be aware of the medication they might use and how the disease changes with time. Clearly it has to be somebody who has a reasonable level of intelligence or understanding and they need to be compliant and interested in their condition.

Brian D6<sub>S</sub> (cardiology consultant)

Unfortunately it isn't clear, because I didn't ask, why Brian thought nurses were better educators. Doctors also tended to think nurses were better at using treatment protocols (cf. **Section 6.3.3**).

And I have to say that it's one of the things, I work very positively with the nursing teams in the community, and it's one of the things that worries me about the profusion of the COPD nurse specialists, heart failure nurse specialists because they will simply plough down their particular diseases algorithms and when you get somebody with multiple disease I think it's very difficult.

Luke D5<sub>S</sub>

It may be nurses were better at education and following protocols because a nurse appointment (as reported by these interviewees) was typically at least twice as long as a doctor appointment. Doctors may also be expressing disinterest in education and protocols, or else confidence in nurses' abilities to apply consistent standards. Luke D5<sub>S</sub> (a respiratory consultant) made a clear link between patient education and confidence.

I think....you need to select your patients carefully and...you need to make sure that your patients are educated about what you want them to do; that they understand what you want them to do and they have the confidence to not do it and do it.

Luke D5<sub>S</sub> (respiratory consultant)

He taught with nurses (and other professionals) in a pulmonary rehabilitation programme and in this context stated:

Being a consultant is actually a big barrier with communication with patients as well as a help, I deliberately use all the presentational tricks that I know to actually engage them: so I will take my jacket off; I will sit down; and we've got them in a curve rather than in a set-up.

Luke D5<sub>S</sub> (respiratory consultant)

This suggests that, even though consultant expertise is valued by patients, their perceived (high) status makes them less effective educators; but that they can (at least partially) overcome this barrier if they have the time, inclination and communication skills. Luke D5<sub>S</sub> encountered patients that were more or less willing (at least initially) to consider self management, although his primary aim was to educate the patients about their disease rather than promote self management as such. Education and willingness to self manage were also linked by David P3<sub>S</sub>, a pharmacist with experience of the coronary rehabilitation programme.

**You say selected patients - how do you think they would be selected?**

Well various criteria I suppose: patients who were able to; patients who were willing to; patients who felt comfortable with the whole scenario of taking responsibility for their health rather than having a doctor having responsibility for their health so we're looking at patients really who are motivated, reasonably educated, but we'd step in and educate and competent. I don't know how many patients that would include but there will be some patients who just don't want to be involved. I don't think you can anticipate which patients it would be because we've got several elderly patients who are quite willing and able and capable of the self management aspect of their heart failure.

David P3<sub>S</sub> (hospital pharmacist)

Note that while recognising the potential impact of age, David P3<sub>S</sub> (like others) didn't find age itself a barrier to self management. Unwillingness can also be overcome, Luke D5<sub>S</sub> reported that people talked more freely as his education session progressed (cf. **Section 6.2.3**) and Sarah N1<sub>S</sub> (a heart failure nurse) reported that patients can become more confident with the practical aspects of self management:

I have patients that ring me, because we do the diuretic manipulation over the phone and I say "OK then, take another Frusemide", "Are you sure love, are you sure, are you sure?", "Yeah, I'll ring you in a couple of days", "Will you?", "Yeah". Put the phone down, ring back "So that's one extra", "Yeah", "Which one was it again love?" and "OK, it's the frusemide, do you want me to spell it out for you?", "Do you need any more? Do you need me to ring your GP to get you some more? How many have you got left?" *So you might get that at the start* or you might get someone who is unhappy to do it but if they're overloaded they'll start to feel worse. So what's the logic in that?

Sarah N1<sub>S</sub> (heart failure nurse) ((emphasis added))

On the other hand patients' skills may fail to improve or get worse. Luke D5<sub>S</sub> talked about ways to enforce adherence to clinical self management protocols, which firmly places his approach in a medical model and provides the sort of oversight Douglas D1<sub>S</sub> (elderly care consultant) called for in his quote above.

I tell people at the beginning that I sort of use a 'two strikes and you're out' and if you've used your steroids and antibiotics twice, outside of the written protocol that we've given them, then we ask the GP not to issue further home supplies and if you say that up front I think you actually get better compliance with the plan, although it does require careful handling when you remove that ability later on.

Luke D5<sub>S</sub> (respiratory consultant)

Factors other than age or capacity may make effective education particularly challenging. James D4<sub>P</sub> expressed concern that confusing information may worry the patient, especially those without family support.

I think you've just got to assess the individual really haven't you and there's some people who wouldn't cope ... they're often very complex patients because they've got other co-morbidities so obviously if you confuse patients it's not going to be any good. I think people feel, if they live on their own, I think they'd be a bit worried by it. I think that's all really.

James D4<sub>P</sub> (GP)

The major source of clinical confusion identified in these interviews was that between heart and lung disease. Neither Brian D6<sub>s</sub> nor Luke D5<sub>s</sub>, consultants in the respective specialities, saw this as a persistent barrier to self management, for example:

I think step one in allowing patients to self manage is to make sure that you're clear what disease they're self managing but there will be some patients with both ((heart and lung disease)).

Luke D5<sub>s</sub> (respiratory consultant)

It's unlikely that those remaining confused or lacking capacity would demand self management or express willingness to self manage. However, it seems likely that clinical need for and willingness to self manage will on occasion clash, as Sally C1 (a clinical psychologist) explained:

I think on one hand we do have to be very respectful of what people's wishes are, but on the other hand I can see the frustration with healthcare professionals who perhaps get somebody continually presenting with the same symptoms. And there's something about not really understanding or being able to rationalise and change the way they ((the patients)) are dealing with things to actually help themselves. It's like a self fulfilling prophecy.

Sally C1 (clinical psychologist)

It's among those patients suffering from the 'revolving (hospital) door' syndrome that Tom D2<sub>s</sub> (cardiology consultant) saw the greatest capacity to benefit from self management.

Usually they're ((those selected for self management)) quite advanced disease and usually they've, they've had several hospital admissions so they kind of understand; they've usually had both kinds of hospital admissions. Hospital admissions where they come in you know with oedema up to the knees and hugely fluid overloaded and they need IV diuretics then to get them better and they've also had the opposite admission where they come in when they're like a crisp, you know?

Tom D2<sub>s</sub> (cardiology consultant)

Breaking this cycle of frustration was also important for James D4<sub>p</sub>, but as a GP he wouldn't necessarily care for patients when symptoms were at their worst, and there were hints of uncertainty in this response:

**So in general you kind of be happy if somebody had one of these plans?**

Yes I think so, I wouldn't see any harm in it. It's very frustrating for err, because often in the past they've, especially when things are deteriorating, they get into

hospital and then they come out and then they're back in and anything that can break that, that cycle is good isn't it? Cause I'm sure it doesn't do them any good.

James D4<sub>p</sub> (GP)

Among patients it was the 'logical adopters' that saw potential to self manage by changing diuretic doses in a similar way (cf. **Section 6.2.2**). Most patients would simply accept what doctors told them was necessary and didn't really make a connection with symptom severity. Among professionals the somewhat conflicting responses, lack of consensus and differing priorities point towards the need for individualised patient assessment.

There is clearly a continuum of both current and idealised practice. This ranges from those that offer (or would offer) limited self management opportunities to a few patients, through to those that would offer active self management to a majority of patients. There were no feelings that full clinical self management would suit all patients all the time. Professionals, unsurprisingly, believed that access to their support remains important at all times. The main problem with the 'tailor made' approach, while patient centred and fine in theory, is that professionals differed greatly in both their experience of self management and their particular views on patient suitability. The clash in views was most acute and relevant between highly respected GPs and specialist nurses. Patients meet different professionals; they will interpret a range of views (correctly) as indicating uncertainty about need and effectiveness.

#### **6.4 Issues and dilemmas in the provision of self management**

Self management of long term conditions is promoted for three general sets of reasons:

- clinical (improving health);
- economic (saving healthcare resources);
- psychological (increasing autonomy).

Patients in this study were inclined to consider their current general health status as the best achievable in the circumstances, they didn't bear the costs of healthcare and they didn't generally see greater interest in healthcare as the answer to any pressing problems. Consequently the barriers to the promotion of self management are high. The

following sections discuss, firstly, how the general barriers may be lowered and, secondly, several aspects of self management with debatable utility.

#### **6.4.1 General issues hindering service development**

Patients lacked awareness about: the nature of their diseases; how easily (or not) symptoms and prognosis may be modified; and the range of clinical management options available. They managed ups and downs as independently as possible, but valued professional advice when it was given. They generally trusted that following this advice was enough to optimise health. Patients seemed naturally resistant to change once they had a settled healthcare routine. Professionals' opinions about what patients knew about their health and their desired level of involvement were generally accurate. Patient potential remains un-assessed: this is especially the case for older patients.

Patient routines may be disrupted naturally and periodically by worsening symptoms, social issues or family crises. Self management awareness raising could stimulate demand for change, but at the cost of making (most) patients artificially dissatisfied with current care arrangements. We see in Tony 55 and Felicity E2 how dissatisfaction may lead patients (respectively) to 'tinker' with routine treatments or seek more holistic answers to healthcare problems. Professionals would need to discuss the seriousness of symptoms and potential for bad outcomes in order to encourage patient engagement. They would have to speak directly about the limits of professional competence and risk patient anxiety about symptom control.

Patients were willing to consider changes recommended by their doctors, because they trusted them and the system responsible for medical education. It would be a sign of great strength in the patient-professional relationship if this trust could survive more therapeutic discussion and openness. Patient would also need to see value in their own perspective on health, which many currently lack. Most lacked a belief that they were capable of understanding the medical information required for self management. A few obviously lacked the capacity to understand more on the basis of the dependence reported and frailty witnessed during the patient interviews.

For patients, these general barriers to self management (reliance on doctors, lack of knowledge, lack of confidence, lack of capacity) could probably be related to any potential choice that changed the way care is provided. For professionals changes in care provision are usually called ‘service development’, and in theory should be embraced as part of good practice. Changes recommended by professionals have a good chance of acceptance by patients. However, just as patients have routines, professionals have settled ways of working and can be equally resistant to change.

Moving more specialist care into the community has the intentions of expanding service capacity, improving patient access and engaging patient interest; which would, if successfully achieved, resolve many clinical management issues. Changes in heart failure management are mirrored by similar changes in most therapeutic areas. However, some services (for example, cancer care) are being centralised. Shifting ‘aftercare’ into the community is partly necessary because hospitals have successfully reduced the length of many in-patient stays; Tom D2<sub>s</sub> thought this left many people with the wrong impression about how ill they had actually been. Professionals’ opinions about self management are an example of more general thoughts and feelings. Certain professional factors are a *general* hindrance to service development: communication, practice environment and professional responsibilities.

The difficulties of improved patient-professional communication are outlined above. As far as patients were concerned GPs and consultants were the most respected individuals, therefore, the way they communicate and with other professionals is important. It’s clear that GPs didn’t communicate well with professionals outside their practice unless there was some clear direct need but they did recognise this. James D4<sub>p</sub> (a GP) discussed the practice’s lack of engagement with their onsite community pharmacist.

The other thing about pharmacists, I work at ((local mental health unit)) and they’re often very, they are very knowledgeable and we don’t in primary care we don’t use that knowledge really, which is a bit of a shame. I know in hospital it’s probably easier because they’re much more specialised but in general there’s a lot of knowledge out there but we’re not really, here anyway and perhaps it’s different in other practices but we don’t tap into it as much as we could here.

**Is that just because you don't or do you think there are any particular is it just kind of cos that's just the way it's been done or are there particular barriers do you think to?**

It's probably largely historical isn't it? It's probably not being the barriers between professions hasn't been broken down so much probably. Maybe, I don't know what it's like in dispensing practices, presumably it's a bit different there.

James D4<sub>p</sub> (GP)

His partner Mark D3<sub>p</sub> discussed worsening links with social services and the declining frequency of home visits:

I mean our links with the social services aren't very good, they were there in the building next to us and they moved away. Certainly, I wouldn't say that at home we do too many assessments in the elderly. In one of the older ((GP)) contracts you had to go and see every 75 year old and assess their homes every few years but we don't really do that. But I think if patients request that we do anything, we certainly do refer them onto the social services for home helps to provide as much care as they can.

Mark D3<sub>p</sub> (GP)

A large part of the modern matrons' job in the community seemed to be directed towards resolving these inadequacies; this can lead to professional 'toe stepping' and protectionism.

They're like nurses, they're changing into doctors aren't they? Maybe pharmacists could as well. No there's definitely roles for other professionals isn't there. I know doctors are a bit reluctant to give up their empires but there's just not enough of us and there's not going to be enough us so I think we've got to use these other professionals.

James D4<sub>p</sub> (GP)

As independent contractors GPs can be excused a little nervousness since change can directly affect their incomes; GPs' views seem qualitatively different from professionals in salaried posts (that is, all other clinical professionals). In inner cities particularly an increase the number of salaried PCT employed GPs may lead to better alignment of organisational and personal objectives. However, empires, crossed wires and invisible walls are not restricted to primary care. The Acute Trust is a unified care organisation and its specialists provide a high level of clinical care, yet it struggles to treat patients in the most obvious way.

You have to remember that a lot of patients, if you're a GP and you see somebody who's got chest pain and it's vaguely possibly angina, you'll be sent to a

cardiologist and that cardiologist may well discover heart-burn or a lung problem. If you're just breathless, most GPs will send you to a chest consultant and therefore we actually pick up a large number of people with heart failure as part of our routine and we would consider that we are able to manage that so we would put them on their diuretics, their ACE inhibitors, beta blockers, spironolactone, whatever else; we'd arrange the echo; the ECG and do all that; we wouldn't cross refer to a cardiologist necessarily unless we thought it was valvular heart disease.  
Luke D5<sub>s</sub> (respiratory consultant)

The ability of Luke D5<sub>s</sub> (a respiratory consultant) to deal confidently with cardiology is comforting in many ways. This cardiology consultant isn't too concerned that some of his potential patients are elsewhere in the system:

I mean they probably do it reasonably well, in the same way I have quite a lot of people who come in with respiratory disease and I don't think I manage them as well as a respiratory physician would, so I think we probably do need to share patients more in that sense and getting involvement of other colleagues when we recognise that they could deal with the problem better. I think particularly with the heart failure patients, I don't think the respiratory physician at the moment has access to the same specialist nurse follow up for instance that I would have, so the patient might be missing out. He might be on the right medicines but whether he gets the right doses and gets the additional education, I would be less convinced.  
Brian D6<sub>s</sub> (cardiology consultant)

However, cardiology patients that remain under the "lung man" may be unsurprisingly confused, and Luke D5<sub>s</sub> expects clinical developments to make this worse.

And in the future I think it's going to get more confusing because there's now big interest in what happens to heart failure patients during sleep with things like CPAP ((continuous positive airways pressure)) etc. We've got fifteen to sixteen hundred people on CPAP machines so we're now providing the CPAP for the heart failure patients so, as you say, organisationally there's a cross over.  
Luke D5<sub>s</sub> (respiratory consultant) ((CPAP supports breathing))

From Brian's perspective at least communication within the Acute Trust is getting better:

I think we are much better at that than we used to be and I think generally we are better at that and certainly across ((the City)) there is quite a good system of referring patients from one cardiologist to a different cardiologist within the same hospital or across the city, or whatever, so we work together quite well in doing that. Whether we are quite so good at working with other specialty groups so respiratory medicine or whatever, I don't think we are as good at doing that and

indeed whether we need some more combined services which are directed at the breathless patient rather than the heart failure patient. That's something that a lot of people have suggested and we haven't got very far to achieving yet but that will certainly help a number of patients as well.

Brian D6<sub>S</sub> (cardiology consultant)

Brian D6<sub>S</sub> (a cardiology consultant) wants a patient focused service but the organisation seems to lack the effectiveness required to provide one. GPs at least can change the organisation of their own practice if they choose to but more often than not this is in response to financial incentives rather than patient need. Here, Sally C1 (a clinical psychologist) effectively summarises the barriers *between* organisations that supplement those *within* them:

You know see my big difficulty with all of this is that I don't think the links at the moment are well enough set up between PCTs and the acute setting and I know this is all change very much in the fore at the moment, each day there seems to be some other change with a lot of our team that (are) currently still moving out so in a way, potentially that's got an advantage because I think if we can get better links and ensure the people are trained in a similar way with a similar kind of ethos then I think that can only be of benefit to the patient and I think, because it is really unfair, isn't it we do give these mixed messages all the time, and we don't think about it, we don't have time to think about it ... I think one of the problems as I see it is that the way things are currently set up is that we don't also know who to go to, so I know working in the acute setting who I go to if there's a problem with a symptom, you know I'll go to the heart failure nurse specialist or the consultant. However, I think when someone's out in the community you know they don't necessarily know what we do here and we don't necessarily know what they're doing out there and I think that's a problem and I think that could be addressed somewhat in people having the time, to spend time with each other, we just don't do that, it's not in place.

Sally C1 (a clinical psychologist)

For patients, practice environment provided a tangible cue to the sort of care they should expect at any given time. The source of these associations between environment and care is likely to be deep seated 'custom and practice': that is, related to the culture of healthcare in the UK. Those responsible for the EPP use a non-clinical environment for courses and saw themselves as facilitators rather than educators. The main problems faced by EPP seemed to be marketing (to patients and professionals) and lack of experience training under-motivated patients. Clinical self management seems to demand a clinical environment if patients are to take it seriously and it is important to

provide easy access to professional advice outside actual consultation time. Community pharmacists are faced with the greatest environmental problems.

Dentists, opticians, doctors are seen in a professional environment; pharmacists are seen in a shop so that it's hard to get that credibility that they are experts in something so I think there's that.

And again I think it's the environment as well that going to a surgery, it's perhaps it's a more professional environment than having your cholesterol tested on a sales floor in effect when you know people are doing their shopping; perhaps that doesn't inspire confidence in patients, I don't know.

Susan P2<sub>C</sub> (pharmacy area manager)

David P3<sub>S</sub> (a hospital pharmacist) and Vanessa P4<sub>P</sub> (a practice pharmacist) confirmed the sense that it's not who you are but where you are that makes the biggest difference to patient expectation, for example:

I think it's different when you are in a GP setting, they trust you more than if you are in the chemist anyway because like you say, where you are sitting at a desk you do seem to have more authority than if you were in a dispensary.

Vanessa P4<sub>P</sub> (practice pharmacist)

Geetha P1<sub>C</sub> (a community pharmacist) was able to offer continuity to regular customers and open access for queries, but had no support or space to offer more than a brief (not very private) consultation. Asked how her organisation (a large retail chain) responded to the challenge of new service development she said:

To be honest with you it's just muddle through, trying to get done what I can get done. To be honest.

Geetha P1<sub>C</sub> (community pharmacist)

This contrasted sharply with the relative clarity of others, but she does think that she could have a role "signposting" or directing people to services she can't offer. The confidence to do more than this requires better professional education.

On the whole a pharmacist is a shopkeeper and when I was working in community pharmacy, even after I'd done my degree, you didn't, only with experience and with doing this job and then doing the ((clinical)) diploma have I felt that I'm able to field those questions and will actually engaged somebody in a conversation about the medicines instead of in the past you weren't confident so you just handed the medication over more or less but now I will try and engage and I feel confident enough to. That will start the patient asking questions but for them, even now doing locums, patients generally don't want any information off you other than the tablets.

Vanessa P4<sub>P</sub>

Current service development plans for heart failure would provide additional specialists in the community setting rather than re-skilling existing primary care professionals. It is not clear whether this will resolve or perpetuate inter-professional communication issues. However, there is no reason why primary care professionals with a special interest in heart failure could not participate in new developments. It's safe to say that professionals without a special interest would declare themselves fully occupied already. Finally, there may be a need to clarify who (if anybody) retains ultimate professional responsibility for the overall package of patient care.

Well the person who retains the overall responsibility if they are fit enough is the patient who would should be making the ultimate decision about what they want to happen taking the advice of the people who are around them

Dawn N4<sub>p</sub> (modern matron)

Dawn's vision of patient responsibility seems a long way down the line. Resolution of the dilemmas discussed in the following sections will determine exactly where we end up.

#### **6.4.2 Disclosure versus hope**

One of the most fundamental professional roles is to provide patients with a clear understanding of disease aetiology, diagnosis, treatment and prognosis. I think that without significant understanding (especially around diagnosis and treatment cf. **Section 2.2.1**) patients would not be capable of safe, consistent clinical self management or feel confident as self managers. Patient interviews suggest that most patients lacked understanding in one or (usually) more of these areas: in particular the simple knowledge that they have a heart failure diagnosis. Barriers to professional disclosure included diagnostic uncertainty, the complexity of heart failure and the fact that heart failure prognosis is frequently poor.

All professionals are called upon to deliver bad news at least occasionally, whatever their current views on disclosure regarding heart failure. In future news about health may be more complicated and nuanced. Professional capability must therefore be improved, Luke D5<sub>s</sub> (a respiratory consultant) showed that this is possible for the mechanism of heart failure.

I think lung disease is easy to explain to people because you say you've destroyed part of your lung; this is how much you've got left. I saw a lady yesterday who could not understand why she was breathless but her lung function is slightly bigger than a coke can and I was able to say, "Here's a coke can; this is the size of your lung; you're breathing on this, that's why you're breathless" and it was very easy for her to go away with that as an image. For heart failure my usual explanation to people is that your heart is a pump and just like a pump in your garden pond, if it's not working properly, water dams up on one side of the pump and that can dam up in your ankles and in your lungs so your ankles swell and you get breathless and people can understand that pump analogy.

Luke D5<sub>s</sub> (respiratory consultant)

His pump analogy is widely used but less often with a detailed explanation. I turned to a psychologist for some arbitration on the merits, or otherwise, of diagnosis disclosure. She remained unsure that there was a right answer but emphasised the positive impact early disclosure may have on future planning.

I guess the approach which suggests that people don't need to know I think is, what's the word I'm looking for, a little bit derogatory towards the patient in that it suggests to me that people don't think the patient can hear this truth and of course we do know that there are circumstances in which people are unable to hear things because they are very anxious or very upset but I do think there is a lot of scope in actually taking a very steady, very gentle approach and being honest with people that they have this diagnosis this is what it means and this is what we can do to manage and help you manage the condition ... most people want to know, they might not like what they hear but often it allows people to plan and I think that's really important.

Sally C1 (clinical psychologist)

The main justification for not fully disclosing known medical facts to patients appears to be the maintenance of hope. Dawn N4<sub>p</sub> (a modern matron) implied that patients are more likely to be told the truth if they know what questions to ask. I'm not sure why anyone with only a vague understanding of their diagnosis would ask for their life expectancy, or how you would let a professional know your intentions. The majority of patients didn't seem to have any clear idea that they suffered from a condition with a terminal (but variable and modifiable) prognosis, and were more likely to attribute deterioration to the inevitable consequences of ageing. It may be more in the professional's than the patient's interest to withhold knowledge.

If I thought that they wanted to know that I would do it. It's not very, it's never easy to tell someone that the likelihood is that they won't survive more than a couple of

years, particularly with the uncertainty because we don't know at the time what their prognosis is. It's different with cancers where you usually have a better idea, so I don't think I've ever told someone with heart failure or had the time, well we do have more time now, we have altered our schedule so we do have more time for our appointments, but I'm not sure that that really has meant that we spend more time discussing people's prognosis and diagnosis with them. Of course with our new contract a lot more of this time is spent reaching targets and doing what the computer tells us to do other than treating the patients any better.

Mark D3<sub>p</sub> (GP)

Professionals are, therefore, making judgements about what level of understanding is appropriate or achievable for patients. Sometimes the judgement is pragmatic and relates to the time available or the professional's own uncertainty.

...things are often very nebulous when they're before us which makes life tricky ... particularly with heart failure it's often, before the diagnosis, it's often quite insidious and it can sometimes be a long time before the diagnosis is actually made.

James D4<sub>p</sub> (GP)

Specialist nurses with longer consultation times for a single set of issues reported giving more information and being asked more questions as this information is digested by patients. GPs operated in a more limited time frame, without clear boundaries of clinical responsibility.

I think in a way that's the hardest thing for us to do because we have only got 10 minutes and people don't just come in with a. I often think when I'm reflecting, I think it would be really nice just came in and said, "I want you to deal with my heart failure today and this, and this and this", but it's not like that, they start saying, "I'm breathless" and then they say it's "It's me big toe and I've just been down to the travel agents" and it's like this really, it's like a bee buzzing around in their head. If they'd just come in and say, "It's me heart failure" and then you could be in heart failure mode then but life's not like that and it never will be.

James D4<sub>p</sub> (GP)

From a time rich perspective, Julie N2<sub>s</sub> (a heart failure nurse) saw the communication of heart failure prognosis as being in a dark age from which cancer has long since emerged.

I feel very strongly that heart failure is like cancer was 20 years ago. You know when we used to say you had a growth or you know something like that, you would never quite say the C word whereas now we are very open and honest about it and

I think hopefully in 20 years time people will be told they've got heart failure as soon as they've got it. I think your know we live in a day and age now where we should, we can't withhold diagnosis from patients, people need to know, for whatever reason, be it planning their life or they career or you know any aspect of their life it's very important.

Julie N2<sub>s</sub> (heart failure nurse)

The key for her, and her colleague Sarah N3<sub>s</sub>, was to go beyond the label to explain the implications more clearly and positively.

I think they need to have the information and the knowledge given to them after they've been told but as long as they've got that then it's definitely not a negative ... they might have heard "You've got a big heart" or they might have heard "Oh your heart's not pumping properly" and I think all that really does for the patient is exacerbate fear that they have no control and all these different problems that they don't think are necessarily related and they can do nothing about ... as long as someone is there to explain what it is and what it means to that person then it isn't a negative thing, however, it's hard for doctors because to tell someone they've got heart failure, they think their heart's failing and that they are going to die imminently.

Sarah N1<sub>s</sub> (heart failure nurse)

Brian D6<sub>s</sub> (a cardiology consultant) seemed to agree entirely with the specialist nurses, however, in contrast Tom D2<sub>s</sub> (also a cardiology consultant) did what he could to be positive but also vague.

I think my style of talking to them – I hope it's factual but does tend to be a bit optimistic. I do kind of tend to be kind of optimistic with them and I know not everybody does that with heart failure and if you take the whole group of heart failure patients, then what they'll say is that the, the mortality from overt heart failure is about 50% at five years ... heart failure ((in contrast to cancer)), they hardly ever ask you ... they rarely say, "What's going to happen?" and I actually don't think there's anything to be gained in most people by telling them there's a 50% chance that they'll be dead in 5 years. I don't actually think it's a particularly useful thing to do because, because you can't predict which 50%.

Tom D2<sub>s</sub>

Mark D3<sub>p</sub> (a GP) didn't like to give a heart failure diagnosis because of "fear" related to the patient's reaction. Sarah N1<sub>s</sub> (a heart failure nurse) who had experience of this thought extreme reactions and initial "denial" relatively rare but nevertheless hard to deal with. Douglas D1<sub>s</sub> (an elderly care consultant) thought that that diagnosis was itself difficult for GPs faced with vague symptoms and without specialist equipment. James

D4<sub>p</sub> (a GP) thought he was more likely to give full information to patients with the worst symptoms, when presumably the diagnosis is more obvious and the patient may be actively seeking answers.

Heart failure's like that really and they're obviously very symptomatic. I think they must, I think you've got to tell those people what's going on. Like that lady really, didn't know she had anything wrong with her heart, she err people like that, it's not really that helpful to tell them I would say.

James D4<sub>p</sub>

This raises the issue of not just *what* but *when* to tell patients about a particular diagnosis. Brian D6<sub>s</sub> (a cardiology consultant) said he was trying to “tell everyone ... that their label is heart failure these days”, while James D4<sub>p</sub> (a GP) questioned this. This issue is of growing importance for other diseases, for example, renal failure is routinely detected when it is pre-symptomatic and predictive genetic testing is likely to become part of clinical practice. The problem of what might be called ‘creeping diagnosis’ is discussed by Tom D2<sub>s</sub> (a cardiology consultant) and analogous to laboratory results of chronic kidney diseases (CKD) supplied to GPs when they order U&Es.

One of the difficulties is that the, the heart failure diagnosis has been extended recently. Heart failure used to mean symptoms; heart failure used to mean breathlessness, ankle swelling, you know couldn't lie flat and all that kind of stuff and that was heart failure and those were the symptoms of heart failure. And, and that's caused by your left ventricle not pumping properly and what's happened is that as we've had techniques to investigate that, with echo and things, a huge number of patients have been unearthed where the left ventricles don't function properly, may be because of coronary disease, or hypertension or valve disease but actually they don't have much in the way of symptoms. They're not very breathless, you know they can have fairly normal activities and there's a kind of issue about whether you call them heart failure and most people tend not to call them heart failure.

Tom D2<sub>s</sub> (cardiology consultant)

The consensus position would seem to be that it is proper and useful to tell patients as much as possible when the medical facts are clear, unless there are exceptional circumstances. However, to do this effectively requires good communication skills and plenty of consultation time, which some professionals may lack. Therefore, in some circumstances telling patients little may lead to better outcomes than telling them more badly. In the context of patient-centred care this is hardly defensible. There are patients who truly want to know as little as possible, which can be acceptable but is increasingly

seen as undesirable. All patients should at least be asked a straight question about their knowledge requirements.

### 6.4.3 Care versus targets

Self management should move more healthcare out of institutions and professional control. In primary care at least, there is a debate about whether providing the greatest level of care available is best encouraged by appealing to the better nature of healthcare professionals or offering some sort of financial incentive (Roland, 2004). The ability to offer direct incentives is, however, somewhat limited for most professionals except GP partners and community pharmacists. These professions operate under NHS contracts the terms of which are occasionally renegotiated, and PCTs may commission local services directly from them.

All the professionals interviewed were salaried employees of the NHS except: Mark D3<sub>P</sub> and James D4<sub>P</sub> (who were GP partners); Geetha P1<sub>C</sub> and Susan P2<sub>C</sub> (who were employed by large retail pharmacy chains); and Felicity E2 (who was a volunteer). The rest of the primary care professionals were employed by a PCT and the secondary care professionals were employed by an Acute Trust. The PCT and Acute Trust have organisational targets based mainly around waiting times and financial management.

As you know with everything these days we're trying not to follow up everything long term. I mean we're trying to discharge everybody so people with hypertension, we're trying to discharge people with coronary disease; we're trying to discharge the heart, the bad heart failure patients are the ones you can't really discharge; you tend to keep them coming...

...we can't cancel the patients inside the 6 weeks ((appointment target)) but the flip side of that is that the clinic's actually made up for 6 weeks so the clinics for the next 6 weeks are fully booked so if somebody phones and says, "I'm sorry, I can't come on Thursday, can I come the next Thursday" well the reality is "I'm afraid not" because the next six weeks are booked. You know, and you can squeeze in emergencies if you have to as extra cases but because it is hospital and Government guidelines that you have to give people lots of notice and if you do that you lose the flexibility so it has to be 6 weeks really.

Tom D2<sub>S</sub> (cardiology consultant)

These targets lie behind the push of specialist services into the primary care setting (Department of Health, 2006). Retail pharmacies are businesses with complex objectives, but must have good cash flow or make trading profits to survive. An overriding profit motive can make clinical developments difficult, as the following quote demonstrates.

At the end of the day you know community is about running a business you're there to generate money and that and it's hard to put the two ((clinical and commercial)) together.

Susan P2<sub>C</sub> (area pharmacy manager)

Only the GPs faced personal financial incentives linked to their practice's overall performance in the QOF. GPs generally have been so adept at responding to these financial incentives that their average pay has increased substantially ahead of inflation in recent years. Consequently, methods of GP payment have received greater public attention but are probably still not fully appreciated by the public.

You're working in a shop they're know that you're about profit but because you're a doctor sitting in your surgery they think you work for the NHS and don't understand probably the way that doctors are remunerated.

Susan P2<sub>C</sub> (area pharmacy manager)

There was no suggestion in any *patient* interviews that GPs were motivated by anything other than patient welfare. So either this is true, or GPs are good at disguising any baser motives, or patients only want to see the noble side of professional life. Mark D3<sub>P</sub> (a GP) said that care was sometimes being driven by messages that flash up on the computer, that "It's turned us into robots" but also that "We would have been going for these targets anyway." This and the following quote suggested that the GPs believed targets didn't influence care outcomes but did influence the process of care.

Of course with our new contract a lot more of this time is spent reaching targets and doing what the computer tells us to do other than treating the patients any better.

Mark D3<sub>P</sub> (GP)

Targets are often expressed as the percentage of people on the chronic disease register that have certain interventions (for example, diagnostic tests and prescribing) recorded. Vanessa P4<sub>P</sub>, a pharmacist working on the PCT's behalf running clinics in GP surgeries, thought this did have an influence.

Within this Quality Outcomes Framework there is also a target for heart failure but expressed as LVD ((left ventricular dysfunction)) and (they're) only expected to see (those) currently on the CHD register (who) have LVD, so if they were just LVD on their own it doesn't encourage the practice to see those people. ((To ensure they are taking an ACEI, which is the target.))

Vanessa P4<sub>p</sub> (practice pharmacist)

Elsewhere, Vanessa P4<sub>p</sub> described as “unfortunate” those who had a chronic disease that wasn't “on the QOF.” It seemed to be Vanessa's opinion that GPs' standard of treatment for heart failure (or any other disease) would only improve consistently if it was made a greater financial priority. She saw GPs as a “private business” responding to whatever incentives were offered. Louise P5<sub>p</sub> had a similar role to Vanessa P4<sub>p</sub> and supported the idea that “QOF points” influence GP priorities; Dawn N4<sub>p</sub> (a modern matron) also stated that the QOF “tends to drive things.” Luke D5<sub>s</sub> (a respiratory consultant) believed these targets had an impact, but his quote leaves open the possibility that the impact is symbolic rather than substantive.

The GMS ((general medical service)) contract to the GPs actually specifies now that all new patients with COPD should have spirometry and it's one of the standards that they're getting paid for so there is a political driver now for that.

Luke D5<sub>s</sub> (respiratory consultant)

For an old (small) PCT, Nicola N3<sub>p</sub> (development nurse) estimated the costs of a nurse-led specialist heart failure service at £150,000, which might generate savings of £600,000. She gave the formalisation of care standards in the NSF for CHD (National Health Service, 2000b) much of the credit for developments in cardiac rehabilitation.

Oh definitely yes, and I think we have the NSF to thank for that, we have got the NSF to thank for everything that's happened within cardiology over the last what 8 years, 7, 8 years because that's certainly brought cardiac rehab to the forefront because prior to that cardiac rehab had always been a Cinderella service a service that was provided on good will and people doing things in their own time.

Nicola N3<sub>p</sub> (development nurse)

There seems little doubt that formal targets or standards, particularly those linked to incentives, can have a tangible and sustained effect on the process of care. The impact on outcomes is less certain. Targets are also imperfect for at least two others reasons. Firstly, treatment of a ‘targeted’ condition can push out treatment of an equally worthwhile ‘untargeted’ one. Secondly, unless carefully thought through targets can have unforeseen or perverse effects. Both these problems are seen with the GP QOF.

More QOF targets could improve the treatment of heart failure or even the general uptake of self management, but the true cost would take time to be clarified.

#### **6.4.4 Process versus continuity**

The landscape of care has changed considerably since the NHS was founded in 1948. Demands on the service are greater, the range of effective treatments is wider and the risks associated with inappropriate care are greater. The traditional GP who acted as sole carer for you and your family has more or less gone, although many older patients will have grown up with this model of individual care. Perhaps as a surrogate for this, both patients and professionals identified contact time and continuity as key factors in the success of a clinical consultation. Government targets on the other hand prioritise waiting time, choice and provider contestability (Department of Health, 2008b).

Patients wanted time to be listened to and wanted to see the same person more of the time. Professionals would need this time and continuity to develop more useful therapeutic relationships. Since the issue of continuity had been raised by patients as their most wanted service improvement, all clinical professionals were asked what they could do to provide it. Among the professionals interviewed, contact time and continuity were provided by both specialist heart failure nurses (medium to long term) and modern matrons (short term). However, one needed to be a patient with severe symptoms or high healthcare utilisation to warrant such personal attention. GPs did seem able to provide a degree of continuity but lacked contact time.

Consultants could routinely provide neither contact time nor continuity for most patients. However, patients also valued the level of expertise offered by consultants and the comprehensive medical tests in hospital. As a GP, lack of continuity in secondary care was of little concern to James D4<sub>p</sub>, but he recognised the concern of patients.

It doesn't, it doesn't bother me too much particularly ((continuity in secondary care)), continuity bothers me within primary care because that's becoming more of an issue now I think, especially as more primary care is hived off to perhaps private companies. There are ways around it in secondary care. The psychiatrists seem to do pretty well. If somebody is under the psychiatrist they tend to allocate them to

the registrar and then they discuss the cases afterwards. It's a lot easier for psychiatrists because they're dealing with a smaller numbers. There are probably some ways you can deal with it in secondary care and it must be difficult for patients, especially when they've been going to the hospital for a long period of time. I suppose if you've had a fairly brief episode of illness and you're just being investigated, it's a bit easier but if you've been going for ten or twenty years it's not ideal is it?

James D4<sub>p</sub> (GP)

Mark D3<sub>p</sub> (a GP), however, thought it unlikely that secondary care generally could perform any better than it already does.

I think it's impossible to get continuity of care in hospitals and I wouldn't expect them to alter that. I think the patients get the continuity of care with us and can use us to interpret what the hospitals have said and that's probably the best they are going to get really ... I'm providing the nearest they are they are going to get continuity of care really.

Mark D3<sub>p</sub> (GP)

There isn't a direct relationship between quality of care and continuity since a single carer may repeatedly make the same mistake or lack insight into a long standing problem. James D4<sub>p</sub> (a GP) highlighted both this and how continuity may be traded for faster access.

Yes, I mean it can be, I think it works most of the time. You can't, I mean it can be a bit of a problem, things can go the other way that if you're seeing the same person all the time, sometimes you need a fresh look at something don't you? ... The difficulty is if it's not somebody you know, you don't really know because we've got ten thousand patients here and particularly at the moment we've moved to a more advanced access system where people just book pretty much on the day really. There's been much more shifting of patients and continuity is not as good as it was so we are seeing more people you, you don't know, you've never seen before so it's difficult with those people.

James D4<sub>p</sub> (GP)

When continuity can't be offered, and even when it can, ensuring good process and procedures is very important. The two way relationship between process and continuity is also illustrated by Tom D2<sub>s</sub> (a cardiology consultant). He explained how experience allowed him to have a less procedural and more personal approach to the patient.

Well you're more procedural and you can follow the algorithms, sometimes you get down the wrong one you have to go back again and change, whereas actually

when you've, there's a limited number of responses, there's a limited number of ways that people describe heart failure symptoms and you get the impression very quickly whether this is or isn't so I think you know.

Tom D2<sub>S</sub> (cardiology consultant)

Regardless of the balance achieved the standard of inter-professional communication is of particular importance. Within a complex health system the speed, accuracy and completeness of written communication are vital. Long standing problems are beginning to be addressed by changes in professional practice (greater awareness of importance) and the roll out of universally accessible electronic health records.

I suppose continuity is a big thing because certainly when people are seeing different health professionals, nurses, healthcare assistants, pharmacists, GPs, there's so many different people in the surgeries, continuity is very important. I suppose also it's communication really as well between the people that are involved with the care as well and that is, often if it's secondary then the communications back to primary care are not always what they could be and certainly when people go to other clinics, the information we get back is not always complete. I can't think of anything else in particular really.

Louise P5<sub>P</sub> (practice pharmacist)

Within the secondary care system David P3<sub>S</sub> (a hospital pharmacist) also pointed out that understanding and communication skills are needed to "break down that perception of the patient as a patient versus a patient as a human being." Community pharmacy can and should offer a degree of continuity, but long opening hours and relatively poor working conditions often make this difficult as Susan P2<sub>C</sub> described.

The turnover is high, especially with the newer pharmacists, the newly qualified pharmacists sort of dipping their toes in the water, deciding what they want to do and that means that they do a job for a year and move on and it's very, very difficult to get continuity.

Susan P2<sub>C</sub> (area pharmacy manager)

Staffing problems were also apparent in secondary care, especially within a small specialist service like heart failure. Patients wanted continuity but services also need to be robust and reliable.

The other thing that's very frustrating is that there's me here, or there's two heart failure nurses here but it works out as one full time post because we both work part time. If either of us are on annual leave there is no cover, there is no clinic and there is no cover. That is not ideal. You need enough people to achieve continuity

to keep it tight, but so that if you are not here, if you are sick for a day, that person isn't going to lose out.

Sarah N1<sub>s</sub> (heart failure nurse)

Sarah's clinic may be easily disrupted. A traditional out-patient service is always on, or only off in extreme circumstances. To achieve this, the number of different professionals patients will be exposed to on repeat visits is higher. Patients disliked the changes in staffing and time wasted while waiting that is inherent in this model of care. Douglas D1<sub>s</sub> (an elderly care consultant) explained how clinical goals are monitored in such an environment.

They certainly do see different doctors, we change quite rapidly. My own clinics it is myself and usually two SHOs and the SHOs change every two to three months or even more frequently than that and so inevitably there will be, they won't be seeing the same person but when we see patients obviously we tape letters and what we are actually trying to do is to have a list of the patient's diagnoses and a list of the treatments, as a general impression of what we are trying to do and you know (the goals of) treatment last time, and say we've increased this or decreased that and (put down) blood tests, the results of that, so that hopefully it should be clear what the problem is and what we are trying to do about it.

Douglas D1<sub>s</sub> (elderly care consultant)

Training needs provide a major explanation for organising out-patients in the traditional way. The impact of training on continuity of care may be even worse for in-patients. A situation made more acute by implementation of European Working Time Directive, which limits the hours that individuals may legally work. More positively this should mean that the doctor the patient does see is less tired.

One of the difficulties is that part of our function as a teaching hospital is to train junior doctors so they have to see patients so that you don't really learn by sitting in with someone, you only learn by doing, albeit with supervision or whatever, so inevitably there will be junior doctors having to learn about different chronic conditions. It would never be possible to get away from that and with dealing with directives and hours and things it's, inpatients are even more bewildering you get a sort of the clinical team, it's bizarre, I mean sometimes a registrar and sometimes not, two SHOs, one doing nights, may not be nights may be holiday, houseman may be on nights, so there are mainly four people there, only one person there, may be two people and it'll vary continuously, never the same you see. All for very good reasons but it certainly cuts down continuity.

Douglas D1<sub>s</sub> (elderly care consultant)

Innovations to improve continuity therefore need to contend with organisation targets, legal requirements on working hours and the logistics of training. Placing training secondary to the care of individual patients may seem wrong. Nicola N3<sub>p</sub> (development nurse) pointed out that the specialist nurses required to expand access to heart failure services in primary care actually come from secondary care. Destabilising current training provision therefore presents a risk for all patients in the medium to long term. Making patients hold some medical records and be more responsible for elements of their care may help them to maintain the focus of different professionals. However, it is not clear how unwilling patients can be persuaded to place personally held goals at the centre of care rather than the wisdom of doctors.

#### **6.4.5 Dependence versus independence**

The dilemma faced between dependence and independence was one of the most contested and the hardest to characterise. Most patients did not regard themselves as being particularly dependent on anyone or anything, but there were those who said they could not cope without a particular medicine, person or service. Secondly, dependence itself is not necessarily a bad thing. We all depend on each other and a wide range of services to some degree. Healthy behaviour is not necessarily independent but rather resourceful, resilient and self-reliant. When professionals talk about dependence what they seem to mean is over reliance on them or the services they provide. This hampers their perceived ability to give all patients in need a fair share of healthcare resources, so the issue at stake may be justice rather than concern to make patients more autonomous.

Relatively asymptomatic patients often operated fairly independently from professional input but possibly with sub-optimal quality of life. The route to (generic) self management involves shifting the internal focus of these patients so they are happy to learn from (and risk dependence on) others. Another group of patients had a lot of professional input because of their symptoms and the goal of clinical self management would be to make them less physical dependent on healthcare. A further group of patients had psychological needs for professional contact that may make their presence in generic self management groups problematic. A final group had complex medical needs that may make clinical self management risky.

Changing the balance of management requires some dissatisfaction with current care and a belief that self help can make things better. This is easier to demonstrate for some elements of care than others. Sarah N1<sub>S</sub> (a heart failure nurse) found it relatively easy to discuss diuretic dose changes but not the titration of other medicines.

It's a bit different for some patients with the ACE inhibitor and beta-blocker titration, they tend to be happy on a dose and not want to change it and not understand why we would change the dose and not want a nurse to change it sometimes, they specifically want the doctor to change it.

Sarah N1<sub>S</sub> (heart failure nurse)

Even for those medicine doses patients are willing to change, initially more rather than less professional support may be required. This may explain why it seems so hard in practice to optimise doses (cf. **Section 5.2.6**).

If they ((patients)) want us to take that away from them ((the final decision on dose changing and call first for guidance)), if they are nervous about it, because a lot of this is self-empowerment isn't it, saying you can do this. If you have been taking medications for years and you've never perhaps had any control, the doctor tells me to take this and I take it, it's harder. Younger patients are much more eager to manipulate their own medications. Some patients have been doing it for years. No-one every told them to they just gradually got to know that they needed to, more or less.

Sarah N1<sub>S</sub> (heart failure nurse)

Nicola N3<sub>P</sub> (a development nurse) supported the idea of having someone to ring and ask for advice or support, but didn't think this level of service was needed out of hours. Moving away from professional control is something Sarah N1<sub>S</sub> (a heart failure nurse) saw as a clear advantage. Mark D3<sub>P</sub> (a GP) reported that this was difficult in his practice and he was not sure the outcome was desirable. In normal service hours he would prefer to deal with patients personally.

I often tell people to weigh themselves and then to come and see me, or if they have any increase in weight, and that's in a way giving them an attempt to participate in their illness but invariably they don't. I think by seeing them more often they get more dependent on me and they just come back and report how they feel rather than any attempts they've made to be involved in their illness.

**Do you see that as a problem? Would you like them to be more kind of independent, would that be a good thing?**

I don't like patients to be more independent and it may just be my personality, my either lack of trust in other people and I'm not, it doesn't certainly make me a

control freak, thinking I'm controlling all these patients but I do tend to be more concerned about or worry more about these people and it may be a lack of sort of, more of a loss of confidence, lack of confidence in my abilities, that I am seeing them more often and therefore can make sure I'm doing the right thing. But if it turns round that they become more dependent on me because of that.

**So you want to offer good care and you want to know what's going on and you want to have an awareness, but the down side of that is that people might?**

Lose the control.

Mark D3<sub>p</sub> (GP)

It seems hard for professionals to detach a decision about what would be best for the patient from decisions about their personal practice style and philosophy. As a psychologist Sally C1 took a much more patient-centred approach, but her task is a difficult one.

If they're struggling that usually suggests that the resources they're using at that time aren't helping perhaps as much have done previously so I might review with them what's worked in the past and why that's not working now and if there's some way of altering what they're doing a little bit to make it a bit more straightforward or whatever, as a psychologist we get quite a diverse training so you know I will use cognitive behavioural techniques so looking at the way people think about things how that affects the way they feel and therefore their behaviour ... however, there are another group of people particularly those who are at the later stage of the illness for whom the issues are much more existential so they're often talking about, or they can talk about what it's meaning to them personally to come to the end of their life. So I might (be doing) work around a life review with them. Which can be very emotional work can be very draining the person as well as for myself.

Sally C1 (clinical psychologist)

This suggests that what is essentially 'guidance counselling' on the direction of one's life might be better left to professionals (or lay people) without a vested interest in the patient's decisions. It might be hard for a patient to continue to seek clinical advice and support from a professional who takes every opportunity to discourage such behaviour. Aspects of dependence and independence are inevitable on both sides of a constructive relationship.

Generic self management training helps patients to determine what they want from professionals, why they want it and how to get it. Perhaps professionals need an equal

amount of help to get what they need from patients? Paterson reports that despite a drive to empower patients with long term conditions professionals frequently discount experiential knowledge and fail to provide resources for informed decision making (Paterson, 2001). In the context of asthma, Jones et al report disagreement between patients and professionals on the role of the “responsible patient” (Jones et al., 2000). They recommend training for professionals on behaviour change techniques and the development of management plans focused on individual patient need.

#### **6.4.6 Acceptance versus activity**

Those classified as ‘doctor trusters’ (**Section 6.2.2**) above seemed more likely to demonstrate depressive symptoms. Whereas these were relatively absent in those classified as ‘logical adopters’ (**Section 6.2.2**) and both types of ‘socialite’ (**Section 6.2.3**). Patients actively rejecting dose changing tended to have settled comfortable routines. ‘Doctor trusters’ sometimes claimed to accept their condition, but could be at the same time be frustrated (passively) by the activities they can no longer manage. Perhaps they hope for some improvement even if they do not expect it?

The possibility of improving symptom control by the proper use of medication was near the bottom of most people’s list of concerns. It was common to ‘accept’ the current level of physical function as a unalterable consequence of ageing or disease processes (see above) or make favourable comparisons with others. Ideas like this were expressed by Ethel 83, Rose 82, Edward 71 and Clara 86. For Edward 71 (below) and Rose 82 this coming to terms was a slow painful process following the initial shock of illness. However, gradual change could be accepted and reviewed less dramatically as a simple part of life (Ethel 83, Clara 86).

##### **How did it make you feel to become ill so suddenly?**

It was a shock. The first year after I was you know off ill, my mother was alive at the time, I used stand here on a morning...watch them going to work...The first year nearly killed me believe me and I mean that...I used to dash out on a morning to work and just to stand there at the window watching...God what have I done to deserve this, but there you are and of course you get used to it obviously. You know you have to so there you are you have to put up with it, get on with life.

Edward 71

Felicity E2 (an EPP tutor) also discussed the notion of acceptance among EPP participants.

And also the anger, fear and frustration; a lot of people don't address that, they get angry with the healthcare professionals but what they have to come to terms with is that they're angry with their illness or their restrictions and the changes in their lives and the course does allow people to do that and I think once they've done that they can then move forward because you've got that acceptance, right this is what it is, what can I do about it as apposed to being frustrated and getting nowhere.

Felicity E2 (EPP tutor)

Felicity E2 was talking about acceptance of limitation as a springboard to activity, but if patients (usually older) expect to have limitations, then accepting them may just lead them to focus on other issues that do seem modifiable. That is, a more usual response may be to work within capability rather than actively seeking to enhance it.

In patient interviews, most 'passive accepters' (**Section 6.2.2**) were older women and frustration at lack of capability was common among (but not confined to) younger men. Professionals noted some attitudes towards acceptance and activity that were related to gender. Sarah N1<sub>S</sub> (a heart failure nurse) described how a change in physical function badly affected men who acted as a traditional "bread winner" while his wife "stayed at home". Tom D2<sub>S</sub> (a cardiology consultant) thought men more likely to want "all out treatment and the aggressive treatment", whereas, "Yorkshire women in their 70s" might say "It's a waste of time and it's a waste of your time and it's a waste of money." Overall, he thought women more "realistic", but men wanted action and struggled with their emotions. Broad perceptions of differences between patients could also be related to age. Jenny N5<sub>P</sub> (a modern matron) thought young people more likely to want "some quality out of life". Sally C1 (a clinical psychologist) described how younger people may lack experience of ill health.

Yes and I think it's that, it's the fact that it's outwith ((outside)) the developmental reference point ((of much younger people with heart failure)). I mean, none of their friends are going through these symptoms so it makes it much more difficult for them to manage it and cope.

Sally C1 (clinical psychologist)

There are two recipes for inaction either believing something isn't a problem or believing something is such a big problem that nothing can be done about it. The middle

ground involves a belief that personal action can achieve desirable goals: both action and goals need to be clarified for individuals.

## **6.5 Chapter summary**

The patients suffered from a range of symptoms that were more or less disabling. A minority of patients (often those that were younger or in active work) found this extremely frustrating. They might resign themselves to inactivity (potentially suffering depression) or try to fight against it. The majority of patients (usually those older or less active) were able to more easily accept limits on their activity. When symptoms became troublesome they would rest and only seek professional help if the symptoms were severe or persistent.

Both generic and clinical self management would offer patients a different way to view their symptoms and lifestyle. The components of clinical self management were more or less acceptable to the majority of patients, and professionals believed that a wide range (but perhaps a small number) of patients were suitable for clinical self management. However, the tangible benefits of clinical self management were greatest for those with the worst symptoms or the greatest healthcare utilisation. For many patients the costs were much more apparent, and the required investment of time and energy may not be obviously worthwhile. The components of generic self management (chiefly group work) were less acceptable to patients but probably of greater potential benefit to most.

Adoption of either type of self management requires a fundamental joint reappraisal of patient and professional responsibilities. There is no single right or wrong way to proceed, and this reappraisal would be better if individualised. Professionals and their organisations probably lacked the willingness and/or capacity to both explain and provide truly individualised care.

## 7 General summary and conclusions

The main purpose of this chapter is to summarise the empirical findings in this thesis (**Chapters 4 to 6**), and provide conclusions for healthcare policy, practice and research. I try to summarise, amplify and explain what I consider to be the key findings, without necessarily repeating all the previous summaries and conclusions. There is extensive cross referencing to the previous chapters. In **Section 7.1** the importance of the topic is reviewed and key points from the current literature are highlighted. In **Section 7.2** the aim and objectives, chosen methods and study limitations are discussed. In **Section 7.3** key points from the empirical findings are summarised and a unified explanation for the pattern of findings is offered. In **Section 7.4** a list of action points for healthcare practice is provided. In **Section 7.5** priorities for future policy and research are suggested. **Section 7.6** offers a brief personal final reflection.

### 7.1 Study focus and current literature

The focus of this investigation was the self management of chronic heart failure by patients living in their own homes and routinely cared for in a primary healthcare setting (**Section 1.1**). This was the focus for four main reasons:

- observation in the secondary care setting highlighted a large number of potentially avoidable hospital admissions for people with heart failure;
- clinical and generic self management had been suggested as a way to avoid these admissions (alongside other elements of comprehensive disease management);
- the uptake of self management appeared to be limited and growing only slowly;
- research on self management had tended to focus on patients from clinical research studies, volunteer programmes and secondary care settings.

Despite the passage of time, the focus remains as important today (if not more so) as it did when the study began. The potential clinical and psychological benefits of self management were well known (**Section 2.1** and **2.5**). However, healthcare policy has now firmly integrated self management as part of an agenda that promotes choice and personal responsibility for health (**Section 2.6**). I defined *clinical* self management of heart failure as involving the patient in the following tasks, which are closely related to normal medical practices:

- monitoring signs and symptoms, for example, weight gain;
- recording chronologically any changes in signs or symptoms; and
- taking diuretics to normalise these signs and symptoms.

In addition, patients can be trained in peer groups, by lay facilitators, to participate in *generic* self management activities, which include setting themselves functional goals and making better use of professional consultations.

The existing evidence suggested that:

- heart failure patients' general health knowledge and knowledge related to self management was limited (**Section 2.2**);
- patients suffered from a range of symptoms that they did not properly understand and could not effectively cope with (**Section 2.3**); and
- the implementation of clinical guidelines for heart failure (including aspects of self management) by professionals was variable (**Section 1.3.3 & Section 2.4**).

These conclusions are all supported by and consistent with the findings of this study.

The literature was limited in its consideration of heart failure patients receiving general rather than specialist care; and said little about the attitudes of professionals towards self management (**Section 2.7**). Suggested solutions to identified problems tended to be fairly general (for example, better education), rather than focused on the specific reasons why people think and act as they do.

## **7.2 Aim, methods and limitations**

The aim and objectives (**Sections 3.1 and 3.2**) were deliberately broad in scope to capture the full range of participants' relevant experiences and potential influences on future healthcare. Qualitative methods were believed to be particularly appropriate so that a 'thick description' (cf. **Section 1.2**) of experiences could be obtained and interpreted in context (**Section 3.2**). This allows us to understand how people make sense of what is happening to them within a network of social relationships. One-to-one interviews focused first of all on the experience of symptoms (for patients) or providing

care (for professionals); and then moved on to opinions about selected aspects of self management (**Section 3.3.2** and **3.3.3**).

Healthcare created when patients and professionals interacted, and research data created when I interviewed participants were both considered to be constructed realities (**Section 3.2.1**). As previously explained (**Sections 3.2.2** and **4.1**) this investigation took on the characteristics of a case study, which wasn't the initial research design but was nevertheless appropriate and productive. At the heart of this case study are patients from a *single* GP surgery in a relatively deprived area close the centre of a major city (cf. **Sections 3.3.1** and **4.1**). This may call the wider applicability of the patient related findings into question. However, the practice workload (patients per GP) was in line with the national average for England (cf. **Section 4.4.1**); and we see nothing in the comments of professionals from outside the practice to indicate that the patient views expressed were atypical. It was always the intention to interview patients who were not predominately from higher socio-economic groups or natural participators. Patients' experiences led me to interview a wide range of professionals from the local healthcare economy. Justification for my view of the wider applicability of the findings is found in in **Section 3.6.2**.

In bringing together different sources of information to create the data for investigation I sought triangulation (**Section 3.3.2**) and exhausted the pool of potential participants. Patient recruitment was purposive, based on clearly defined inclusion and exclusion criteria (**Section 3.3.2**). Professional recruitment was theoretical, based on direct links to patients, involvement in service development initiatives and a desire to seek views from the main professional groups (**Section 3.3.3**). It proved hardest to recruit community pharmacists and primary care nurses. In hindsight, informal carers and practice managers could have been recruited, and more research could target these groups. The range of views expressed among both patients and professionals, from antipathy to empathy, suggests that the interviews captured most possible viewpoints.

I do not claim that the views of the sample are representative in the ordinary (quantitative) sense of precisely matching the prevalence, preference or strength of preference that might be found in the population. However, the themes identified are likely to be representative, and the detail provided allows their external relevance to be judged. My aim was to move beyond a descriptive account of specific interviews. The themes are located in theory (emerging and existing) and the empirical literature. The specific or unique contextual issues of most significance seemed to be personal rather than organisational. Therefore, the characteristics of participants (**Sections 4.4** and **4.5**) are important for those deciding if the results reported here have relevance in their own situation. Very few of the issues identified by participants appear to be dependent on the *particular* structure and organisation of local services. The organisational context is typical of the sector, for example:

1. Patients discussed assessment for social care services, but similar assessments take place in other MDCs within national guidelines (**Section 4.4.3**).
2. Professionals discussed the transfer of care between primary and secondary settings, which is typical in the NHS (**Section 5.2.3**).
3. The symptoms and functional restrictions experienced by patients were typical of those described in the clinical literature (**Sections 4.4.2** and **6.1**).
4. The extent to which prescribing was optimised left room for improvement, as suggested by national service review (**Sections 1.3.3** and **5.1.2**).
5. Local developments in primary care heart failure management had so far been concentrated in neighbouring localities (not the locality investigated).

These examples imply general applicability limited to similar urban areas in England at an early stage of heart failure service development. Wales and Scotland now have significantly different systems of health and social care. In less densely populated and/or rural areas it is very likely that (among other things) transport and the logistics of specialist care provision would have been more important issues.

The perceived limitations of my study depend somewhat on the readers' point of view and preferred methodology. From a purely positive and/or quantitative perspective one might find the findings and discussion interesting (as a narrative) but unreliable.

Qualitative researchers do not tend to have a shared view of the world, even though they share methods. So the work could be fundamentally criticised from a number of alternative qualitative perspectives. Even as ‘case study’ we see little agreement in the literature about quality criteria (Yin, 2003) (Stake, 1995). In **Section 3.6**, I present the quality issues as I saw them (including consideration of alternative perspectives) and describe my attempts to ensure rigorous and reliable analysis.

In hindsight, I am not personally disappointed with any of the fundamental choices I made as the empirical work progressed, even when some of these choices were influenced by events outside my control. It would have been helpful to confirm the NYHA classification of patients, since the initial application of the inclusion criteria was done for me by the GPs. It was also difficult to recruit clinical staff (other than the GPs) from the practice at the heart of the study. I failed to consider the recruitment of administrative staff, which could have been novel and valuable. A period of time embedded in the working life of the practice and observing people at work may also have been valuable. I could also have obtained further documentary evidence such as QOF performance and comparative prescribing data. The study has probably been completely over too long a period, due to my other professional and personal responsibilities. I think it would have been beneficial to complete the data collection and analysis over a shorter and more intensive period. Perhaps the scale of the study (number of participants) should have been larger and the scope more narrowly defined.

### **7.3 Key findings**

In presenting these key findings, I relate them to the existing literature (where appropriate) and I also use them to offer a commentary on current policy and practice. This minimises the simple repetition of findings previously summarised and is in keeping with an interpretive approach to qualitative analysis (Silverman, 2006). I make more specific suggestions for practical action (change in practice, new policy and required research) in the following sections (**Sections 7.4 & 7.5**).

As my findings show, when ill, these patients’ expectations of treatment and prognosis seem to be managed in a number of ways, for example, with regard to:

- the nature and severity of symptoms (**Section 6.1**);
- the care environment and type of referral (**Section 5.2**);
- the personality of professionals they interact with (**Section 5.2**);
- verbal and written information provided, especially verbal (**Section 5.1.3**);
- comparison with social contacts of a similar age (**Section 6.1.7**).

Unless explicitly told otherwise or symptoms persist, patients assume that their problems can be adequately managed simply by doing what they are told by professionals, for example, taking medicines, having a healthy diet or giving up smoking (**Section 5.1.2**). The relative levels of adherence found to different self management behaviours (medicines taking highest, diet restrictions lower, daily weighing lowest) are consistent with the existing literature (van der Wal & Jaarsma, 2008) (**Section 2.1.2**).

The findings show that patients trust doctors (especially GPs and consultants) and value the continuity that a long-standing relationship with a professional provides (**Section 5.2.1**). This is consistent with findings from systematic review that effective doctors are warm, friendly and reassuring (Di Blasi, Harkness, Ernst, Georgiou, & Kleijnen, 2001) (**Section 2.1.3**). However, it was common practice for professionals *not* to be explicit with patients about the name of the illness or its prognosis. Many heart failure patients seem to be consciously denied clear accurate information that is offered to others: this has been shown previously (Barnes et al., 2006) (**Section 2.4.2**). The lack of information provided was demonstrated in the patients' lack of knowledge. Patients awareness of symptoms was good (**Section 6.1**) but many could not link these symptoms to heart failure; which is perhaps one of the first steps towards better understanding of their treatment (**Section 2.2.2**) These low levels of knowledge are consistent with previous qualitative reports (**Sections 2.3.2. & 2.3.3**). There are few reasons or incentives for patients to ask questions about their diagnostic labels, but hospital doctors are perceived to carry out more tests before taking action (**Section 5.2.2**). Patients' perceptions of communication difficulties between primary and secondary care are quite widely reported (for example: Preston, Cheater, Baker & Hearnshaw, 1999). A view that patients may be willing to trade quality and effectiveness (which was best demonstrated by secondary care) for continuity of

relationships (which was best demonstrated in primary care) was also apparent in the findings. I think that a diagnostic label (if it was given) might help patients in a number of ways, for example:

- to search independently for more information if required;
- to explain their symptoms to social contacts; and
- to prepare them for the possibility of future deterioration.

When asked about what they knew about their health problems, only nine patients expressed a good functional understanding of heart failure and only three directly mentioned 'heart failure' (**Section 5.1.1**). Professionals often admitted that their explanations were not as clear or direct as they might be, perhaps because they were uncertain of what to say or they lacked the time to say it properly. Similar findings are discussed by Barnes et al (2006) (**Section 2.4.2**). Consequently, most patients' knowledge is poor because they have been told little, not because they have forgotten lots or lack capacity to understand. Professionals were often careful about what they said to patients because they were unsure of the prognosis. They thought that news of 'heart failure' would drain hope and serve no practical purpose. However, specialists dealing with symptomatic patients were more likely to consider time spent explaining heart failure a worthwhile investment (**Section 5.1.1**). Maintaining hope as heart failure progresses along its uncertain course is reported elsewhere as an important aspect of clinical care (Davidson, Dracup, Phillips, Padilla & Daly, 2007).

A brief review of prescribed medication suggested possible under-treatment with ACEI and beta-blockers (**Table 5.3**), which are key components of evidence based care (**Section 1.3.3**). This under-treatment is expected (**Section 2.4.3**) but the fact that prescribing remains sub-optimal should be a concern for patients, their professional carers and health service managers. Changes to the QOF will reward GPs for co-prescribing ACEI and beta-blockers from 2009/10 (NHS Employers, 2009). Despite a lack of knowledge, patients' reported adherence to medication they were prescribed was good (**Section 5.1.2**) as expected (**Section 2.1.2**). Patients exhibited some self management behaviours when they adopted personal systems to promote medicines adherence and varied the timing of diuretic doses for social reasons (**Section 5.1.2**). Such behaviour has been previously reported (**Section 2.3.2**). High levels of reported

adherence seemed most closely related to high levels of trust in prescribers. Trust is considered an important part of healthcare (Gilson, 2003) and Simpson et al (2000) reported an association between trust and medicines adherence in heart failure (**Section 2.3.3**). Another qualitative study in the US focused on medicine adherence in heart failure (n=19, 9 male, care sector and stage of disease unclear) and concluded that influencing factors were: a desire to be healthy; making connections between medicines and symptom control; and positive relationships with doctors and family (Wu et al, 2008). In a Swedish survey (n=302) run as a sub-study of a large heart failure RCT (COMET) belief in medicine effectiveness was associated with adherence (Ekman et al, 2006). In the context of another chronic condition (IBD), Nguyen et al (2009) report trust-in-physician, increasing age and worsening health status as indicators of adherence.

Patients were typically unsure precisely what their medicines were for, which has been previously reported (in heart failure) by Rogers et al (2002) among others (**Section 2.3.3**). Patients in this study were, however, happy to accept that medicines were necessary and took the (relative) absence of symptoms as evidence of effectiveness (**Sections 5.1.2 & 6.1**). Lack of information probably leaves patients with little option other than to trust the doctor's judgement in this regard. The impossibility of shared decision making without initial sharing of information has been previously established (Stevenson, Barry, Britten, Barber & Bradley, 2000). Ultimately, therefore, a desire to maintain hope (by withholding information) may lead via trust to dependence. Patients may become dissatisfied with professional care when symptoms are uncontrolled or unexplained (**Section 5.2.3**). An Australian study demonstrated that for older heart failure patients (n=205, aged 60 or over) dissatisfaction itself was not related to readmission to hospital (Candlish, Watts, Redman, Whyte & Lowe, 1998). Patients in my study commonly accepted ageing as an explanation for a range of symptoms and general deterioration in health (**Section 6.1.7**), which is consistent with coping strategies previously described (**Section 2.3.5**).

Lack of knowledge and communication mean that patients expect and are expected to rely on professional management (**Section 5.1.1**). Patients were happy to choose and change a GP (or more frequently a community pharmacist) and expect that person will

do a good job until a problem or crisis proves otherwise (**Section 5.2.1 & 5.2.4**). Qualitative and quantitative studies suggest that in England patients who change GP without changing address most often have accessibility issues, but may also have encountered problems with practice organisation, staff attitudes and/or clinical care (Billinghurst & Whitfield, 1993) (Gandi, Parle, Greenfield & Gould, 1997). No information is easily available on why patients choose to change their community pharmacist. However, no registration with pharmacies is required and choosing a pharmacy for geographical convenience (as reported in this study) is considered routine. Pharmacies now almost always have repeat prescription collection (from GPs) and delivery (to patients' homes) services to help retain regular customers.

To participate in clinical self management, better understanding of diagnosis and treatment would be required. With this knowledge patients would also be better able to monitor current care and self management activities. For example, patients might be more able to: check they are having necessary blood tests at the recommended frequency; judge the safety of their own diuretic timing adjustments; and be more accepting of professional attempts to titrate ACEI doses. Since patients in this study tended to be more satisfied with the clinical quality of secondary care, enhanced patient knowledge may present a greater threat to primary care professionals. Without more knowledge patients' capacity to make safe independent decisions or understand changes to treatment is restricted, and dependence is encouraged (**Sections 6.4.2 & 6.4.5**). In a Dutch cohort study (n=501 consecutive patients hospitalised with heart failure) knowledge was more strongly related to adherence with self management behaviours than beliefs (van der Wal et al, 2006).

Patients managed symptoms not diagnoses, perhaps because they lacked clear clinical information, and made no distinction between the short and long term goals of treatment (**Section 5.1.2**). The current literature is almost exclusively focused on engaging patients in short term management of symptoms that could lead to hospitalisation (**Sections 2.2.3 & 2.3.4**), rather than longer term management that could have an impact on mortality. The latter is clearly seen as a professional priority (**Section 1.3.3**), but as professional performance is sub-optimal (**Table 5.3 & Section 2.4.3**) perhaps a role for patients could be considered? Patients did not generally want more knowledge or

clinical responsibility, but would often accept these things if offered by a doctor that they trusted (**Section 6.2.2**). Existing literature suggests that a preference to delegate decisions is widespread and stronger when the significance of the decision is greater (Joffe, Manocchia, Weeks & Cleary, 2003).

An offer of greater clinical involvement (by doctors to patients) would at least imply that current care is sub-optimal and that improving care was in part the patient's responsibility. Presenting to patients an argument for the (economic) efficiency of self management rather than its (clinical) effectiveness might challenge their current assumptions about care less. However, efficiencies would only be apparent (if at all) in the longer term. Professionals would need to coordinate patient communication to avoid confusion. Multi-disciplinary care has been shown to be effective for heart failure and other chronic diseases, but the literature often concerns intensive short term programmes with specially trained staff (cf. **Sections 1.3.3 & 2.4.1**). We know little about the (potentially conflicting) information patients receive in daily contact with different professionals. However, in this study professionals professed a range of views on desirable attributes of care, which could produce conflict if they were all actively promoting their particular vision. We do know that increasing numbers of patients seek information from the internet when that provided by professionals is inadequate (McMullan, 2006). Just one or two examples of this were provided by the patients I interviewed. Providing more information from the start of a care pathway could increase patient's overall consultation time, at least initially (**Section 6.4.4**). However, making medical notes available to heart failure patients has been shown not to increase consultation time despite doctors concerns that it would (Earnest, Ross, Wittevrongel, Moore & Lin, 2004).

There would be little or no (philosophical) resistance from patients to the regular monitoring and recording of signs such as weight. Even though such behaviour was (in this study) and is reported to be uncommon (**Sections 2.3.4 & 2.3.5**). For practical reasons monitoring weight would be difficult or impossible for some patients. I know of no study specifically designed to increase the prevalence of patient generated and held records of weight, except as part of more comprehensive self-management where take up is variable (**Section 2.4.1**). To sustain monitoring activity it would need to have a

clear purpose. So patients would need to use the data generated to change their own diuretic doses (which may not be frequent if they are usually asymptomatic) or professionals would have to review it as part of regular consultations (**Section 6.2.1**). Since patients typically only have a relatively short time in each consultation, the review of an objective record of signs or symptoms may be a useful practical focus for sharing information between patient and professional.

Changing diuretic doses according to agreed instructions was actively resisted by some patients (active rejecters) and only passively accepted by most (doctor trusters), a minority saw it as practical and logical (logical adopters). In practice, the ‘doctor trusters’ may not trust themselves very much, and may call on professionals to validate intended actions. This was common and even encouraged in the early stages of specialist heart failure management (**Section 6.2.2**). Like providing more detailed information for patients, providing a back up service for self managers could lead to a short term increase in professional consultation time. Certainly GPs’ fears of increased consultation time are now one reported barrier to the development of self management (Blakeman, Macdonald, Bower, Gately & Chew-Graham, 2006).

Patients were most resistant to group work with peers, which often forms part of self management training and rehabilitation programmes (**Section 2.4.1**). Concerns were raised about the potential for patients at different stages of disease to frighten each other. The only people keen on group work wanted to meet others for social reasons or thought others could learn from their experiences. Therefore, group work would have to be carefully managed or participants thoughtfully selected (**Section 6.2.3**). Studies do show patient satisfaction with group work (like the EPP) that has been delivered to selected individuals (Kennedy, Reeves et al., 2007) (**Section 2.5.3**). However, unselected patients’ *a priori* attitudes towards group work (and the consequent impact on care) do not appear to be widely considered in the healthcare literature concerning chronic disease management, rather group activities are assumed to be beneficial for all. There are exceptions in which user views guide support activities, for example, in HIV care (Visser & Mundell, 2008). A conceptual framework to guide research and practice has been offered (Schopler & Galinsky, 1993). The composition of self help groups has also been investigated. It was found that patients with diseases viewed as stigmatising

were most likely to seek mutual support and that patients with heart disease were among those least likely to talk to other about their condition (Davison, Pennebaker & Dickerson, 2000).

Enhancing patient knowledge about health is necessary to support any greater involvement in disease management. A working assumption used by most professionals I interviewed seemed to be that patients want to know little unless they clearly state otherwise (**Section 6.4.2**). However, we see in my findings and the existing literature that: professionals' ability to judge individual patient preferences may be poor; and patients' expectations can be unrealistic (Robinson & Thomson, 2001). Professionals should more actively seek preferences and manage the expectations of patients (**Section 6.3.4**). Clinical self management may only benefit a minority of the most symptomatic patients, and the skills required may be more easily explained when they are actually needed (**Section 6.3.3**). Group work, which is resisted the most, may actually have the greatest capacity to benefit the greatest number (at any stage of disease) if it can be adequately organised. Consideration should be given to involving patients in the design of group activities.

The individual key findings are generally not novel or surprising (though some are), yet they are critical of some aspects of current policy and practice (cf. **Sections 7.4 & 7.5**). The lack of support for group activities may be explained by the initiative naivety in my sample of patients. They have not been encouraged to share and then internalise their healthcare problems; nor do they necessarily want to establish relationships outside their established social circle, which are based on shared ill health. They are more inclined to rely on professionals taking responsibility for medical matters, but are willing to take on certain medical roles. Those capable would look for professional encouragement before becoming engaged in more active disease management, but my findings suggest that patients were unlikely to be offered such encouragement routinely.

The case study approach presents these findings in context as they relate to particular patients, with a particular disease and in a particular location. It may, therefore, be easier to see how competing pressures produce the (relatively) stable state we see as

common or usual practice. The difficulties of ensuring consistent and beneficial changes in practice are also clarified. At an individual level better care requires more mutual understanding and constructive discussion between patient and professional. Studies such as this one can help to raise awareness of the agendas that will be uncovered when the actors actively seek engagement with each other.

#### **7.4 Recommendations for practice**

The Department of Health's general model for the management of long term conditions includes: supported self care; consistently applied disease specific protocols; and individual case management for identified "high intensity" users of unplanned secondary care (Department of Health, 2009c) (cf. **Section 1.4.2**). These graded levels of support are deemed necessary to deal with the increasing burden (clinical and economic) of long term conditions in an aging population (Department of Health, 2009c). I agree, to a large extent, that both that the model of care is appropriate and that the justification presented is sound.

However, reading available Department of Health guidance (for example, documents listed in **Appendix 10**) reveals some fairly consistent, but unhelpful, attributes:

- patients' views on self care are claimed to be in accord with public policy concerning, for example, choice and responsibility for health;
- it is assumed that professionals are at least willing (if not yet able without development support) to make the suggested changes;
- empirical evidence is only presented if it supports the suggested changes; and
- case studies focus on the characteristics of success stories rather than the reasons why implementation may be delayed (which it often seems to be).

The Wanless Reports (Wanless, 2002 & 2004) published by HM Treasury are exceptional in assessing future states of the world in which people have not engaged with public policy. While supporting the main thrust of what the current Government (and its likely successor) hopes to achieve, I seek to provide a realistic assessment of those factors that could and (sometimes) should hold back full implementation.

In my opinion, current policy fails to examine sufficiently the communicative aspects of healthcare, that this, the way continuously developing personal relationships influence the provision of services. The reasons for the lack of engagement that Wanless (2004) considers may, therefore, be subtle and deeply contextual. Many people (including most of the patients I interviewed) have never had the case for increasing self care presented to them. Those that understand a desire to promote self care, may nevertheless think it is inappropriate in their personal circumstances. A failure to consider the subtleties and complexities of peoples' real lives (both personal and professional) means that the promise of self care may not be realised (cf. Wilson et al, 2007). Future blame for this may be placed (by policy makers) at the door of patients and professionals who have 'failed', rather than a policy that has the inherent flaws I have outlined.

We see in this study and elsewhere that patients naturally self manage to some extent, but this is limited by health knowledge and perceived competence (cf. **Section 2.2.3**) (Riegel et al., 2004). The professional promotion of self management seems (curiously) to be a second line activity suggested when standard clinical care is failing or of limited effectiveness (**Section 6.3.4**). Patients themselves are also prompted to enhance self management behaviours when clinical care seems not to be working (**Section 6.4.1**). Professional specialists in the managed health service seem to be more supportive and aware of the potential of self management than their generalist colleagues who are independent NHS contractors (**Section 6.3.1**). However, it is generalists who: are in more regular contact with patients; provide more continuity of care; and who could most effectively encourage self management from the earliest opportunity (**Section 5.2.1**).

Patients claimed to be adherent to medicines largely because they trusted the prescribing GP, if GPs are willing I believe they can build on this trust to facilitate change in patient behaviour. This study demonstrates that professionals generally tend to underestimate the willingness and capacity of their patients to change current behaviours (**Sections 6.2.4 & 6.3.4**). To encourage dialogue a rationale for change should be clearly elucidated (Wissema, 2000). If self-management has a more prominent place in practice then it is important to both identify that place and facilitate timely movement towards it. However, practice change should only be promoted if it is cost effective, that is the

costs of change are outweighed by the value of the potential benefits (Severens, 2003) (Wellingham, Tracey, Rea, & Gribben, 2003).

One major downside of change is that many patients' current acceptance of health limitations as a function of aging (**Section 6.1.7**) has the utility of protecting mental health (**Section 2.2.4**) (Gottlieb et al., 2004). Asking patients to enhance self management may risk some aspects of mental health for the *possible* increase in physical health and other aspects of mental health. The patient's response to a proposal to self manage might then depend on their attitude towards risk and their personal valuation of different aspects of health. The acceptance of poor physical health seems to imply that it is already heavily discounted by older patients in particular, that is, they value it less highly and perceive it to be outside their locus of control. However, mental health continues to be highly valued for longer and considered under the influence of personal agency at least to some extent (**Section 6.1.6**).

I found that professionals also tended to value the mental health of patients very highly and demonstrated practice styles that maintain hope. I have described this as disavowal (**Section 2.3.5**) (Buetow et al, 2001) (that is, positive re-framing of health information) *on behalf* of patients rather than through the patients' direct agency (**Section 5.1.1**). It is possible that the prevailing culture causes patients and professionals to collude in 'hoping against hope' (Romans 4:18) in many consultations about serious threats to health, although the type of analysis I have conducted could not demonstrate this. It is possible to say that maintaining hope without active open consideration of the known (and uncertain) issues (found also by Barnes et al, 2006; **Section 2.4.2**) precludes other opportunities to develop patients' own strategies for disavowal and their self efficacy (**Section 2.5.2**) (Bandura, 1997). Current practice may save time, but is paternalistic (**Sections 2.1.3 & 5.2.1**). More honest (and equal) engagement may be worthless and sterile if patients' informed choices cannot then direct the use of healthcare resources (**Section 2.6.1**) (Le Grand, 2006).

Notwithstanding these issues and difficulties, we can draw up a practical short list of options (from which patients and professionals may choose) that relate to the improved management of heart failure:

- do nothing, continue with present management;
- optimise dose of long term medication;
- involve patient in symptom monitoring;
- professional adjustment of diuretic doses;
- patient adjustment of diuretic doses;
- encourage generic self management.

We are faced with dilemmas about:

- encouraging professional awareness of all these options;
- if, when and how to present these options to patients;
- how to best support option selection by patients or professionals;
- how to provide practical support for the options(s) selected;
- how to ensure that the costs and benefits are monitored.

The resolution of these dilemmas lies in the establishment of good organisational systems and better interpersonal relationships, that is, action from the top down and the bottom up. This is consistent with recommendations previously made for GPs who wish to support self care activities (Greaves & Campbell, 2007) (**Section 2.4.3**) At the highest levels, there is no shortage of policy with respect to the management of long term conditions (**Appendix 10**) (**Section 1.4.2**) (Department of Health, 2009c) or specific guidelines with respect to the treatment of heart failure (**Section 1.3**). However, there is evidently great variation in local awareness about central initiatives and (more importantly) the way in which different actors actually amend their daily routines in response. Collectively, care processes and outcomes remains un-optimised, yet individual actors aren't behaving irrationally from their own perspectives.

Perhaps if the 'world views' of patients and professionals were opened up (that is, they were encouraged to adopt broader perspectives) more positive change would be

facilitated? This would mean encouraging people to openly consider feelings of adequacy for (potential) future roles and fears about the negative consequences of change. However, professionals should not simply ‘dump’ the truth on patients; disclosure should be planned and purposeful (**Sections 5.1.1 & 6.4.2**). Policy often sets out an ideal, which is some way from actual practice, for example, that all patients with long term conditions should have a personalised care plan (Department of Health, 2009d). Implementation varies greatly in effectiveness (Foy, Eccles & Grimshaw, 2001), but must start with the situation as it is on the ground, rather than as it may be in the fullness of time. It was clear from the interviews that for most patients their GP or consultant was the most trusted source of medical advice, the importance of this trust is well documented (Pearson & Raeke, 2000).

So I place professional awareness at the top of the list of dilemmas given above. The most popular (and perhaps reliable) way to communicate health advice to appropriately selected patients is via a professional carer that they trust and see regularly (Hesse, Nelson, Kreps, Croyle, et al, 2005). Mass media communication (for example: social marketing, reports in newspapers) is untargeted by definition and widely used, but not generally perceived as trustworthy. (Brodie, Kjellson, Hoff & Parker, 1999).

Communication via selected patient support groups will necessarily miss uninvolved patients, who are likely to be in the majority (**Section 6.2.3**). Both mass media and group communication risk spreading misconceptions that cannot be immediately corrected. Some group members may be active agents of misconception (**Section 6.2.3**). Mass media is at least passive and regulated by various independent agencies. Enhanced self management would provide patients with opportunities (which they currently lack) to apply interactive and critical health literacy (**Section 2.2.5**) (Nutbeam, 2000) in a controlled context; and move up the levels of medical knowledge identified by Field et al (2006) (**Section 2.3.3**).

From within the technical options available, I believe patients should be free to choose those most desirable, with as much or as little help as they want from their professional and unpaid carers. Professionals should implement or support the options selected to the best of their ability and within the resources allocated by the State, providing the effort involved does not compromise the duty of care they hold for other specific individuals.

This philosophy may differ from common practice in that I believe all patients with capacity should at least be aware that there are options they can select from, even if they choose not to. It may differ from the policy ideal in that I believe most patients will not want complete independent responsibility for their health. If patients did have individualised management plans, then this would make clear inter-professional communication very important. The whole professional team should be able to support the patient, who is herself in a good position to monitor and direct the help received. Support should be responsive to fluctuating need and capacity (**Section 6.1**), which adds to the practical problems of providing healthcare. Telemonitoring or automated checks on clinical signs and symptoms may help, but the benefits and cost effectiveness of this are as yet unclear (Louis, Turner, Gretton, Baksh & Cleland, 2003).

Individualised care is consistent with the Good Practice Points (GPPs) found in NICE CG5 and SIGN 95, which were summarised in **Section 1.3.3**. There seem to be quite serious problems implementing all these GPPs, in comparison to the more clinical interventions supported by higher grades of evidence. Perhaps this shouldn't be surprising because prescribing a particular medicine (for example, an ACEI) constitutes a relatively well defined intervention clearly within a doctor's competence, whereas many GPPs (for example, being more open about prognosis) require more complex intervention and greater psycho-social awareness. Doctors would have to engage more actively in the patients' processes of adaption to the disruption of chronic disease (**Section 2.6.2**). However, whereas many clinical interventions are only proven for patients with heart failure caused by LVSD, many GPPs seem sensible for all types of heart failure. The actual cause of heart failure was not easy to determine from the general practice records I examined and clarification would probably be helpful.

If more self management is encouraged, then (relatively independent) primary care professionals perhaps face the most significant changes to their routines and practices. The establishment of effective organisational systems means the giving up of some professional autonomy (Mathews & Pronovost, 2008) and the development of self efficacy in patients means loosening the ties of dependence. Secondary care professionals employed in large complex organisations and have already ceded more autonomy to systems, which they often want to work more efficiently. Nor do

secondary care professionals define effectiveness (particularly) in terms of longer team continuity of care and the quality of relationships. The optimal titration of all prescribed medicines also needs to be achieved (**Section 5.2.6**). I believe this would be easier if patients were more involved in their care, and understood the difference between medicines prescribed to control symptoms and medicines prescribed to prolong life.

## **7.5 Policy and research**

This study found that self management of heart failure was being implemented in two main ways:

- clinical self management is encouraged for relatively symptomatic patients who consult specialists or attend heart failure management clinics, but sometimes the instructions they receive may be a little *ad hoc* (**Section 6.3.4**); and
- motivated patients (at whatever stage of disease) can refer themselves for generic self management training in the EPP (**Sections 2.5 & 6.3.2**).

However, awareness of and practise of self management is clearly not reaching all those patients with the potential to benefit (**Section 6.2.4**). Practice is changing, but not quickly or consistently (**Section 6.2**) (Foy et al, 2001). The over-riding reasons for this may be that:

- professionals don't share a single vision of desirable change; instead this depends on current roles, expectation and practice (**Section 7.3.1**); and
- patients have few reasons to agitate against the comfort and security of the *status quo* (**Section 7.2.4**).

We may take a view that healthcare policy exists to promote and support four widely accepted ethical principles (Barber, 1996):

- do good, that is, maximise the clinical effectiveness of healthcare;
- do no harm, that is, minimise the adverse effects of healthcare;
- promote justice, that is, use available resources wisely and fairly; and
- respect autonomy, that is, give individuals choice about their own health.

Clinical policy concerning the maximisation of effectiveness and the minimisation of adverse effects is very well developed; as is the monitoring of resource use in healthcare organisations (**Section 1.4.2**). Clinical policy with respect to heart failure treatment was described in **Section 1.3.3**; it is supported by NICE and an NSF for CHD. It appears from this study (and others) that professionals are often well aware of policy promoting the evidence based treatments for heart failure, but they may still struggle to implement it (**Sections 2.4.3, 5.2.6 & 7.4**). For example, professionals were aware that doses of medicines were not optimally titrated (**Section 5.2.6**) and patients perceived monitoring to be more intensive in hospitals than in general practice (**Sections 5.2.1 & 6.2.2**).

Systematic methods to improve implementation have been tested (Newton, Davidson, Halcomb, Denniss & Westgarth, 2006) (Schouten, Hulscher, Everdingen, Huijsman, & Grol, 2008), but no particular proven method of implementation is apparent in commissioning guidance (Department of Health, 2009d). It may be necessary to do further work on the way guidelines are written, the way resources are distributed to support implementation and the incentives that can be given for providing comprehensive care packages. My results say little about how this can be achieved; except to say that guidance should acknowledge (a) the demonstrated difficulties (b) the variability of all actors' objectives and (c) that there might be good reasons (locally or individually) to do nothing different.

Poor implementation may be linked to a lack of coordination and confusion about responsibilities within and between healthcare organisations (**Section 5.2.3 & 5.2.4**). The Department of Health has already taken steps to bring heart failure treatment into the general practice QOF (cf. **Section 7.3**) and despite professional concerns (**Section 6.4.3**) I would expect these changes to increase the proportion of patients on appropriate medicines. It is hard to collectively and objectively define the point at which 'optimisation' of a medicines regimen has been achieved. This depends on medicines initiation (first prescribing), regular review (repeat prescribing with dose changes and clinical monitoring), patient adherence and the incidence of patient reported side effects.

Further investment could be made in information systems to ensure that once a long term care plan has been developed for a particular patient it is effectively disseminated to all their potential carers and can be easily (and verifiably) modified at any point. A combination of community heart failure specialist nurses working to standardised protocols (**Section 6.3.3**) and the on-going roll out of national electronic health records could be very successful in this regard. However, specialist community based professionals can be an expensive resource with limited caseload capacity. There is evidence in this study that the (presumed) clinical capacity of community pharmacists is under used and poorly appreciated (**Sections 4.5.1, 5.1.3 & 5.2.4**). A framework exists for making better use of this capacity but progress is painfully slow (Department of Health, 2008a).

Community pharmacists do now conduct a large number of Medicines Use Reviews (MURs) which assess patient knowledge and adherence; they could be asked to focus this activity on particular conditions like heart failure and the clinical content of the reviews could be expanded if pharmacists had better access to medical records. Community pharmacists may need more training and an improved practice environment (**Section 6.4.1**). Targeted MURs could be the foundation for a community pharmacist QOF that parallels and supports the general practice QOF (**Section 6.4.3**). The contracts and objectives of general practitioners and community pharmacists could be aligned (horizontal integration) within the existing structure of the NHS and using established methods of negotiation.

Achieving better vertical integration between primary and secondary care is more problematic because the framework of financial incentives is so different. My experience in the sector suggests it is currently hard to directly reward individual secondary care professionals for good performance. Past attempts to achieve vertical integration have focused on GPs (as fund holders or practice based commissioners) or PCTs directing secondary care activity. This study says little about how to go forward, but does establish the practical influence of misaligned systems and objectives (**Section 5.2**).

Broader healthcare policy supports the self management of long term conditions (Department of Health, 2009c) to promote both justice (Wanless, 2004) and autonomy (Le Grand, 2006). With respect to justice this means involving patients in their own clinical management because it is (potentially) cost-effective to do so and because the NHS as it currently functions is not expected to cope well with the demands of our aging population. With respect to autonomy this means giving patients more choice because they say they want it (Medicines Partnership Programme, 2007) and because this gives all patients access to options that were only open to the economically and socially advantaged (**Section 2.6.1**). Most fundamentally this study demonstrates that although some patients want and would accept more choice, these desires are not necessarily universal (or even very common) in disadvantaged groups (**Section 6.2.4**). This has the potential to make ‘choice’ what economists sometimes call a ‘merit good’, that is, something you don’t want that somebody else thinks you should have. Clearly, the Government has programmes like the EPP, which are designed to promote and prepare patients for an active role in care management (**Section 2.5**). This study found awareness of EPP by patients and professionals (in what was an important pilot area) somewhat limited and some evidence that take up in different patient groups was variable (**Section 6.3.2**).

If we accept the policy of increased choice (either because patients want it or because we consider it a merit good) then even more needs to be done to promote choice to all types of patient, explain what it means in practice and prepare patients for greater involvement in decision making. Nevertheless, it is likely that some patients would rather (and some patients must) rely on their professional carers (**Section 6.2.2**). In the interests of justice, one should perhaps be concerned to make sure that greater patient involvement in decision making is not the only way to improve patient care, or reduce the long term increase in healthcare expenditure. Otherwise disadvantaged patients may be further disadvantaged by not accepting (or making full use of) the solution that is offered to them. We can see some parallels in education policy that raises the school leaving age and pushes more people towards university education, but still leaves large numbers (especially, working class white males) without minimum levels of qualification (Educational Failure Working Group, 2006). Government may wish to

raise expectations, but also needs to provide services that meet existing expectations and actively pick up those the (welfare) system ‘fails’ on their journeys.

The development and promulgation of healthcare policy generally involves public consultation and meetings. Records are available online alongside the respective White Papers. These activities are open to all, but I can find no evidence that they target disadvantaged groups. Instead they seem to largely involve patients who are already advantaged or at least engaged. The patient influence on policy is, therefore, somewhat partial. Government can meet people where they are by actively and directly seeking opinions on healthcare policy in the community and workplace; as well as via charities, self help groups and online consultations. The promotion of policy should also use existing channels of communication, among which the most trusted is the GP (**Section 5.2.1**). This study demonstrates, as do many others, that for most patients the GP is the most important and well trusted provider of information and shaper of healthcare preferences (**Section 5.1.3**). The EPP is always likely to miss out patients that currently lack engagement if it relies on self referral (**Section 2.5.2**). Convincing GPs of the utility of EPP and similar arrangements (**Section 6.3.2**) should be a continuous and evolving national priority as a way to reach all patients with a consistent message.

My perception of existing policy is that it is too idealistic and not pragmatic enough. Even policy that is evidence based is not clearly rooted in and cognisant of the world in which people lead their everyday lives. A world, that is, of compromise, competing objectives and uneasy relationships. With regard to generic self management, professionals do recognise limits to their capability and the effectiveness of medicines, but seem slow to encourage (or fail to know enough about) self help strategies that might enhance care. GPs in particular should be encouraged to actively facilitate patient engagement, especially among patients that are typically regarded as passive or accepting of paternalistic care.

Healthcare policy gives insufficient attention to the actual interactions between patients and professionals. Not only is there no shortage of policy ideas and guidelines, there are probably far too many for most reasonable people to digest. Targets emphasise

collective outcomes rather than the needs of individuals. A way should be found to encourage open and honest dialogue at every stage of disease management. In my opinion, every patient should be given the opportunity to be fully engaged in healthcare, even if they make the decision not to take this up. The findings demonstrate that professionals often make too many assumptions about what level of input is in the best interests of individuals, and have few incentives or opportunities to tailor care packages.

Some evidence suggests that, the financial incentives offered in the QOF have been relatively effective in improving the standard of collective care (Rawlins & Moore, 2009). Further work could also establish the changes to healthcare systems that would be supported by those patients and front line professionals who face the most profound changes in personal relationships. This is the first step in the change management process of: engage, educate, execute and evaluate. Effective change management requires the constructive union of evidence based medicine and evidence based management (Shortell, Rundall & Hsu, 2007). However, we must have confidence that the objectives, evidence and policy truly reflect (or account for) the broad range of patient and professional priorities.

## **7.6 Final reflection**

This study contributes to what is known about healthcare development in general and the implementation of heart failure self management in particular. It makes this contribution using an approach that is both qualitative and interpretative. This can be criticised for a lack of generalisability and because definitive conclusions are not supported by hard evidence. However, the case study reports on and examines the relationships that are the foundation of healthcare, but remain relatively under explored. What is particular and contextual may, therefore, help the reader to understand how individual actions build systems and services in other contexts. This study and others that take a similar approach suggest a need to engage more with how individuals make sense of their illness and their role as self managers (Bury et al, 2005) (Wilson et al, 2007) (Gately et al, 2007).

Qualitative enquiry is a useful if imperfect way to understand what cannot be regulated and standardised. Further enquiry is justified to elucidate different influences on clinical and generic self management. I did not fully appreciate the significance of this when designing the study. It seems that in the clinical setting there is no real substitute for the honest sharing of ideas between patients and professionals, and the holistic assessment of treatment options in relation to patient needs. The development of screening tools to assess health literacy and affective capacity maybe beneficial. There is in fact no guarantee that clinical or generic self management would improve the outcomes of patients, but they are particular manifestations of greater patient involvement. Since, a call for patient involvement is based more on philosophy than proven outcomes, the monitoring of patients that adopt more self management is of paramount importance.

Carrying out a qualitative enquiry has allowed me to do something that all healthcare professionals should be able to do at the earliest possible opportunity: which is to spend focused periods of time talking and listening to their patients and colleagues. Patients' experiences of symptoms and medicines were largely as expected on the basis of current literature. However, their lack of diagnostic knowledge was worse than I expected and their attitude towards group work was particularly surprising. Unusually, I have been able to determine the views of professionals on self management and the way that this can influence patients in their care. It appears that patients and professionals frequently fail to openly discuss their treatment expectations and the extent to which health outcomes may (or may not) be modifiable.

Given these findings, repeated re-organisation of the NHS and national development programmes for patients seem unlikely to optimally achieve policy objectives. Real healthcare involves the interaction of patients and professionals in response to individual need. However, a target driven culture offers few incentives to develop mutual understanding. Patients are generally not asked about their preferences for information and treatment. Professionals do not generally explain diagnoses and treatment goals. Consequently, although care is improving against collective standards, patients' satisfaction with overall packages of care is in danger of being ignored. If patients' knowledge and skills can be willingly enhanced, then they are well-placed to monitor and improve their own health-related outcomes.

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## Appendix 1

### ***Topic guide for patient interviews and question justification***

Thanks for agreeing to talk to me. I'm mainly interested in your views on learning more about heart problems and their treatment, which might mean you could make more decisions yourself and visit the doctor less. I'll start by asking some more general questions about you, your health problems and your medicines. This might take about an hour altogether. I'd like to record our conversation if that's OK?

#### **1. Introduction**

Purpose: to build rapport with participant, make them comfortable with the recording equipment and become familiar with their immediate family (if any), housing choice and daily activities.

*I would like to ask some straightforward questions about you (and your family).*

Other occupants.	Family nearby.	Housing choice.
Work.	Daily activities.	

*Concrete experience. Explanation. Feelings.*

#### **2 About your health problem(s)**

Purpose: to understand the participant's awareness of their health problems (especially heart related), the changes they've experienced and their coping mechanisms. Good awareness and 'approach' coping might be associated with greater desire for self-management or be predictors of success in self-management. Influence of disease progression unclear? Number of problems and medicines may also have an influence on preferences.

*Now I want to ask some questions about your health.*

Health problems?	Heart problems?	First awareness.
Feelings and actions.	Causes?	Physical and emotional change?
Treatment – views.	Coping – belief?	Better or worse? How?
Worst: impact, amelioration.	Down or anxious?	Prognosis.

*Concrete experience. Explanation. Feelings.*

### 3. Social Relationships

Purpose: to understand the support available to and used by the participant, and the limitations that heart problems place on activities. The existing support network should inform any self-management package and may also influence participant need/preference for self-management. Perhaps a desire for more capability would make the participant desire self-care. Poor capability may lead to low self-efficacy?

*The next few questions are about your family and friends.*

Coping of others.	Influence on daily activities.	Help and support.
Family's knowledge.	Key helper	Unmet activities goals?

*Concrete experience. Explanation. Feelings.*

### 4. Medical and professional care

Purpose: to understand current use of medical services and obtain views on quality. High use may indicate a potential benefit from self-care, but dependence may also be an issue. Dissatisfaction with current care might increase interest in self-care.

*Now I want to ask about the care you get from doctors, nurses and others who look after you occasionally.*

Recent episodes of care: 1 year.	Recent carers.	Alternative carers.
Hospital admissions: 5 years.	Pharmacist.	Best carer?
Service vision?	Media?	Advice sources?

*Concrete experience. Explanation. Feelings.*

### 5. Medicines information

Purpose: to identify current style of communication with healthcare workers and access to medicines information. To judge preferences for and understanding of that information. Since self-management of whatever form will involve exposure to and processing of more information, current access, coping and understanding are important.

*Now I want to ask about information you may have been given about your heart or medicines.*

Last appointment: reflection.	Preference for heart advice.	Preference for medicines advice.
Unvoiced agendas.	Written information?	Preference for information
Adherence: too many?	Medicine list.	Compliance aids.

*Concrete experience. Explanation. Feelings.*

## 6. Self-management

Purpose: to obtain views on key aspects of certain types of self-management and broad preferences, including likelihood of take up and personal 'healthcare objectives'.

*Finally, I'd like to ask some questions about the symptoms of your heart problem and how you cope with them.*

What do you hope your treatments do/achieve? (medium/long term)

Improve quality of life (e.g. reduce pain, increase daily activities) (short)

Prevent (further) heart attacks or stroke etc. (medium) Keep you alive longer (long)

Keep you out of hospital/away from doctor (healthcare resources)

What do you think the doctor is trying to do/most worried about?

Have you every discussed this with a health worker?

Would you like to? In what ways would this help you?

Do you notice any changes in your symptoms from day-to-day? (short term)

Weight. Swelling (where). Shortness of breath. Any record keeping?

Do you think your medicines are working?

If not why not? What works best? What works worst?

If there are times when you don't take your medicines or don't take them as instructed...

Which medicines? Why do you change dose or stop taking?

What do you do? How does this make you feel?

Is there anything you wouldn't alter or change?

Do you have a special diet or try to avoid certain foods?

Who gave you this diet? Do you think it works?

Do you stick to it? If not why not?

Do you do anything to help yourself when symptoms get worse?

How do you decide what to do?

Has a doctor or other carer told you to do anything in particular if your symptoms get worse?

When your symptoms get worse, would you be interested in making more decisions on your own without speaking to a doctor first? E.g. changing your medicines/doses, calling 999.

Imagine you did have some instructions about what to do when symptoms get worse? (For example, if feet are swollen or weight has increased take two water

tablets instead of one.)

What would be good about this? What would be bad about this?

(Overall) Do you think you would like this and be able make decisions?

If not, why not? If yes, why? What back up would you need?

How would you feel about keeping an eye on (monitoring) something you can measure (e.g. weight), something you can see (e.g. swollen feet) or something you can feel (e.g. shortness of breath).

Could you do one or all of these things?

Would this help you to cope and/or understand your health problems?

There are lots of people around with heart problems similar to yours...

Do you ever talk to anyone else about your/their problems?

Friends & family? People you meet in clinics or at the doctors?

What sort of things do you discuss? Regularly?

Does this help you to cope? Practical? Emotional?

Anything you wouldn't discuss? Who with?

Would you like the chance to discuss your treatment and the way you cope with other people who have heart problems? (For example, share stories about last hospital admission, what caused it and how you plan to keep well.)

What would be good about this? What would be bad about this?

How would you feel about talking to other people (perhaps strangers at first) about your heart problems?

Would you go to meetings? Held where? Group size? Single sex?

Would you like talks from other people/experts?

How about acting out times when you are unwell or discussions with health workers?

Would this help you to cope? In what ways?

Would you like more written or perhaps taped information about your heart problems and their treatment?

Do you have any suggestions for anyone trying to help people with heart problems cope and keep well?

Is there anything else that you want to tell me or ask about?

## **Appendix 2**

### ***Topic guide for professional interviews (outline)***

Current role and/or responsibility for patients with heart failure.

Previous experience and training (brief).

Views on current management of heart failure.

Views on patient participation in care (general) and examples of practice style.

Views on self-management of heart failure: advantages and disadvantages.

Reflections on patient perspectives (given as anonymous quotes):

- Knowledge of health problems
- Doctor/patient relationship
- Role of other professionals
- Patient needs and ability to meet them
- Participation in decision making
- Learning from other patients

Experience of policy implementation.

Suggestions for patient support and/or future developments.

## Appendix 3

### *Patient Information Leaflet*

#### Understanding Your Heart Problem

##### Introduction

I invite you to take part in a research project.

- You do not have to say yes.
- If you decide to say no, then you don't need to give me a reason.
- Please ask me if there is anything you don't understand.

Please read this information carefully before you decide what to do. I will give you time to think about taking part and ask other people for advice.

##### **What is the purpose of this study?**

I want to find out more about how heart problems affect people's lives. I will use this information to design better ways for people with heart problems to look after themselves at home.

##### **Why have I been chosen?**

- Your doctor (GP) agreed to make a list of people with heart problems. I am asking people like you on that list to take part in an interview.
- This list included people with mild to moderate heart problems.
- I will interview 30 people altogether.

##### **Do I have to take part?**

- It is up to you to decide whether or not to take part.
- If you do agree, I will give you this information sheet and ask you to sign a form saying that you agree to take part.
- If you decide to take part, you are still free to change your mind at any time and without giving a reason.
- This will not affect your care in any way.

##### **What will happen to me if I take part?**

- You will have an interview with me that lasts about one hour.
- You can choose to have this interview at you home or your GP's practice.
- I would prefer to interview you at home, as you are likely to be more comfortable.
- During the interview we will talk about your heart problem and medical care.

This will include:

- When you found out that you had a heart problem
- The medicines you take
- The care you get from doctors and nurses
- How your heart problem has changed over time
- What you know about your future health.

I may also look at your medical notes at your doctor's surgery and the hospital. This is to confirm medical details and help me to understand your illness and how you cope with it.

**What do I have to do?**

If you agree to take part and are selected:

- I will ring or write to arrange a suitable time and place for the interview.

If you agree to take part and are not selected:

- I will write a letter to tell you.

It is possible for selected people to leave the study. If this happens:

- I may ring some people who were not selected at first, but only within the next 6 months.

**What are the possible disadvantages and risks of taking part?**

Interviews have very few risks. However, we would discuss your health and it is possible to touch on uncomfortable or distressing subjects. Examples would be times when you have been in pain or how well you expect to be in the future. I will try not upset you in any way. You can also stop our interview at any time. I will tape the interview to make sure my record of what you say is accurate. If you think of any questions about your heart problem or treatment, then I can pass these on to your doctor.

**What are the possible benefits of taking part?**

You will not get any personal medical benefits from agreeing to take part. However, the study may highlight better ways of coping with heart problems. This could help patients in the future.

**What happens when the research study stops?**

At the end of this study, I will examine the interviews, and some people's medical notes. I will use this to review the treatment of heart problems and possible ways to improve patient care.

**What if something goes wrong?**

If you are harmed by taking part, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it.

If you wish to complain about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms is available.

I am employed by the Leeds Teaching Hospitals Trust and my line manager is: Mrs E Mellor, Clinical Governance Lead Pharmacist, Pharmacy Services, Gledhow Wing, St James's University Hospital, Beckett Street, Leeds, LS9 7TF. Telephone 0113 206 6492.

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the research will be kept private and confidential. It will be stored in a locked filing cabinet in a secure office. I may discuss your medical history with your GP and a specialist doctor. If the specialist is not your

own hospital consultant, then the discussion with him/her will also be anonymous and confidential. Any information about you that leaves NHS premises will have your name and address removed.

**What will happen to the results of the study?**

The interview tape will be copied out and looked at to find topics often raised by participants. The results will be sent to a medical journal. If it is accepted, I will write to offer you a copy of the published paper.

I will also prepare a detailed report (thesis) for my research degree (MPhil or PhD), this will be held in the University of Leeds library if a degree is awarded. The results will be used with other information (from interviews with doctors, nurses and pharmacists) to assess the role of self-management methods for people with heart problems.

It will not be possible to identify you in any way from the publications, reports and guidelines that are produced.

**Who is organising and funding the research?**

The research is organised by the Pharmacy Practice and Medicines Management Group, School of Healthcare Studies, University of Leeds. Research expenses will be paid by a grant from the Royal Pharmaceutical Society of Great Britain. I will use a report of the study for a research degree (MPhil or PhD) from the University of Leeds.

**Who has reviewed the study?**

The West Leeds Research Ethics Committee has reviewed this study.

**Contact for further information**

Jonathan Silcock, Research Practitioner

Room 2.23, Baines Wing, School of Healthcare Studies, LS2 9UT

Tel: 0113 343 1230 or 0113 206 6681

E-mail: [j.silcock@leeds.ac.uk](mailto:j.silcock@leeds.ac.uk) or [jonathan.silcock@leedsth.nhs.uk](mailto:jonathan.silcock@leedsth.nhs.uk)

**Thank you for reading this information and  
thinking about taking part in this study.**

**If you agree to take part, then you will be given a copy of this  
information leaflet and a signed consent form to keep.**

## Appendix 4

### *Patient consent form*

#### Agreement to take part in research interviews and analysis

Title of Project: <b>Promoting Self-management of Heart Problems</b>		
Name of Researcher: <b>Jonathan Silcock, University of Leeds and Leeds Teaching Hospitals.</b>		
		<b>Please tick to say yes</b>
•	I have read the information sheet for this study.	<input type="checkbox"/>
•	I have had the chance to ask questions about the study, and to discuss it with family and friends.	<input type="checkbox"/>
•	I understand the reason for this study, and how I will be involved.	<input type="checkbox"/>
•	If I take part in the study I will not get any direct personal benefit from it. I understand and accept this.	<input type="checkbox"/>
•	I understand that all information collected in the study will be held in confidence. If it is presented or published, all my personal details will be removed.	<input type="checkbox"/>
•	I give permission for the researcher named above to see my medical notes if it is needed for the research. I understand that no personal details that might identify me will be discussed, presented or published.	<input type="checkbox"/>
•	I confirm that I will be taking part in this study of my own free will. I understand that I may withdraw from it, at any time and for any reason. I understand that my medical care or my legal rights would not be affected.	<input type="checkbox"/>
•	I agree to take part in this study.	<input type="checkbox"/>
Participant's Name: _____		
_____	Signed	Date _____
Researcher: Jonathan Silcock _____		
	Signed	Date _____

*You (the participant) will keep one copy of this consent. The researcher will keep one copy and add another to your general practice medical records.*

## Appendix 5

### *GP record summary for patients*

<i>Participant details and demographics</i>		
Initials:	Code:	Interview date:
Age (at interview):	Sex:	Date of birth:
GP:	GP acceptance date:	Data collection date:
<i>Health promotion details</i>		
Latest BP:	BP date:	Smoker: Yes No Former
Height (m):	Weight (kg):	BMI (wt/ht <sup>2</sup> ): C E
<i>Medical summary</i>		
DATE	DETAILS	
<i>Referrals</i>		
DATE	REASON	PLACE/CONSULTANT

<i>Current repeat prescription details</i>					
DRUG AND FORM		STRENGTH AND DOSE		DATE FIRST PRESCRIBED	
<i>Changes to repeat since interview date</i>					
OLD MEDICINE		NEW MEDICINE		RATIONALE	
<i>Laboratory results</i>					
RESULT	DATE	RESULT	DATE	RESULT	DATE
N (133,149)		CL (5.2)		AP (20,100)	
K (3.5,5.3)		HDL (0.9,2.3)		ALT (5,30)	
U (2.5,6.5)		TG (<2)		TB (2,20)	
GL (3.3,7.8)					

## **Appendix 6**

### ***Professional information leaflet***

#### **Self-management of Heart Failure**

##### **Introduction**

I invite you to take part in a research project.

- You do not have to say yes.
- If you decide to say no, then you don't need to give me a reason.
- Please ask me if there is anything you don't understand.

Please read this information carefully before you decide what to do. I will give you time to think about taking part and ask other people for advice.

##### **What is the purpose of this study?**

I am exploring the potential for self-management of heart failure. I have completed some patient interviews on this topic. I now want to compare and contrast patients' and health professionals' attitudes towards and beliefs about self-management of heart failure in a primary care setting. This information will help to inform the implementation of health care policy.

##### **Why have I been chosen?**

You have been chosen for one of these reasons:

- You are a GP or nurse at the surgery where the patient participants were registered.
- You are a hospital consultant mentioned by name during a patient interview (or his/her nominee).
- You are a community pharmacist whose premises are used by one or more of the patient participants.
- You are responsible for health care policy implementation in West Leeds PCT or West Yorkshire StHA.

##### **Do I have to take part?**

- It is up to you to decide whether or not to take part.
- If you do agree, I will give you this information sheet and ask you to sign a form saying that you agree to take part.
- If you decide to take part, you are still free to change your mind at any time and without giving a reason.

**What will happen to me if I take part?**

- You will have an interview with me that may last 20-40 minutes, but this depends on the time that you are able to spare.
- You can choose where this interview is held, but I expect that this will generally be your usual place of work.
- During the interview we will talk about your views on the self management of heart failure, and I will ask you to reflect on some patients' views.
- I may also ask questions about your previous experience, current role and future professional developments.

**What do I have to do?**

- Please return the pro-forma attached to the covering letter that came with this information sheet.
- If you wish to participate I will contact you shortly to make an appointment, please indicate if you have a preferred means of contact.
- If you do not wish to participate, then I will not contact you again about this study.

**What are the possible disadvantages and risks of taking part?**

Interviews have very few risks, particularly as these interviews are not about your personal health. You have to give up some of your time. You can stop our interview at any time. I will tape the interview to make sure my record of what you say is accurate.

**What are the possible benefits of taking part?**

At the end of the study I will provide you with a full report or its executive summary. This will be a case study about the implementation of heart failure self-management in your locality, or a locality you serve in some way. This may help you to reflect on practice and professional developments.

**What if something goes wrong?**

If you are harmed by taking part, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it.

If you wish to complain about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms is available.

I have an honorary contract with Leeds Teaching Hospitals Trust and I am responsible to: Mr C Acomb, Professional Development Manager, Pharmacy Services, Gledhow Wing, St James's University Hospital, Beckett St, Leeds, LS9 7TF.

Telephone 0113 206 4057 or pager 07659 516565.

**Will my taking part in this study be kept confidential?**

All information which is collected during the research will be kept private and confidential. It will be stored in a locked filing cabinet in a secure office or on password protected computer systems. Any personal details and contact information will be destroyed at the end of the study. Anonymous tapes and transcripts will be retained for four years and then destroyed.

**What will happen to the results of the study?**

The interview tapes will be transcribed, analysed and compared with patient interviews already completed. Papers will be prepared for peer-reviewed journals. I will write to offer you a copy of any published papers.

I will also prepare a detailed report for my research degree (PhD), this will be held in the University of Leeds library if a degree is awarded.

It will not be possible to identify you in any way from the publications, reports and guidelines that are produced.

**Who is organising and funding the research?**

The research is organised by the Pharmacy Practice and Medicines Management Group, School of Healthcare Studies, University of Leeds. Patient interviews were funded by a grant from the Royal Pharmaceutical Society of Great Britain. There is no specific funding for this part of the study.

**Who has reviewed the study?**

Harrogate Research Ethics Committee has reviewed this study. Research Governance approval has been gained from the Leeds Teaching Hospitals and PCT R&D Office. The methodology has been reviewed by my research supervisors and independent researchers at the School of Healthcare Studies, University of Leeds.

**Contact for further information**

Jonathan Silcock, Lecturer in Pharmacy  
Room 2.23, Baines Wing, School of Healthcare Studies, LS2 9UT  
Tel: 0113 343 1230 or 0113 206 6681  
E-mail: j.silcock@leeds.ac.uk

**Thank you for reading this information and  
thinking about taking part in this study.**

**If you agree to take part, then you will be given a copy of this  
information leaflet and a signed consent form to keep.**

## Appendix 7

### *Professional consent form*

#### Agreement to take part in research interviews and analysis

Title of Project: <b>Self-management of heart failure: a place in practice?</b>		
Name of Researcher: <b>Jonathan Silcock, University of Leeds.</b>		
		<b>Please tick to say yes</b>
•	I have read the information sheet for this study.	<input type="checkbox"/>
•	I have had the chance to ask questions about the study, and to discuss it with family, friends and colleagues.	<input type="checkbox"/>
•	I understand the reason for this study, and how I will be involved.	<input type="checkbox"/>
•	If I take part in the study I will not get any direct personal benefit from it. I understand and accept this.	<input type="checkbox"/>
•	I understand that all information collected in the study will be held in confidence. If it is presented or published, all my personal details will be removed.	<input type="checkbox"/>
•	I understand that no personal details which might identify me will be discussed, presented or published without my permission.	<input type="checkbox"/>
•	I confirm that I will be taking part in this study of my own free will. I understand that I may withdraw from it, at any time and for any reason. I understand that my legal rights would not be affected.	<input type="checkbox"/>
•	I agree to take part in this study.	<input type="checkbox"/>
Participant's Name: _____		
_____	Signed	Date _____
Researcher: Jonathan Silcock _____		
	Signed	Date _____

*You (the participant) will keep one copy of this consent,  
the researcher will keep another copy.*

## Appendix 8

### ***Conceptual framework: concepts, definitions and elements***

<p>Activity (AC)</p> <p>Household and other regular activities e.g. personal care, cleaning, washing and shopping. Occasional activities e.g. holidays. Limitation on activity e.g. SOBE, hearing, vision, immobility, cognition and dyslexia. Relates to patient activity only.</p> <p>Elements: AC<sub>H</sub> (household), AC<sub>O</sub> (occasional), AC<sub>R</sub> (restriction)</p>
<p>Adherence behaviour (AB)</p> <p>Admissions of intentional and unintentional non- adherence with medical instructions e.g. on medicine labels. Nature of non- adherence, frequency, context and authorisation. Relates to patient behaviour.</p> <p>Elements: AB<sub>A</sub> (adherent), AB<sub>D</sub> (directed non-adherence), AB<sub>I</sub> (intentional non-adherence), AB<sub>U</sub> (unintentional non-adherence).</p>
<p>Assistance (AS)</p> <p>Help and assistance (non-medical) provided with regular and occasional activities. Providers of such assistance e.g. family and home care. Provision of assistance to others.</p> <p>Elements: AS<sub>F</sub> (family &amp; friends), AS<sub>H</sub> (helping others), AS<sub>P</sub> (paid), AS<sub>S</sub> (social services), AS<sub>V</sub> (voluntary).</p>
<p>Communication (CN)</p> <p>Views about and experience of communication with other individuals and in groups. With respect to professionals: nature of information to be communicated to patients and also expected advantages (or disadvantages). Issue: honesty and extent of disclosure.</p> <p>Elements: CN<sub>C</sub> (clarity), CN<sub>B</sub> (barriers), CN<sub>H</sub> (HF diagnosis), CN<sub>G</sub> (group), CN<sub>D</sub> (disclosure)</p>
<p>Coping (CP)</p> <p>Self-perception of ‘coping’ either as outcome or process. Evidence of coping strategies (process) in dealing with demands of ill health or everyday life. Interpersonal comparisons with friends, family and fellow residents.</p> <p>Elements: CP<sub>A</sub> (acceptance), CP<sub>C</sub> (comparison with others), CP<sub>H</sub> (hope), CP<sub>S</sub> (strategies), CP<sub>T</sub> (trust)</p>
<p>Demographics (DG)</p> <p>Age and sex. Type of housing and co-habitants (if any). Occupation of patient or professional. Comment on changing social environment.</p> <p>Elements: DG<sub>A</sub> (age), DG<sub>F</sub> (family), DG<sub>H</sub> (housing), DG<sub>O</sub> (occupation).</p>

<p>Diagnostic and Laboratory tests (DT)</p> <p>Diagnostic and laboratory tests and their results.</p> <p>Elements: DT<sub>B</sub> (blood pressure), DT<sub>E</sub> (echo), DT<sub>S</sub> (scans), DT<sub>T</sub> (therapeutic trial), DT<sub>U</sub> (Us &amp; Es).</p>
<p>Diet &amp; Lifestyle (DL)</p> <p>Modification of eating, drinking or exercise patterns in response to advice or self-directed. Advice given on these topics. Drinking, smoking, BMI.</p> <p>Elements: DL<sub>A</sub> (alcohol), DL<sub>E</sub> (exercise), DL<sub>F</sub> (food), DL<sub>S</sub> (smoking), DL<sub>W</sub> (weight).</p>
<p>Environment (EN)</p> <p>Physical environment that supports or hinders professional practice.</p> <p>Elements: EN<sub>H</sub> (hinders), EN<sub>S</sub> (supports).</p>
<p>Expert Patients Programme (EP)</p> <p>Knowledge about and opinions on this programme.</p> <p>Elements: EP<sub>A</sub> (aims), EP<sub>F</sub> (format), EP<sub>O</sub> (organisation), EP<sub>P</sub> (participants).</p>
<p>Finance &amp; benefits (FB)</p> <p>Problems associated with lack of money and/or access to particular state benefits. Relates to patients.</p> <p>Elements: FB<sub>H</sub> (housing), FB<sub>M</sub> (mobility)</p>
<p>Health Knowledge (HK)</p> <p>Participants' knowledge of health problems: aetiology (causes), diagnosis and description. Perception of clinical prognosis both with and without treatment. Personal beliefs (I think) &amp; recollection of information given (s/he said). With respect to professionals: perception of patients' health knowledge. Objectives of better communication regarding diagnosis, treatment and prognosis. Limits of health knowledge compared to that of doctors.</p> <p>Elements: HK<sub>A</sub> (aetiology), HK<sub>D</sub> (diagnosis &amp; description), HK<sub>P</sub> (prognosis).</p>
<p>Medical care (MC)</p> <p>Care provided directly by or under the supervision of physicians and surgeons.</p> <p>Elements: MC<sub>C</sub> (conflict), MC<sub>E</sub> (emergency), MC<sub>G</sub> (general practice), MC<sub>H</sub> (hospital), MC<sub>R</sub> (responsibility).</p>
<p>Medical information (MI)</p> <p>Sources of medical information. Preferences for provision of information. Use made of information provided. Evidence of questioning and enquiring approach to healthcare professionals. Involvement in decision making. For professionals: views about provision of medical information.</p> <p>Elements: MI<sub>A</sub> (access &amp; disability), MI<sub>V</sub> (verbal), MI<sub>W</sub> (written).</p>

<p>Medicines (MD)</p> <p>Supply and administration issues. Knowledge of individual medicines: name; indication; beneficial and adverse effects. Use of compliance aids, administration 'systems' and issues.</p> <p>Elements: MD<sub>A</sub> (admin &amp; aids), MD<sub>D</sub> (diuretics), MD<sub>E</sub> (effects &amp; side-effects), MD<sub>S</sub> (supply).</p>
<p>Mental health (MH)</p> <p>Self-assessment of worries or feeling down. Cognitive function demonstrated by coherence and/or responses to questions. Worries related to the health or welfare of others e.g. friends and family. With respect to professionals: assessment of or concern about mental state of patients.</p> <p>Elements: MH<sub>A</sub> (anxiety, worry or upset), MH<sub>D</sub> (depressive symptoms or low mood), MH<sub>C</sub> (concept of self).</p>
<p>Modus operandus (MO)</p> <p>Practice style, working practices.</p> <p>Elements: MO<sub>C</sub> (continuity), MO<sub>G</sub> (guidelines &amp; protocols), MO<sub>L</sub> (workload), MO<sub>M</sub> (multi-disciplinary team), MO<sub>O</sub> (objectives), MO<sub>P</sub> (practice style).</p>
<p>National Health Services (NS)</p> <p>Views about health service in general rather than personal medical services. Note that this relates to both patients and professionals – but that patient needs may be related to professional resources.</p> <p>Elements: NS<sub>N</sub> (needs and demands), NS<sub>R</sub> (resource use &amp; restrictions).</p>
<p>Records and payments (RP)</p> <p>Practice registers and other documentation.</p> <p>Elements: RP<sub>Q</sub> (QoF), RP<sub>S</sub> (single assessment), RP<sub>C</sub> (contract)</p>
<p>Related care (RC)</p> <p>Care provided by professionals other than physicians and surgeons. Includes nursing, pharmacy and professions allied to medicine.</p> <p>Elements: RC<sub>A</sub> (CAM), RC<sub>C</sub> (chiroprapist), RC<sub>D</sub> (dietician), RC<sub>P</sub> (pharmacy), RC<sub>N</sub> (nurse), RC<sub>T</sub> (physical therapy).</p>
<p>Relationship (RS)</p> <p>Relationship of professionals to patients interviewed. Those with a direct relationship have actually personally cared for or been mentioned by patients. Indirect relationship means impact on local service provision or developments.</p> <p>Elements: RS<sub>D</sub> (direct); RS<sub>I</sub> (indirect).</p>

<p>Role (RL)</p> <p>For professionals, Patient care or service development focus to job. Few participants wholly or mainly engaged in service development. For profession and sector see participant identification code.</p> <p>Elements: RL<sub>C</sub> (patient care), RL<sub>D</sub> (service development).</p>
<p>Sector (SC)</p> <p>Professional sector of work.</p> <p>Elements: SC<sub>C</sub> (community), SC<sub>P</sub> (primary), SC<sub>S</sub> (secondary).</p>
<p>Self-management (SM)</p> <p>Awareness and recording of changes in weight, shortness of breath, ankle swelling, tiredness or other physical signs &amp; symptoms. With respect to professionals: Awareness of and suitability of patients for self-management</p> <p>Elements: SM<sub>B</sub> (benefits), SM<sub>C</sub> (concerns), SM<sub>D</sub> (dose changes), SM<sub>G</sub> (group work), SM<sub>M</sub> (meaning), SM<sub>R</sub> (recording), SM<sub>S</sub> (suitability selection).</p>
<p>Symptoms (SY)</p> <p>Subjective physical or mental experience related to ill health.</p> <p>Sub categories: SY<sub>A</sub> (ankles), SY<sub>B</sub> (shortness of breath), SY<sub>C</sub> (cough), SY<sub>D</sub> (diuresis), SY<sub>F</sub> (forgetfulness), SY<sub>I</sub> (itch), SY<sub>L</sub> (lethargy), SY<sub>P</sub> (pain), SY<sub>W</sub> (weight loss or gain), SY<sub>S</sub> (sleep), SY<sub>V</sub> (vertigo).</p>
<p>Titration (TN)</p> <p>Change and optimising doses of medicines.</p> <p>Elements: TH<sub>E</sub> (effects), TN<sub>S</sub> (supervised), TN<sub>U</sub> (unsupervised)</p>

## Appendix 9

### Worked example of analysis

#### (a) Example of transcription, coding and indexing

<i>Patient Participant: Mike 56. Shaded paragraphs link to Appendix 9 (b).</i>			
<i>Concept/Element Code</i>		<i>Verbatim transcription</i>	<i>Ref</i>
MD <sub>E</sub>	SM <sub>D</sub>	<b>Yeah. So you've been told for some time to take some more of your reliever inhaler when you feel...</b> Oh yeah yeah. He said take it whenever you feel badly.	239
MD <sub>A</sub>		<b>Yeah</b> And this other one I take two puffs in a morning, well it says here take one puff.	240
MD <sub>A</sub>		<b>Right</b> But other it said take two puffs twice a day.	241
MD <sub>A</sub>		<b>Yeah</b> So I take couple in a morning and couple on a night before I go out.	242
			...
SM <sub>D</sub>		<b>But you know you can take more of the inhaler if you want to?</b> Oh yes.	246
SM <sub>D</sub>	MD <sub>E</sub>	MI <b>Would you be interested in similar things with your tablets?</b> To be honest I don't know actually what they're doing to me you know so. I know they're suppose to be, one is for me cholesterol, ones for this, ones for that.	247
MD <sub>E</sub>	CP <sub>T</sub>	<b>Yeah</b> So I assume that they're doing the right job like.	248
MD <sub>E</sub>	SM <sub>R</sub>	<b>Yes. So maybe it's easy to judge with the inhaler isn't it cos you know what its doing?</b> Oh yeah (if it doesn't cure it) you use it more often don't you?	249
SM	MI <sub>w</sub>	<b>Yes. Yes that's interesting. If you did have more information about what the tablets did, do you think then you'd be more interested in making...</b> Oh yeah. I've just looked through, there's that much that much jargon written on it. If it said this for your cholesterol and it does this, you know, I'd be happy with that.	250
MI <sub>w</sub>		<b>Yeah</b> In terms of a big long page, you know, you skip half of it, what the hell are they on about?	251
MD <sub>E</sub>		<b>Yeah. One of the tablets that you take is a water tablet.</b> Is it, oh.	252
MD <sub>E</sub>		<b>I think on your list here. The frusemide.</b> Oh yeah.	253
MD <sub>E</sub>		<b>And I don't know if you notice it might make you go the toilet more, it might not.</b> I'm going to the toilet a lot more yeah.	254

DL <sub>A</sub>			<b>Right</b> But it could be with drinking.	255
SY <sub>D</sub>			<b>Possibly I suppose.</b> No I go to the toilet a lot yes.	256
				...
SM <sub>D</sub>	SY <sub>A</sub>		<b>Imaging you had some instructions that said if your ankles do swell take an extra frusemide.</b> But nobody, this is the first time it's been mentioned to me.	259
SM <sub>D</sub>			<b>No. Well this is what I'm saying that it's not what's happening at the moment, and I'm not suggesting you do but its about things, how things can possible change.</b> No.	260
SM <sub>D</sub>	CP <sub>T</sub>	MI <sub>V</sub>	<b>In the future. So I'm not telling you this is good advice I'm just trying to get your feelings about it.</b> Oh if I was told to take two, I'd take two like you know.	261

**(b) Section of chart for concept of self-management**

<i>Mike's comments from transcript section (Appendix 9 (a)) charted alongside related comments from other participants</i>			
<i>Patient</i>	<i>Element</i>		
	Recording	Dose changes	Group work
Edward 71	74: Have done	87: Leave to doc 91: Would do (if he said)	98: Rely on doc
John 67	106: Have kept "lung man" "no difference"	92: Painkillers 101: Trust docs	109: Enough problems of own 110: Might to see specialist
Mike 56	206: Suppose so "wouldn't bother me"	239: Does with asthma meds 261: Would if told	274: Want to forget 279: Not to see doc (been cured)
Ruth 86	157: Not bothered	191: Would do	194: Keep to self
Rose 82	159: If had to	153: Would follow instructions	167: No don't dwell on it

### Appendix 10: Official documents relevant to heart failure management (Year, title and type)

	White Papers (Policy)	Research Reports/Consultation	Implementation/Updates	Guidelines/NSFs
1999	Saving Lives: Our Healthier Nation (Cm 4386)			
2000	The NHS Plan: a plan for investment, a plan for reform (Cm 4818) The NHS Plan: The Government's response to the Royal Commission on Long Term Care (Cm 4818 II)			National Service Framework (NSF) for Coronary Heart Disease
2001			The expert patient: a new approach to chronic disease management for the 21st century	
2002		Securing Our Future Health: Taking a Long-Term View (Wanless Report 2002)	Delivering the NHS Plan: next steps on investment, next steps on reform (Cm 5503)	ESC Guidelines for Chronic Heart Failure
2003	Building on the best: Choice, responsiveness and equity in the NHS (Cm 6079)	Choice, responsiveness and equity in the NHS and social care: a national consultation MORI Choice Survey		Coronary Heart Disease: Delivering better heart services - Progress report 2003 CG5 Chronic heart failure: NICE guideline
2004	Choosing Health: making healthier choices easier (Cm 6374) The NHS Improvement Plan : Putting people at the heart of public services (Cm 6268)	Securing Good Health for the Whole Population (Wanless Report 2004)	Improving Chronic Disease Management	Coronary Heart Disease: Winning the war on heart disease - Progress report 2004 Management of medicines (NSF support)
2005			Creating a patient-led NHS: Delivering the NHS Improvement Plan Health reform in England: Update and next steps Delivering choosing health: making healthier choices easier Mainstreaming the Expert Patients Programme (EPP)	The National Service Framework for Long-term Conditions Coronary Heart Disease: Leading the way - Progress report 2005 Long-term conditions information strategy: Supporting the National Service Framework for Long-term Conditions ACC/AHA Guidelines for Chronic Heart Failure

2005 <i>cont.</i>			Self care - A real choice: Self care support - A practical option Supporting people with long term conditions: An NHS and social care model to support local innovation and integration Supporting people with long term conditions: Liberating the talents of nurses who care for people with long term conditions	
2006	Our health, our care, our say: a new direction for community services (Cm 6737)	Your health, your care, your say - Research report The national evaluation of the pilot phase of the Expert Patients Programme - final report	Choice matters: Increasing choice improves patients' experiences The expert patients programme (progress on policy) Supporting people with long term conditions to self care: A guide to developing local strategies and good practice A stronger local voice: a framework for creating a stronger local voice in the development of health and social care services	
2007		Research evidence on the effectiveness of self care support Commissioning framework for health and well-being	Choice matters 2007-08: putting patients in control Better information, better choices, better health: putting information at the centre of health	Coronary heart disease: Shaping the future - Progress report for 2006 Coronary heart disease ten years on - improving heart care Pushing the boundaries - Improving services for patients with heart failure.
2008		Self care: a national view in 2007 compared to 2004-05	Disease Management Information Toolkit (DMIT)	The Coronary Heart Disease National Service Framework: Building for the future - progress report for 2007 Heart failure service commissioning guide (NICE)