PATIENT PERCEPTIONS, EXPERIENCES AND EXPECTATIONS OF RECOVERY AND PROGNOSIS IN LONG-TERM CONDITIONS

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ABSTRACT

Background: Whilst the experience of chronic physical conditions is well documented and has been recognised as relevant for health policy and practice little is known about notions of recovery and prognosis from the point of view of those with long-term physical health conditions. The extent to which people consider the future outcomes of their conditions is relevant to health policy which seeks to engage people in shared decision making, care plans, and self-management. This gap in knowledge about lay perceptions of recovery and prognosis becomes more pronounced when compared with literature from the mental health field in which recovery is one of the dominant foci, is comparatively well researched and in recent years has fed into policy and management approaches.

Aims: The aim of the thesis is to explore perceptions of recovery and prognosis with people with long-term physical health conditions and to compare these with perspectives on recovery and prognosis apparent in the mental health field.

Methodology: Using qualitative methods, a two phased approach to data collection and analysis was undertaken. Phase 1 used secondary data analysis with two existing datasets to examine whether notions of recovery and prognosis were implicit in narratives about the experience of illness. Phase 2 built on the findings from phase 1 and utilised longitudinal, primary data collection in the form of narrative interviews undertaken at two time points (baseline and 12 month follow-up). The analysis in both phases involved a cross case thematic analysis to look for commonalities and differences across individuals. Data from phase 2 were also subject to a narrative emplotment of individual stories which were used to capture the longitudinal changes in patient perspectives over time.

Results: There were similarities with findings from the mental health field (recovery as a complex, nonlinear journey, the input from friends and family, notions of burden and the impact of condition on sense of self). However, there were nuanced differences in relation to physical health conditions which related to expectations about mortality, the experience of time, the extent to which narratives were future oriented and the experience of stigma. The dual focus on mental and physical health recovery proved useful for understanding those experiences of multiple morbidities. The results were used to develop a model of recovery narratives based on two dimensions (expectations and responsibility) which gave rise to four typologies of narratives. The aim of this model was to further highlight and summarise the themes arising from the data analysis.

Discussion: The results of this study highlight the importance of understanding notions of recovery and prognosis in order to better understand the experience of illness and self-management. The thesis challenges the blanket use of health promotion strategies for those with and without chronic health conditions and supports a shift in policy focus from improved choice and autonomy to what Mol (2009) refers to as ‘enhanced care’.

The University of Manchester
Helen Louise Brooks
Doctor of Philosophy (PhD)
Managing long-term health conditions in primary care: patient perceptions and expectations relating to recovery and prognosis
2012
DECLARATION

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THE AUTHOR

I originally studied psychology as an undergraduate. After graduating, I obtained a research assistant position at the University of Northumbria exploring the mental health impact of events such as Omagh bombing and the Paddington Rail Crash. I then moved to the Primary Care Development Centre (PCDC) as a senior research assistant and worked on a number of projects including a number of service evaluations (e.g. the electronic booking system, walking the way to health schemes and a specialist weight management programme). During my time at PCDC, I also undertook a part-time MRes in Social Science and Health. I have had a varied career since then including working on both mental and physical health projects predominantly based within primary care. I am currently employed within the School of Community Based Medicine at Manchester University and my work focuses on the social networks and types of ‘work’ implicated in long-term condition management.

During my career, I have developed a particular interest in self-management and recovery as a result of my previous experience and both my undergraduate and postgraduate degrees. This interest in recovery arose, in part, due to its interface between psychology and sociology which is reflective of my career to date. This relates specifically to the fact that recovery incorporates how an individual sees them self as well as implicating a wider group of people around the individual.
CHAPTER 1: INTRODUCTION

This thesis explores the perceptions of recovery and prognosis from the perspectives of patients with long-term physical health conditions and aims to identify what is unique about these. This becomes important when it is seen in the context of recent policy initiatives and developments elsewhere.

The value of including patient perspectives within the study of health and illness and broader health services is widely accepted as well as politically desirable (Entwistle et al. 1998). The incorporation of lay experiences has been shown to contribute to the appropriateness and acceptability of health and community services (Kennedy, 2010). This need to acknowledge the value of patient perspectives is central to the modernisation of the NHS and is a focus of current policy (see section 1.1.1 below). Patients are no longer solely considered to be passive recipients of health care and instead are increasingly viewed as ‘critical consumers’ (Department of Health, 1999a; May et al., 2004).

As well as the policy imperative to incorporate lay perspectives, there are epistemological, moral and consequentialist arguments supporting their inclusion (University of Sheffield, 2012). Researchers have looked to lay discourses of health to illuminate wider elements of the illness experience and to increase the relevance and impact of health research. This is because ‘knowledge, culture, attitudes, experience, and healthcare organisation are the key determinants of when, why, and how people access formal health care’ (Rogers et al. 1998, p.1816). In addition, information obtained from lay people’s expertise or ‘life world’ approaches may complement that provided by professional health care providers (Biley and Galvin, 2007; Entwistle et al. 1998).

The understanding of patient perspectives is well developed in the experience of living with, and the impact of, long-term physical conditions. What remains underexplored however are the perceptions and expectations of those with chronic physical conditions in relation to recovery and prognosis. Narrative life world approaches are likely to be pertinent to exploring this, given their attention to the social construction of meaning within

---

1 The focus of this thesis is on the experience of long-term physical conditions without the acknowledged presence of mental illness. Throughout the thesis, it is argued that notions of recovery within the mental health field are well developed; therefore it was considered feasible to focus instead on solely those with physical health problems as this is so far relatively underexplored. This will be explored in more depth later in the chapter.
an individual’s social life. In addition, the notion of recovery has been applied with increased frequency and traction within mental health policy, practice and research over recent years but it has not had the same prominence in literature on the experience of chronic physical illness and its management.

In this chapter, I will outline the relevant policy initiatives before moving on to describe the rationale for the study which includes the reasons for focusing on recovery and prognosis and how notions of recovery differ from the mental health field. The second part of the chapter identifies the research questions to be addressed along with a synopsis of the structure of the thesis.

1.1 Background

1.1.1 Policy context

In England, current estimates of the number of people living with one or more long-term condition, which are often referred to as chronic conditions lasting a year or more, range between 15.4 million (Department of Health, 2008a; Wanless, 2002) and 17.5 million (Department of Health, 2005b). Numbers are expected to rise further due to an aging population and unhealthy lifestyle choices. This increasing prevalence of non-acute conditions - ‘the demographic and epidemiological transitions that have increased the prevalence of chronic illness throughout the world’ together with newly emergent ways of management has been referred to as a ‘care transition’ (Taylor and Bury, 2007, p40).

Long-term health conditions such as diabetes and heart disease impact substantially on an individual’s lifestyle in terms of increased mortality and disability (Woolf, 2001; Roper et al. 2001). The increasing prevalence of chronic illness has led some to claim that the ‘existing allocation of social responsibilities between the state, the family, and the caring professions and institutions are no longer appropriate when measured against the extent of need for care’ (Illsley, 1981, p.327). These conditions represent a significant challenge to practitioners, particularly those within primary health care, complicated further by the changes to the divisions of labour within health services, and the often intractable nature of chronic conditions (May, 2005).
Traditionally, care for patients with long-term conditions has been reactive and poorly planned, which has meant that some patients have, unnecessarily, overused secondary care services (Wagner, 1998). One creative response to this has been the development and use of the chronic care model which sets out a policy and organisational structure to better manage chronic illness. Developed in the US in 1998 this model appealed to policy makers in the UK. A central tenet of the model is the acknowledgement that a large proportion of self-management occurs externally to traditional health services and a diagrammatic representation is provided in figure 1.

*Figure 1: The chronic care model*

![Chronic Care Model Diagram](source:wagner_1998)


Recent publications highlight the need for service improvement for those with long-term health conditions (Department of Health, 2008b; National Audit Office, 2012; Wanless 2002; 2004), which has the potential to cut costs within the NHS. The NHS and Social Care Long-Term Conditions Model (Department of Health, 2005b) represents care stratified on three levels (figure 2). By 2010 it was envisaged that everyone living with a long-term
condition would be offered a personalised care plan. These plans would be constructed and compiled collaboratively by patients and professionals and reviewed on a regular basis.

*Figure 2: Three levels of care within NHS and Social Care Long-term Conditions Model*

![Diagram showing three levels of care within NHS and Social Care Long-term Conditions Model](image)

*Source: Department of Health, 2005b*

The main aim of the NHS and Social Care Long-Term Conditions Model was initially to direct resources to the most intensive users (level 3) through case management led by community matrons (Department of Health 2005b). These matrons were to carry caseloads of approximately 50-80 patients with the most complicated needs and those who required medical intervention in addition to case management. It was also envisaged that multi-disciplinary teams would be set up in primary or community care to provide specialist advice related to specific conditions across a variety of different settings (level 2).

The first level of the model, promoting self-care, represents the most commonly used way of supporting patients with long-term health conditions with the promotion of self-care consisting of five elements; healthy lifestyle choices, support networks, skills and confidence training, and tools such as self-monitoring devices (Department of Health, 2006). This translated through to provision of information and education to encourage self-
management initially through the Expert Patient Programme (EPP). Self-care also formed a critical component of the NHS Improvement Plan based on the assumptions about its effectiveness for improving health outcomes in a number of conditions (Deakin et al. 2005; Gibson et al. 2003). A number of initiatives have been launched to promote self-care and these can be found in figure 3.

*Figure 3: Summary of recent self-care initiatives.*

- The Expert Patients Programme (EPP) - involves a six-week training course to enable those with long-term health conditions to develop skills to better manage their condition on a day-to-day basis. The course is delivered within primary care by someone with experience of living with a chronic health condition. An evaluation of the EPP demonstrated that attending the course had a strong normalisation effect for attendees and that their motivation and confidence about managing their conditions was improved (Rogers et al, 2006).

- Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND, Davies et al, 2008) which is used in the self-care of diabetes and combines peer support with increasing individual skills and confidence in managing their own condition.

- The government is also testing the use of “assistive” technology to help primary care providers to develop self care models with their populations and help people live at home independently for longer (Department of Health, 2005a). The two main “assistive” technologies are telecare (remote monitoring of conditions in order to enhance independent living such as falls and movement sensors) and telehealth (remote exchange of data between patients and professionals to aid management such as blood pressure monitoring and medication reminders).
Despite these initiatives, recent publications assert that care for those with chronic conditions is still not meeting quality targets (National Audit Office, 2012). This has led some to assert that there is a crisis in care for patients with long-term conditions (Rayman, 2012). A recent Audit Office report demonstrated that 69% of diabetic patients failed to achieve one or more of three treatment standards and 15% were not tested at all against treatment standards. The report also pointed to how the better understanding and management of diabetes had the potential to save the NHS £170 million every year. One of the recommendations from the report was to increase access to education and support for diabetic patients (National Audit Office, 2012). Furthermore, NICE guidelines also highlight the need to incorporate patients’ wants and needs into treatment plans (National Institute for Health and Clinical Excellence, 2008).

Whilst policy has focused on education, skills training and getting people to self-manage better, little is known about how people actually feel about recovery and prognosis, if indeed they think they will recover at all. Such information is likely to be fundamental to whether people engage with these types of policy initiatives on offer or not and whether patients will, and can, actively adopt and integrate self-management techniques and advice. A further point relates to how self-management policy is underlined by ideologies which focus on population governance through lifestyle risk management and notions of patient empowerment (Andreassen and Trondsen, 2010). These have been criticised for their emphasis on patients as rational agents who calculate risks probabilities and behave accordingly to the detriment of understanding the ‘lay person’s construction and enactment of risk, their agenda and contextual needs when living with a chronic condition’ (Morden et al. 2012, p78) beyond the aforementioned simplistic notions of patients empowerment. In support of this line of argument is research indicating that the notion of an empowered patient ‘seems to be an aspirational ideal that has been presumed rather than shown to exist’ (Salmon and Hall, 2003 cited in Andreassen and Trondsen, 2010, p282). There also is a paucity of thinking about whether and how patients think about change and according to some commentators this is based on the imposition of ‘imagined identities’ or ideal ‘types’ of patients (e.g. empowered patients or active self managing patients, Rogers, 2009).
1.1.2 Rationale for the study

The previous section has described recent policy innovations for those with chronic physical conditions highlighting these often fail to account for the personalised needs or beliefs of patients. Additionally, there has been little challenge to the traditional biomedical view of recovery which encompasses a view of recovery in which patients are viewed as recovering following medical treatment for an underlying biologically determined disease and is characterised by a disappearance of the symptoms associated with the condition. By their nature, chronic conditions will not be subject to this type of recovery because recovery can only ever be temporary or because symptoms are in remission rather than permanently resolved. This has led some to infer that the use of this term may be ‘semantically difficult, as colloquially, it connotes improvement or a return to a previous state’ (Irving and Lakeman, 2010, pp.403). However, this is only one way of looking at things and other definitions including biopsychosocial models of practice (Reeve et al. 2012) incorporate a different, broader view of recovery from a patient focused view (‘life recovery’ (Collier, 2010)) which resonates more with recovery and patient-centred care in the mental health field (discussed in the next chapter). Despite the patient-centred assumptions behind the concept being implicit in some of the recent NHS initiatives discussed in the previous section such as the EPP (e.g. self-management and the focus on patient choice) in overall terms relative to mental health there is a lack of application of these notions.

The fact that notions of recovery are less well understood and researched within chronic physical illness when compared to the mental health field warrants some scrutiny here. It may have its roots in a Cartesian dualism (the perceptions that the mind and body are separate entities) associated with medical orthodoxy which is inherent in health policy and until recently practice. There are a number of other possible reasons when health activism and the distinct dominant discourses within each field are considered. Whilst there has been a critique of the medical dominance related to physical health conditions (predominantly from sociologists and health researchers), opposition to the medical dominance in relation to mental health came also came from mental health service users through activism or collective action which constituted one of the main drivers of the recovery movement (Deegan, 1997). This has been less salient in relation to chronic physical conditions.
The reasons for the strong movement of social and political activism within the field of mental health compared with physical health are situated within a period of medicalisation where prognoses for physical health conditions were relatively more positive than those for mental illnesses. This was due in part to the greater development of drug treatments and biomedical technologies for chronic physical conditions (e.g. insulin for diabetes).

Treatment and subsequent prognosis for mental health conditions, on the other hand, were much less optimistic (Kraeplin, 1904) and exacerbated by the perception of over intrusive and ineffective treatments associated with mental health services (Rogers and Pilgrim, 1991). This also meant that health professionals treating physical health conditions were held in high esteem and as holders of medical expertise; this was the case even though technological developments for chronic illnesses were comparatively less advanced than in acute care. Additionally, the at times compulsory nature of mental health treatment (e.g. civil compulsory detention under the mental health act) represents an important difference between the two fields. Activism and demands for a new approach arose as a result of resistance to coercion and civil exclusion that emerged at the time of the closure of large mental hospitals and a move to community orientated management (Crossley, 1999; Rogers and Pilgrim, 1991).

Secondly, the stigma and exclusion experienced by mental health patients also contributed to what can be termed the ‘recovery’ movement. Whilst this was present for those with chronic physical conditions it appears to have had less salience because of the degree that the self is implicated in a diagnosis, e.g. ‘one may have a broken back but one is mentally ill’ (Pilgrim and Tomasini, 2012, p632). This is particularly the case in relation to the stigma attached to treatment (Corrigan, 2004). The recovery movement has contributed to the arguments challenging medical dominance within the mental health field which has been reinforced with recent policy initiatives promoting patient autonomy/choice and the movement of treatment out of hospitals and into community mental health teams (Department of Health, 2011; Sampson, 1995). It appears historically therefore, that there was a greater need and impetus for health activism or a civil liberties movement to challenge the dominance of the medical profession within the field of mental health when

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2 Health activism within the physical health field has tended to come from a combination of those with impairments since birth and others with acquired disability such as amputees. This thesis focuses instead on less visible chronic conditions such as diabetes and heart disease which have less activism associated with them when compared with the field of mental health.
compared to the field of physical health which facilitated the focus on recovery in mental health.

Recently there has been academic argument for considering mental and physical health conditions and management on a par with each other (Gask et al. 2011; Lau, 2005). Arguments centre on the similar impacts the two types of conditions have on disability and quality of life, and point to the co-morbid and often symbiotic relationship between the two. For example, mental health can impact on self-management and management of medical regimens for physical conditions. Similarly, physical health conditions can give rise to depression whilst drug treatment for mental health conditions can lead to physical side effects such as weight gain and glucose intolerance (Lau, 2005). It has also been asserted that both types of condition are subject to discrimination, stigma and oppression (Beresford, 2000); and both types of condition are rooted in a form of deviance (Fabrega and Manning, 1972). Additionally, people with physical and mental health problems are perceived to represent what have been coined ‘dependency groups’ given their reliance on, and significant cost to, health services (Illsley, 1981).

Co-morbidity is an important issue which has relevance to this thesis and merits discussion at this point. For example, the burden of illness presented by experiencing and managing multimorbidities might make notions of recovery more challenging (e.g. the complexity of managing multiple medication regimens and self management strategies for a number of conditions, May et al. 2009). However, it was not the focus of the current study for the following reasons. At the time of commencing this thesis notions of how comorbidity was formulated and experienced were less developed than they are now. Therefore it seemed appropriate at the outset to focus on comparisons with mental health literature, in terms of the most important condition that participants identified with. Focusing on an identified main condition was considered the best way to indicate the priority people had for recovery. In the literature there is now substantive acknowledgement that people prioritise and select from a number of conditions according to the level of intrusion into their everyday lives (Cheraghi-Sohi et al. 2012; Morris et al. 2011) which was also indicated in earlier research (Townsend, 2011). Furthermore, as later chapters will demonstrate, there is limited literature which focuses exclusively on recovery from physical health conditions and the potential uniqueness of this and therefore adding in extra complexity by exploring
multimorbidity is unlikely to be feasible in the current study. Thus, this thesis will concentrate on recovery from physical health conditions, given that this is relatively underexplored when compared with the mental health field. Whilst co-morbidity was not a key feature at the design stage, where it was raised spontaneously in narratives from respondents or was deemed relevant within the analytical process, it was taken into consideration.

The similarities outlined above have prompted researchers to call for greater integration between the two fields especially in terms of treatment and care planning which has been echoed to an extent at a policy level in terms of continuity and co-ordination between the two conditions (World Federation for Mental Health, 2010). However, there has been limited success when attempting to import models from one field to another (e.g. endeavours to apply the social model of disability to mental health problems gave rise to shared concerns within both groups of patients in relation to creating a shared identity (Pilgrim and Tomasini, 2012) and attempts to use self-management models derived from physical health fields within mental health field have been of equivocal value (Davidson, 2005; Lawn et al. 2007). Recent reconceptualisations of the bases on which disorders are defined and managed, and the promotion of new and innovative management approaches seem to hold promise in terms of connecting up the hitherto discrepant fields. However, given the past history and current direction of these two fields it may be that they continue to diverge.

The neurodiversity movement is gaining increased momentum particularly in the field of autism (Jaarsma and Welin, 2012). This approach moves away from deficit models of disorders and focuses on how conditions such as autism can reflect natural biological diversity and, as a result, do not require treatment as traditionally conceived but alternatively focuses on ‘neuroequality’ (Fenton and Krahn, 2007). Recently, this approach is being used with increasing frequency for other conditions such as schizophrenia and depression (Antonetta, 2005; Fenton and Krahn, 2007). The notion that mental illness is not a straightforward biomedical condition is by no means new (Andersen and Larsen, 2012). However, this focus on biological diversity is unlikely to be directly applicable to physical conditions and particularly ones such as cancer given their often fatal outlook. These developments in mental health contrast with the movement in physical health conditions
which emphasise risk minimisation and associated genetic profiling allied to biomedicalisation (Clarke et al. 2003) which implicitly infers a predominant emphasis on striving for cure in the realm of physical illness comparative to the mental health field. Nonetheless, despite the differences, identifying linkages between the two traditions may lead to better integration and application of approaches to recovery and self-management within recent policy initiatives for those with chronic physical conditions.

Understanding people’s expectations about prognosis and recovery from physical health conditions is relevant for understanding how and why people are ready or not to engage with self-management and chronic illness management. There are a number of psychological models of behavioural change (e.g. Theory of Planned Behaviour (Ajzen, 1991)) based on the motivations that people need to change. However, there is little research exploring the actual views and experiences or connecting these notions of motivations to how people feel about recovery. Furthermore, it is likely that expectations about recovery will be socially patterned, influenced by a specific condition, affected by living arrangements as well as individual experience (Newbould et al. 2006; Townsend et al. 2006). These form key foci of this thesis and require detailed elaboration. The need for a fine grained analysis is suggested by anthropological studies which have highlighted the ‘eventfulness’ of recovery concealed in biomedicine and described recovery and healing as complicated social processes which are highly context dependent embodied acts (Mattingly 2010). To date there is a lack of empirical investigation into these processes within the available literature.

The use of in-depth patient narratives combined with the possibility of mapping individual trajectories is one way of addressing this gap. The use of narratives in the field of chronic illness has increased in recent years and the benefits of longitudinal, trajectory type approaches are becoming progressively better understood (including the study of recovery from physical conditions (Halcomb and Davidson, 2005). However, the focus has been on the deterioration and degenerative aspects of illness with a small number of exceptions (Frank, 1997). What is lacking from the current literature is a consideration of the variation in how patients view their prognoses and futures, living with a chronic illness. Bury highlights the importance of understanding views and expectations about the future from the perspective of those with chronic illnesses (Bury, 1982). However, this has not been
addressed in depth or in the context of dominant policy expectations about recovery including self-management support for chronic illness initiatives (Bury, 1982; Rogers et al. 2009a). It seems useful then to explore patients’ perceptions about this recovery approach to chronic illness using the notion of recovery from the field of mental health as a sensitising concept and see whether this would be perceived positively or whether this emphasis on optimism could be perceived to be potentially oppressive.

1.2 Research questions

The principal aim of this study is to investigate experiences and perceptions of prognosis and recovery for those with long-term physical conditions without the acknowledged presence of mental illness. The research questions intended to inform this subject area are:

- What are patients’ perceptions about, and experiences of, prognosis and recovery, and how do they impact on self-management and living with a chronic physical condition?

- Do perceptions and experiences of prognosis and recovery change over time, and if so how and why?

- How applicable are the concepts of ‘recovery in’ and ‘recovery from invalidation’ found in the mental health literature to those with long-term physical health conditions?

- What social factors (e.g. age, gender, and socio-economic status), if any, impact on perceptions and expectations of prognosis and recovery?

- What are the similarities and differences in notions of recovery and prognosis for different conditions (e.g. explore the similarities and differences with the mental health literature and any variation between different physical conditions)?

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3The idea of sensitising concepts was first introduced by Herbert Blumer. These are delineated from definitive concepts such as IQ (more often found in quantitative research) which have clear attributes and are precisely specified. Sensitising concepts, Blumer stated, were those found in social research such as culture. These concepts give the qualitative researcher a general guiding force or framework when undertaking empirical studies (Blumer, 1969). In this study the sensitising concept of recovery was informed by chapter 2 which examines the available literature.
What are the factors that are perceived to promote or inhibit ‘recovery’ from chronic physical health conditions?

The research commenced with an exploratory preliminary synthesis and critical review of the available evidence about recovery from chronic illness. This provided the basis for the use of the sensitising concept of ‘recovery’ to be applied to the primary data collection presented in chapters 5-8.

1.3 Thesis layout and structure

Chapter 2 serves an introductory purpose by critically exploring what is currently known about chronic illness and its experience. The chapter also provides:

- Other available literature pertaining to notions of recovery and prognosis;
- An introduction to, and overview of, the concept of recovery in mental health.

The chapter is necessarily selective given the volume of literature in the above areas. As the chapter develops, potential linkages between the two fields are highlighted and discussed critically.

Chapter 3 provides the aims of the study along with the methodology selected and rationale for it. The use of patient narratives as a method of enquiry and its applicability within the current context is also explored. In addition, the chapter gives a description of the participants involved in the study and the role of the researcher within the study.

Chapter 4, 5, 6, 7 and 8 provide information on the results of the study. Chapter 4 provides data from phase 1 of the study which utilised secondary data analysis of 49 transcripts to explore whether recovery and prognosis were discussed within interviews relating to the experience of illness and what could be obtained and learnt from these. Chapter 5 explores conceptualisations and perceptions of recovery and prognosis from the primary data collection undertaken through narrative interviews whilst chapter 6 focuses on two recurring themes; expectations and responsibility. Chapter 7 provides a typology of participants across the dimensions of responsibility and expectations and then details paradigm examples for each. Finally, chapter 8 compares the data directly with that from the field of
mental health with a particular focus on one model of the process of recovery in mental health.

Chapter 9 provides a summary of the main findings and explores the contribution of using recovery in mental health as a sensitising concept through which to look at the experience of chronic physical conditions. It also discusses strengths and limitations of the study, the potential for future work and implications for practice and policy before ending with some final concluding remarks.

1.4 Summary

This chapter has provided a background to the current study and critically discussed the importance of undertaking this research. Whilst there is a plethora of literature on how patients experience a chronic condition and a policy emphasis on the management of long-term health conditions, a focus on prognosis and recovery is less understood and less researched, particularly in comparison with research in the field of mental health. Yet, understanding peoples’ expectations about prognosis and recovery are likely to be central to understanding how and why people are ready, or not, to engage with self-management and chronic illness management and may be important in accounting for outcomes. In order to improve services for those with chronic long-term health conditions within primary care, services need to fully understand the context surrounding individual patients and the meaning of managing long-term health conditions to them. There is also a lack of literature relating to how this perception is socially patterned and how it varies between conditions and over time, which would need to be explored in order for services to provide truly user centred and holistic care. This led to the development of the research question described within the chapter.
CHAPTER 2: RECOVERY AND PROGNOSIS: A REVIEW OF LITERATURE RELATING TO PHYSICAL AND MENTAL LONG-TERM CONDITIONS

2.1 Introduction

This chapter outlines a review of existing literature regarding chronic physical illness experience before exploring more specifically existing literature pertaining to perceptions of prognosis and recovery from physical illnesses. The chapter then moves to introduce the notion of recovery in mental health as a useful framework through which to guide the focus of the empirical investigation in the physical health field.

2.2 Review methods

The literature reviews undertaken for this study were designed to serve exploratory purposes (in relation to the experience of illness and notions of recovery from physical and mental health conditions) prior to the undertaking of phase 1 of the study. As a result, the chapter is necessarily selective given the breadth of literature available on these topics. All searches were carried out regularly over the course of the study in an attempt to ensure the thesis stayed relevant and up to date. A summary of the fundamental argument for and against the undertaking of literature reviews before primary research is summarised in table 1 (McGhee et al. 2007). It seemed there were distinct advantages to carrying out a literature review in conjunction with data collection particularly in relation to grounded theory research where new and unanticipated topics and themes arise throughout the study. Here, the reviews were constructed to guide the study design and to ensure the approach was novel (see chapter 3). However, in later chapters (4-8) data is described in light of other relevant literature that only arose as relevant once the data had been collected and analysed. Therefore the approach appreciated the value of reviewing the literature but did not want to be constrained by a highly structured review at the outset.
**Table 1: Arguments for and against undertaking of literature review prior to data collection**

<table>
<thead>
<tr>
<th>Arguments for a literature review before developing research categories</th>
<th>Arguments against a literature review before developing research categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>To provide justification for the study</td>
<td>To be strictly in keeping with a post positivist ontology</td>
</tr>
<tr>
<td>To meet the requirements of Local Research Ethics Committees</td>
<td>To prevent the researcher being constrained, contaminated or inhibited</td>
</tr>
<tr>
<td>To avoid conceptual and methodological pitfalls</td>
<td>To prevent recognized or unrecognized assumptions</td>
</tr>
<tr>
<td>To discover the extent of previous knowledge and therefore assess whether grounded theory is an appropriate method</td>
<td>To prevent generating a focus from the literature rather than from the emerging data</td>
</tr>
<tr>
<td>To be ‘open minded’ but not ‘empty headed’</td>
<td>To promote ‘telling it as it is’ rather than ‘telling it as they see it’</td>
</tr>
</tbody>
</table>

Source: McGhee et al, 2007

The search engines and terms used along with the number of articles returned for each search in the chapter can be found in appendix 1. These terms were also used to search the internet through websites including Google and scholar Google. Additional search strategies included:

- Manual searches of key journals;
- Reference list searches of key journals;
- Table of contents alerts;
- Citation searches;
- Key author searches;
- Conference attendance;
- Articles recommended by supervisory team;
- Email correspondence from relevant associations (e.g. Mental Health Recovery Network).
All forms of research design were included in the study. Similarly articles were not discarded based on the age of the study in an attempt to be as inclusive as possible. Different variations of the key words detailed in appendix 1 returned a wide range of literature which was scrutinized for their relevance by reading the titles and abstracts.

2.3 The social and cultural context of chronic illness management

This chapter considers literature on recovery against the backdrop of the relevant broader social and cultural norms and changes about chronic illness and its management. These are summarised by Clarke et al. (2003) who discussed the transition from medicalisation (1945-1985) to ‘biomedicalisation’. This transition framed the changes in norms about how chronic illness and its management are dealt with. Medicalisation was an era defined by the dominance of medical ‘voices’ and opinions over lay and common sense approaches more commonly associated with pre-modernity (Cornwell, 1984). This progression to biomedicalisation is seen as reflecting a shift from ‘control over biomedical phenomena to a transformation of them’ (Clarke et al. 2003, p.161) and a focus on health prevention and promotion. Clarke et al. commented on the potential burden of illness activities this poses for patients summing this up in the phrase ‘no rest for the weary’. For those with chronic conditions, preventing deterioration and making healthy changes to lifestyle (secondary prevention) has the potential to add to the already heavy burden of illness and to disproportionately increase burden for those considered to be most deprived (O’Brien et al. 2011). This concept of biomedicalisation has strongly influenced the design and undertaking of the study and it is particularly relevant to the consideration given to the wider social and cultural context (chapter 3). The main components of interest to the current study are:

- The extension of medical control to encompass health as well as illness (e.g. increased focus on risk minimisation and genetic profiling).

- The notion of the patient as a morally responsible individual with the notion of health being a personally valued goal.

- The notion of health services as ‘customisable’.
• The focus on individualised bodies and niche markets as opposed to universal treatments and approaches (generalism).

• The increase in availability of lay information informing health through increased access to internet resources and lay accounts of illness.

• Stratification of health care based on individual resources (predominantly financial).

Despite this list, little is known about how and to what extent they are expressed as features of the experiences of patients with long-term conditions.

2.4 The experience of long-term physical health conditions.

This section endeavours to highlight from the literature what is currently known about how patients experience chronic illness. The chapter will argue that the experience of chronic illness literature does not extend to its natural conclusion because whilst there is some literature focused on ‘recovery’, this has tended to be implicit rather than subject to a full and critical analysis.

2.4.1 Parson’s sick role

A well acknowledged theoretical model designed to understand the experience of illness emanates from the sociologically informed ‘sick role’ developed by Talcot Parsons (Parsons, 1951). Despite the various critiques being levelled at the sick role (see below) (Freund and Maguire, 1995; Gallagher, 1976; Williams, 2005) it has served as useful starting point for much of the following debate and discussion about the notion of recovery in chronic physical illness explored in this thesis. It has, for example, laid the foundation for much of the presumptions about chronic illness and is therefore why it was important to explore at the outset. The assumptions about the relationship between the doctor and patient contrasts with more recent sociological approaches which track the rise of a more equal relationship such as the mutual consumerist model in which ‘patients set the goals and

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4 In Clarke et al.’s paper this related predominantly to medical insurance (Clarke et al. 2003). However, it is likely that this will still be relevant to UK patients given the stratification based on income. For example, the ability to pay for private medical insurance or access alternative and complementary therapies.
Parson’s social notion of the sick role originally focused on acute conditions and challenged the bases of the medical model’s presumption of illness as a purely microbiological invasion of the body. Rather, sickness was viewed as a temporary role legitimated by the medical profession and governed by social values and norms (Parsons, 1951). Illness was seen as a form of social deviance, which caused problems for both the individual and for the wider social system. Using elements from Freudian theory and a functionalist perspective, he portrayed a paternalistic relationship between the doctor and the patient based on the presumption that people would recover (Williams, 2005).

The ‘sick role’ allowed the patient to abstain from normal activities or social roles (e.g. employment, family duties, etc), to surrender their body to medical treatment as well as externalising the illness from the patient and absolving them of any blame for the condition. The model asserted that it was an individual patient’s moral responsibility to pursue recovery. The sick role has been applied to psychiatric patients (the psychiatric sick role) as a predictor of behaviour (Petroni, 1972). Other research found that once those with psychiatric conditions are ascribed the psychiatric sick role it is harder to leave the role than it was from the original sick role (Petroni, 1972).

Studies have also demonstrated that ‘the rights and obligations of the sick role’ apply directly to physical conditions, but not to psychophysical and psychosocial conditions’ (Segall, 1976, p.163). The main reasons for this appear to be a lack of fit in terms of differences in relation to stigma, personal responsibility for illness as well as the assertion that agreement within society in relation to the admission of patients to the sick role diminishes as psychological and social elements of illnesses increase (Blackwell, 1967, cited in Segall, 1967).

Since the inception of the sick role model in 1951, a plethora of research has followed bringing with it various criticisms and re-evaluations. This centred on the relatively low status of the patient; the limited importance attributed to the patient voice within the illness model when compared with the medical practitioner and also included a lack of
consideration given to social and contextual factors (Levine and Kozloff, 1978; Williams, 2005).

The chronic illness sick role

Chronic illness has a significant and diffuse impact on an individual’s life including how they participate in society. For example, these patients appear to participate in a different way following diagnosis through a withdrawal from the social sphere of activity and increased participation in private social activities (Hirschberg, 2012).

Some authors have critiqued the applicability of the sick role to chronic illness (Williams, 2005) predominantly because those with long-term conditions by virtue of their conditions do not get ‘well’ and may also have asymptomatic periods where they could be considered ‘well’ but still require treatment. This has led some to state that ‘from the perspective of societal standards, such persons are incapacitated (deviant) to some degree, and at the same time they must define the new capacity level as normal for them and find new ways to continue performing their role obligations, since their conditions are permanent.’ (Royer, 2008, pp. 54). As a result expectations for those with acute illness and those considered well may not be relevant to the chronically ill.

However, despite these assertions that the sick role is more applicable to acute illness than to chronic illness, Parsons defended its utility in this arena (Frank, 1991). Others have elaborated the specific attributes of chronic illness sick role which centre on the non-temporary nature of chronic conditions and the partial rather than total exception from role expectations (Gerhardt, 1979; Segall, 1976; Kassebaum and Baumann, 1965). It has also been pointed out that the Parsonian approach to chronic illness ‘assumes a societal structure against which the chronically sick person has to define him - or herself’ (Hirschberg, 2012, p.1).

Gerhardt demarcated two models nascent in Parson’s original theory; the incapacity model and the deviancy model (Gerhardt, 1979; Williams, 2005). The incapacity model focuses on the breakdown of role capacity as a result of illness and treatment. The deviancy model considers illness ‘as motivated deviance from the norm to conform with role expectations, the aetiology of which is related to repressed dependency needs which acts as an unconscious motivation to becoming ill (through greater exposure to risks, for example, of
accident, injury or infection), with therapy conceived as a four-stage process of social control’ (Williams, 2005, p.130). Whilst the Parsonian and subsequent conceptualisations of chronic illness have focused on social roles and diminished capacity, they tend not to directly take into account broader notions of recovery.

Literature on illness as biographical disruption (discussed in the next section) and the use of patient narratives within the study of illness (discussed in chapter 3) also has relevance for this thesis.

2.4.2 Illness as biographical disruption

The notion of illness as biographical disruption (BD) is attributed to Michael Bury (Bury, 1982). However, other researchers have extended Bury’s analysis, or critically developed work in a similar vein (Charmaz, 1991; Corbin and Strauss, 1988). Both represent an opening up and legitimisation of the patients’ voice. In his classic paper, Bury reported on his work with newly diagnosed Rheumatoid Arthritis sufferers in which participants were selected to allow the impact of emerging illness to be explored. Bury criticised the assumption underlying the sick role concept which viewed illness/disablement as a relatively stable condition. The approach argued instead that a person with a chronic illness has a more fluid trajectory, which includes periods of adaptation and other periods whereby symptoms were more pervasive (for example, after a surgical episode or sudden exacerbation of symptoms). He hypothesized that chronic illness had similarities to the experience of other major life events such as war (Giddens, 1979) because both experiences had the potential to highlight personal aspects of an individual psyche (for example, the prospect of one’s own death) that may have hitherto remained in the background or within an individual’s subconscious. For a diagrammatic representation of Bury’s model of illness as biographical disruption see figure 4.
As figure 4 demonstrates, Bury proposed that chronic illness impacts upon ‘common sense boundaries’, ‘explanatory systems’ and ‘mobilisation of resources’. Disruption to ‘common sense boundaries’ refers to a disturbance of the individual’s status quo that leads them to consider aspects of bodily functioning that would not normally be at the forefront of their consciousness, which may or may not lead them to seek help. The second disruption to pre-illness ‘explanatory systems’ relates to individuals having to re-consider their own concept of self. Thirdly, ‘mobilisation of resources’ relates to the adaptive response of the individual to the disruption by mobilising their resources in relation to these differing circumstances. In line with Bury’s work, Corbin and Strauss (1988) introduced the BBC (Biographical Body Conceptions) approach to understanding chronic illness. These BBCs are concepts that an individual has about their body which are not temporal in nature but

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5 The notion of a sense of self has been central to sociological studies of the experience of illness (Charmaz, 1983; Charmaz, 1991; Fabrega and Manning, 1972) and is central to discussions within this thesis.

The notion of self has been defined as ‘the product of a person’s own definitions and evaluations of himself’ (Fabrega and Manning, 1972, p97). It is separate from identity in this respect which has been defined as ‘a social placement and a product of the appearances that a person presents to another, or an audience’ (Fabrega and Manning, 1972, p97). This notion of self referred to in this thesis relates to these definitions and also the notion of ontological security (Netleton and Burrows, 1998) which has been defined as ‘a stable mental state derived from a sense of continuity and order in events’ Bilton et al. 1996, p417 which has clear resonance with psychological notions of self-efficacy.
couched in their biographical history or trajectory. Corbin and Strauss hypothesised that chronic illness can disrupt these BBCs (Corbin and Strauss, 1988). Bury developed his theory further by identifying two distinct types of meaning; the consequences for the individuals (in terms of the impact of the symptoms on everyday life) and the significance attributed to the illness by the individual (Bury, 1988). Bury demarcated three aspects that an individual can draw upon to manage the level of disruption; ‘‘coping’ refers to the methods the ill person uses to manage his or her situation emotionally. ‘Strategy’ refers to the way in which the ill person tries, through his or her actions, to deal with illness. ‘Style’ reflects how different people have different attitudes towards illness’’ (Hubbard and Forbat, 2012, p2034). Charmaz undertook extensive work following on from Bury’s work on the loss of self following chronic illness and identified a number of identities that an individual can pursue depending on the nature and extent of the condition. She specifies these as the: ‘‘supernormal self’ which represents an attempt to surpass previous identities and undertake new challenges following diagnosis; a ‘restored self’ (return to prior identity or sense of self) which includes a complete return to prior identity (‘entrenched self’). Re-evaluations of prior identities are incorporated as part of a ‘developing self’ (Charmaz, 1995b). In addition, Charmaz added that individuals can combat biographical disruption by either adapting to disrupted identity or accepting it (Locock et al. 2009). This echoes the work undertaken by Strauss and Corbin (1991) on the process of overcoming disability through comeback which refers to the ‘process of returning to a satisfactory way of life, within the physical/mental limitations imposed by a disabling condition’ (p.363).

Bury’s work generated a range of academic debate and further research relating to illness as a form of biographical disruption (Charmaz, 1983; 1991; Corbin and Strauss, 1988).

2.4.3 Response to illness as biographical disruption

From the available evidence base developed since its inception, it appears the experience of illness as biographical disruption appears to be related to two main areas; contextual and individual factors including age of onset, biographical trajectory and biographical reinforcement (Lawton, 2003).
**Individual factors (e.g. age of onset and biographical trajectory)**

Bury’s model has been applied to a wide range of conditions (Halcomb and Davidson, 2005). The participants in Bury’s original project were relatively young, recently diagnosed rheumatoid arthritis sufferers. In applying the concept to different populations of varying ages, research has demonstrated discrete differences to his original work (Faircloth *et al.* 2004; Pound *et al.* 1998; Sanders *et al.* 2002). In a sample of predominantly elderly stroke patients all respondents described the considerable ways in which the stroke had impacted on their lives. However, the majority of those interviewed viewed the stroke as a normal part of their biographical trajectory or a ‘normal crisis’ and played down its significance (Pound *et al.* 1998). Furthermore, illness as a disruption appears more pronounced in younger patients and that the cultural assumptions regarding expectations of health in older age mean that symptoms can be experienced as both disruptive and ‘normal’ (Sanders *et al.* 2002).

Bury’s notion of chronic illness as a biographical disruption has been contested for those with congenital diseases or abnormalities inherent from birth (Williams, 2000). The rate of disease deterioration is also likely to impact on the level of biographical disruption experienced (Sanders *et al.* 2002). Additionally, the presence of co-morbidities and previous hardships has been shown to reduce the amount of disruption experienced by individuals as they may have already become accustomed to the illness role or experience of difficult times (Cornwell, 1984; Faircloth *et al.* 2004; Pound *et al.* 1998). However, the latter observation is not always the case. This issue is further explored in the following section.

**Contextual factors (e.g. biographical continuity and stigma)**

Carricaburu and Pierret (1995) explored the experience of illness for asymptomatic HIV-positive men who were infected through medical treatment for haemophilia or same sex relations. Both sets of participants demonstrated having evaluated and considered the past to enable them to reconstruct the present. For some haemophiliacs, an HIV-positive diagnosis reinforced their past trajectory of being considered ill, normalising the diagnosis and reinforcing the previous constraints and restraints imposed by the diagnosis. As such an HIV diagnosis served as what Carricaburu and Pierret (1995) coined ‘biographical
reinforcement’. However, others who had previously tried to lead as normal a life as possible prior to the HIV-positive diagnosis demonstrated severe biographical disruption as it was no longer possible to ignore the haemophilia and live ‘normally’. For some respondents HIV diagnosis disrupted their individual sense of self/biography but this was aligned with the collective experience of the gay community. Therefore, diagnosis reinforced elements of their biographical history which allowed them to construct and demonstrate hope for the future. Similarly, studies have shown that religious beliefs can help individuals to construct continuity and minimise disruption in the face of illness (Hinojosa et al. 2008). It appears from these studies then, that placing the illness in the wider context of religious beliefs or collective experiences helps individuals to believe that the illness was pre-determined or serves to reinforce elements of biographical history (Idler, 1995). As a result, illness is not as disruptive as for others who do not employ these strategies.

Other studies have supported the importance of the macro social context impinging on individual adjustment or response by highlighting the impact of gendered norms and stereotypes (Bendelow, 1993; 1995) and historical and socio-political factors (Ville et al. 1994) on the experience of illness. Another theme in the literature is concerned with why some patients do not display disruption post illness and instead used their illness to construct continuity (Hinojosa et al. 2008). One possible reason put forward is that the self is a multi-faceted concept and, as a result, there can be many ‘selves’ apparent or available to an individual at any one time (Hinojosa et al. 2008). Furthermore, an individual sense of self is likely to be dynamic in nature and change as a result of self-interpretation and re-evaluations that occur in relation to different contexts and life events. Therefore, it has been posited that it is only when changes occur too quickly that disruption occurs (Hinojosa et al. 2008). In this way, and in line with the study cited above, people can use other elements of their identity (e.g. being a granddad, being a member of the gay community or being a Christian) to construct continuity of the self-concept in the face of illness (Kvigne et al. 2004).

It is clear in the literature that the type of illness can also affect the level of biographical disruption experienced by patients. For example, those diagnosed with conditions perceived to have elements of stigma attached to them (e.g. epilepsy) appear to experience greater
biographical disruption (Scrambler, 1989). Alternatively, conditions such as arthritis, which were perceived as a natural progression of ageing or are shared with others, are more likely to be attributed to a ‘normal’ biographical trajectory (Hinojosa et al. 2008; Sanders et al. 2002). The threat of, or actual, stigma appears to give rise to social comparison in the research reviewed (Pound et al. 1998; Sanders et al. 2002) with individuals wanting to distance themselves from those they perceived to be very ill in a bid to be more socially accepted (Bury and Holme, 1991). This becomes increasingly relevant when you consider the context of the interview situation to be undertaken in this study (e.g. healthy researcher undertaking interviews; Radley and Billig, 1996) and highlights the need to be aware of notions of public/private accounts of illness (Cornwell, 1984; Radley and Billig, 1996) which have led some to assert that notions of biographical disruption may be an artifact of the research process (Bury, 2001) This will be discussed in more depth within chapter 3.

More recently, studies have further challenged the ability of biographical disruption to fully capture the lived experience of particular types of illnesses. For some this has related to the centrality of the assumption that the patient is a purely reflexive self in all situations. Specifically, this led to the derivation of two concepts; biographical continuity and biographical fracture. Reflexivity is more commonly associated with periods of biographical fracture (Reeve et al. 2010). Research with cancer survivors suggests that it is not possible to compartmentalise patients into dichotomous categories because ‘some changes to their lives are constructed as permanent and having a profound impact on their anticipated life course and identity, whereas other disruptions are downplayed or presented as being successfully managed’ (Hubbard and Forbat, 2012, pp.2039).

Recently, the notion of biographical disruption has been applied to understanding progressive neurological conditions such as motor neuron disease (considered at the boundary of chronic and terminal disease; Locock et al. 2009). As well as identifying elements of biographical disruption, narratives pertaining to diagnosis as a death sentence led to a conceptualisation of ‘biographical abruption’. Research with newly bereaved parents whose children committed suicide also identified the concept of ‘biographical disintegration’ within the parents’ narratives (Owens et al. 2008). These authors then have highlighted the complexity of biographical disruption and also its potential applicability.
They argue, as a result, for greater understanding of the emotional context of narratives rather than solely on the disruptive events themselves (Reeve et al. 2010).

Others have argued that for slowly developing conditions such as Chronic Obstructive Pulmonary Disorder (COPD) biographical disruption does not occur and instead illness and life narratives unify, and patients slowly adapt their sense of self over the course of the illness (Pinnock et al. 2011). Implicit to some of the findings of the above studies is the notion that meanings, a sense of self, and the impact and perceptions of chronic conditions are not static. As Blumer (1969) pointed out, meaning is expected to change over time as individuals grasp new understandings of their situations. In relation to chronic conditions these new understandings and disruptions can occur as a result of reflection over time as well as a change in physical conditions or events in domestic and social environments (Callero, 2003). These aspects are implied in biographical disruption literature but frequently not harnessed to a longitudinal methodological approach. Hallowell et al. (2006) also makes the point in relation to change over time that pre–illness identity is also absent from the literature on biographical disruption. This apparent gap in the existing literature suggests the need to adopt an approach capable of exploring changes in meaning and identity over time which may influence peoples notions of recovery and prognosis (see chapter 3).

2.5 Recovery and physical health conditions

This section will explore what literature is currently available on patients’ perceptions of recovery in terms of chronic illnesses such as diabetes, heart disease and arthritis and points to the fact that research into physical health condition rarely extends beyond traditional biomedical definitions of recovery. Cancer studies are discussed at the outset because of the consideration given to wider aspects of recovery when compared with other conditions such as diabetes, heart disease and arthritis.

2.5.1 Recovery and cancer

Given increased survival rates, cancer has been considered by some to constitute a chronic condition although this is not universally accepted (Titter and Calnan, 2002). Whilst unique aspects of the experience of cancer remain, studies exploring the experience of
cancer can provide insight into expectations about recovery and prognosis from other chronic conditions.

Recovery from cancer has tended to be framed in terms of ‘survivorship’, focusing on individual determination and decision making via the use of military type metaphors such as ‘invasion’ and ‘battle’ to provoke what has been termed the ‘fighting spirit’ of cancer sufferers (Coreil et al. 2004). Additionally, research has focused on processes of ‘adjustment’ to cancer. This framing has been refuted by some cancer sufferers who question the pressure to conform to a monolithic type of recovery preferring a model that allowed for feelings of doubt and pessimism and highlighted the importance of individual quality of life (Mathews, 2000). Others have argued that the use of military metaphors in discourses about cancer can increase the stigma and isolation experienced by patients (Sontag, 1990). A study by Broom (2001) illuminated how breast cancer sufferers experience challenges associated with the disease extending beyond biomedical symptoms to include the impact of the disease on a sense of femininity, sexual functioning and uncertainty about the future (Little et al. 2000). Studies of the experience of cancer also challenge the traditional restitution models of ‘recovery’ in suggesting other forms of ‘recovery’ akin to Frank’s notion of being successfully ill and highlighting cancer memoirs which are often centred on healing experiences. Other research suggests that patients often do not have detailed plans on how to recover and demonstrate the impact of cancer on an individual’s relationship with their social network (Yaskowich and Stam, 2010).

A darker side to ‘recovery’ or ‘survival’ of cancer can be challenging for people trying to reintegrate into the pre-illness worlds (Little et al. 2000) encompassed in the notion of liminality:

‘An initial acute phase of liminality is marked by disorientation, a sense of loss and of loss of control, and a sense of uncertainty. An adaptive, enduring phase of suspended liminality supervenes, in which each patient constructs and reconstructs meaning for their experience by means of narrative. This phase persists, probably for the rest of the cancer patient’s life. The experience of liminality is firmly grounded in the changing and experiencing body that houses both the disease and the self’. (Little et al.1998, pp. 1485).

Liminality points to an awareness of post illness labelling as a cancer patient, the fallibility of the body being brought to the foreground of consciousness, an awareness of a dangerous

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6 Defined as living post treatment with no recurrent or persistent cancer.
episode and that they, as a person, are alone in this experience (Little et al. 1998). Such liminality disrupts a sense of continuity for patients and in the way they are viewed by others. As a result challenges to self-identify come from within (distorted relationship with body) and from external forces (disrupted relationships with others. Little et al. (1998) defines three responses to these tensions:

- Reactance – manifested in withdrawal from social situations or confrontation with others e.g. healthcare workers, friends and family.
- Acceptance – allows an individual to embrace the cancer label and lead a different life accordingly accepting the limitations and scope of the role of cancer patient.
- Reorientation – a more active response where despite accepting the illness, patients rebuild their lives to allow meaning to be created which extends outside the realm of illness.

Little et al. (2002) elaborated the aforementioned categories with reference to the notion of disruption; embodied discontinuity (permanent changes to the corporeal body), existential disruption (changes to elements of identity, e.g. the inability to undertake paid employment) and disruptions to the memories of others, e.g. friends and family. Little et al. (2000) suggest an individual can deal with these disruptions through the use of anchor points (such as religion, which helps guide them through the difficult periods), resumption (reconstruction of identity through the reinforcing or incorporation of elements of unaffected self-identify), assigning meaning to the traumatic experience (self-construction through the addition of new facets to the self-identity), accepting the importance of future memories (e.g. acknowledging and predicting that in the future there will be experiences and activities that the individual will no longer be able to enjoy or participate in) (Little et al. 2002).

Broom (2001) points to the stigma of a cancer diagnosis and the felt social inappropriateness of talking about experiences with cancer which can lead to isolation (Broom, 2001). Support groups can provide a sense of community for cancer sufferers which create a sense of belonging through the sharing of mutual experiences and information (Ussher et al. 2006). This study also cited the use of humour in talking about
illness which is present in a group setting and contrasts with feeling under pressure to appear well in front of others. In this sense, support groups appear to complement existing support systems such as close friends and family by facilitating the normalization of the disease and enabling participants to get on with their lives or ‘recover’.

From the findings of studies reported above, one can infer some notions of recovery which are wider than biomedical type recovery which appear related to reformed self-identity post diagnosis and the generation of hope and optimism for the future. Parallels can be drawn with the narrative work undertaken by Frank (1995) discussed in the next chapter. This thesis can add to this literature by focusing on individual accounts over time. Individual in-depth interviews may produce different narratives as focus groups may produce more public rather than private accounts. There have been calls for the incorporation of longitudinal methods to explore change over time (Rasmussen and Elverdam, 2007).

**2.5.2 Cerebrovascular conditions and recovery**

For cerebrovascular conditions (namely strokes and chronic heart disease), studies have focused on biomedical elements of functional recovery. However, any references to, or inferences about, wider definitions of recovery could have links to this thesis and for that reason are explored in this section.

Prior to 1968 cerebrovascular conditions and their recovery was predominantly conceptualised as biomedical and it was only after this time that consideration was given to wider social and psychological variables which can often be as debilitating as the medical conditions (Doehrman, 1977). Studies have demonstrated the debilitating effects of invisible symptoms in terms of the impacts that patients report from stroke (Murray and Harrison, 2004). This includes things like romance and sexuality and changes to emotions, social interaction and involvement which may feature in any perceptions relating to recovery and prognosis.

Studies looking at recovery from heart conditions have identified two adjustment strategies; defying the condition and carrying on as before and/or adapting lifestyle and behaviours as a result of the heart attack (Radley, 1989). These are fairly simple categories and there are likely to be further more nuanced perceptions and behavioural impacts operating within these populations and for different conditions.
Other studies have demonstrated a discrepancy between the expected response to information provided by health professionals in terms of recovery and the lived experience of patients. Participants used their own belief system and experience to understand their illness and recovery which was often optimistic compared to the information provided by health professionals (Wiles, 1998). However, this study only had contact with participants two weeks and three months post heart attack so the perceptions of recovery reported are limited notions of recovery and those over the longer term were not examined. Other studies have used quantitative data to highlight the role of work and taking extended sick leave and the impact this had on feeling valued in the workplace and its subsequent impact on wellbeing (Wickhold and Fridlund, 2003), drawing attention to but under exploring an important component in recovery.

2.5.3 Recovery, back pain and arthritis

Traditional measurements of recovery from musculoskeletal conditions include self-reported measures of pain (Hush et al. 2009). However there is evidence to suggest that these do not relate well to individual experiences, recovery or treatment outcomes (Campbell et al. 2003). This suggests that patients’ perceptions of recovery are wider than that of a traditional biomedical focus and are likely to incorporate further social and psychosocial domains and these need to be addressed in the management of arthritis patients (Nicassio et al, 2011).

Studies have found that recovery from low back pain is slow, often not fully restitutitional (Hush et al. 2009) and heterogeneous. Domains of recovery range from the biomedical (e.g. reduction in pain severity) to more socially orientated domains (e.g. improved activity levels, including being able to play with children (Williams and Myers, 1998).

An Australian qualitative study of recovery of lower back pain identified domains of recovery including symptom attenuation (incorporating both a theme of complete symptom resolution and incomplete symptom resolution), improved function in work, self-care, everyday activities, exercise and leisure, obtaining an acceptable quality of life which related to sleep, social participation, and physical and psychological health. These domains were not mutually exclusive but were dynamic and interactional. Furthermore, the study demonstrated that recovery was a not finite but rather an ongoing journey for those with
lower back pain differentiating it from other conditions such as a broken bones where recovery could be restitutinal. Most importantly for this study, the research demonstrated the idiosyncratic nature of recovery for those involved and highlighted that recovery involved getting back a former sense of self that was ‘damaged’ following diagnosis (Hush et al. 2009).

Despite the limited research into recovery and physical health conditions, links have been demonstrated between recovery expectations and a number of outcome measures for conditions such as low back pain (Gross and Battie, 2005) which has led to calls for further research into expectations relating to recovery in order to better understand self-management and behaviours post diagnosis (Wiles, 1998). The next section introduces the concept of recovery from the field of mental health as a possible sensitising concept which may facilitate the illumination of this hitherto underexplored element of the chronic illness experience.

2.6 Recovery and mental health

2.6.1 Introduction to the concept

The notion of ‘recovery’ has emerged as a core concept in the mental health field and thus provides a source of information relevant to chronic physical illness in terms of themes to pursue in the empirical part of this thesis. Prior to the late 1980s, the idea of recovery was more commonly found within literature relating to treatable physical conditions and overcoming deficits which resulted from trauma. For example, in the field of oncology recovery or remission is primarily defined as being disease free (no signs or symptoms of cancer) for a given period of time (Department of Health et al. 2010; Farooq, 2011). The term has acquired a specific meaning in relation to mental health and the purpose of this section is to explore its meaning and application within mental health services. Given that mental health conditions are often chronic long-term conditions, there are likely to be similarities with the experience of chronic physical conditions (Fabrega and Manning, 1972). Exploring what has been found in the field of mental health may allow some notions of recovery to be identified that could be tested or used as a lens through which to look at
the data from physical health conditions to address the aforementioned gap within the literature.

The concept of recovery is aligned ideologically to the ethos of positive psychology, which emerged in the United States informed by humanistic approaches which grew in popularity in the second half of the twentieth century gaining popularity internationally (Rogge, 2012). Positive psychology explores the conditions that allow individuals and communities to flourish by focusing on individual fulfilment and wellbeing - it emphasises salutogenesis (Antonovsky, 1979; 1996) which focuses on why and how people stay healthy, self actualisation and quality of life rather than on dysfunction (Rogge, 2012). Bandura’s theory of self-efficacy is aligned with positive psychology and relates to the beliefs a person has about their capability of attaining goals (Bandura, 1977). This idea has clear relevance to the assumptions inherent within the policy documentation relating to chronic physical conditions outlined in the previous chapter. The positive psychology approach has taken a more academic path since its inception compared to the separate, yet parallel, grassroots journey of the recovery movement. However, positive psychology has previously focused solely on healthy people to the detriment of the study of illness. As a result, despite the separate movements, there have been recent calls for better integration of the two approaches in order to improve the applications of both (Resnick and Rosenheck, 2006).

In terms of mental illness, recovery is a well documented, multi-faceted concept, with at least three definitions operating in the literature (Pilgrim, 2010):

- ‘Recovery from illness, i.e. an outcome of successful treatment (predominantly medical);

- Recovery from impairment, i.e. an outcome of successful rehabilitation rooted in community orientated social psychiatry.

- Recovery from invalidation, i.e. an outcome of successful survival.’ (Pilgrim, 2010, p.296).

Davidson and Roe (2007) provide a useful distinction between ‘recovery from’ and ‘recovery in’ mental illness. ‘Recovery from’ mental illness is associated with the process of becoming asymptomatic following a previous diagnosis and is aligned to Pilgrim’s
definition of ‘recovery from illness’ and ‘recovery from impairment’. ‘Recovery in’ mental illness refers to the remaining proportion of people who do not recover in the traditional sense of the word and relates to the ‘recovery from invalidation’ concept and instead refers to a process of learning to live with and/or coming to accept the illness. These categories of recovery are not mutually exclusive and different conceptualizations of recovery have the potential to co-exist at any one time.

This idea of ‘recovery in’ mental illness accepts that the condition may not go away entirely and concentrates instead on how to live and cope with the condition whilst highlighting an individual’s right to social inclusion despite the diagnosis. It has been described in the literature as:

‘A deeply personal, unique process of changing one’s attitudes, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness’ (Anthony, 1993, p527)

According to this definition, recovery from mental illness implies more than recovery from the illness extending to the stigma experienced by those with mental health problems, side effects or difficulties associated with medication or treatment, and loss of opportunities including employment or access to social activities. In this sense, recovery is not achieved easily and is often complex. This notion of stigma has not been explored within the data from the physical health field to the same extent.

The recovery approach rejects professional authority to define recovery alone and instead emphasises individual service users in framing their own preferred recovery state (Faulkner and Layzell, 2000). Recovery is viewed as a personal journey for individuals involving work in a number of areas including feelings, competencies and aspirations for the future.

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7 It is useful at this point to make the distinction between primary and secondary deviance. Primary deviance is any deviance (signs, symptoms or behaviours) displayed before the person displaying the ‘deviance’ is labelled as such. Whereas secondary deviance relates to any signs, symptoms or behaviours that occur after the aforementioned labelling and relates to the institutionalisation effect.

8 Whilst recovery is referred to here and at other points in the chapter as a singular entity, it is important to acknowledge that each interest group frames the character and ownership of the term ‘recovery’ differently. The only assertion to commonality from politicians, managers, clinicians and users is that it connotes optimism (McCranie, 2011). But even then, optimism about what, for what reason and according to whom becomes complicated. It is not possible within the remit of this chapter to resolve or adjudicate on this complexity but it does need to be kept in mind when reading the chapter.
Health professionals can be involved and are often acknowledged in facilitating recovery though are not necessary for it (Slade et al. 2012).

This notion of recovery outlined above contrasts with some of the ideas previously held within psychiatry. For example, the assertion that mental health problems and schizophrenia in particular were inherited conditions which would degenerate progressively until sufferers ended up ‘severely demented.’ (Kraepelin, 1904). Such negative prospects projected onto those with psychosis have had consequences for negative prognoses and meant that service providers limited the time spent, and treatment provided to, those with mental health problems (Liberman et al. 2002). These negative perceptions relating to prognosis have also been evident as prevalent amongst service users (Deegan, 1997) which are considered to be exacerbated by the system and classification of diagnosis (Andresen et al. 2003)⁹.

These negative prognostic assertions discussed in the above paragraph are challenged by evidence from studies about the prognosis and trajectories of mental health conditions (Ciompi, 1980; Davidson and McGlashan, 1997). Studies have demonstrated the resilience of those with psychiatric disabilities (Deegan, 2005) and that there are a significant and different range of individual differences in outcome for those with mental health problems. Not all are negative (Harding et al. 1987; McGlashan, 1988). It appears then that these studies provide sufficient evidence to refute Kraeplin’s assertions relating to the prognosis of mental health problems and support the different conceptions of recovery proposed (Davidson and Roe, 2007; Pilgrim, 2010).

2.6.2 “Better but not well”¹⁰: An historical account of the development of recovery in mental health

‘Recovery from invalidation’ or ‘recovery in’ mental illness are notions which have gained increased attention within the field of mental health and emerged during 1970s and during the period of deinstitutionalization (Anthony, 1993)¹¹. At around the same time the notion

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⁹ For example a diagnosis of schizophrenia, in the existing format, does not allow for people who do recover (Kruger, 2000).

¹⁰ Term used originally by (Frank & Glied, 2006, cited in McCranie, 2011).

¹¹ However, the term recovery is by no means new, ‘the roots of a concept of recovery – if not the term – have been traced back to over 200 years ago to Philippe Pinel and his treatment moral in Paris asylums’ (McCranie,
of self-help was becoming increasingly popular for a number of reasons including a prevailing distrust of professionals, the need to address stigma, improve services, and to provide sufficient support and a recognized place in society to more disadvantaged sections of communities (Back and Taylor, 1976).

Deinstitutionalisation meant that statutory services in the form of mental institutions were no longer responsible for the care of people with mental health problems. Instead, community based treatment services were established along with other types of inpatient settings. For some these services are still not meeting the needs of users because of a continued, specific focus on biomedical issues relating to symptom alleviation rather than treating the ‘whole person’ (Anthony, 1993). Some longitudinal research has suggested that treatment has not improved significantly for those with mental health problems over this period of deinstitutionalisation (Ciompi, 1980). Post deinstitutionalisation the critique of treatment continued especially regarding the iatrogenic effect of drugs as a main form of treatment (Rogers et al. 1998).

This period of reconceptualisation, in line with the survivor/consumer movement occurring around the same time, along with novel research evidence placed a new emphasis on recovery. This movement occurred against a backdrop of other civil rights movements. It should also be noted at this point that the World Health Organisation developed a model of illness in 1980 that included the illness but also any consequences of this illness in terms of disability and disadvantage (Wood, 1980 cited in Anthony, 1993) which is more reflective of recovery approaches. Table 2 displays a table taken from Anthony’s paper in 1993 in which he describes the rehabilitation model and how it is applied to those with severe mental illness.

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2011, p473) and was behind a self-help treatment group started in 1937 which is still in existence today albeit in a different guise (e.g. Recovery Inc, McCranie, 2011).
Table 2: The negative impact of severe mental illness (Anthony, 1993)

<table>
<thead>
<tr>
<th>Stages</th>
<th>1. Impairment</th>
<th>Dysfunction</th>
<th>Disability</th>
<th>Disadvantage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Definitions</strong></td>
<td>Any loss of abnormality of psychological, physiological, or anatomical structure or function.</td>
<td>Any restriction or lack of ability to perform an activity or task in the manner or within the range considered normal for a human being.</td>
<td>Any restriction or lack of ability to perform a role in the manner or within the range considered normal for a human being.</td>
<td>A lack of opportunity for an individual that limits or prevents the performance of an activity or the fulfillment or a role that is normal (depending on age, sex, social, cultural factors) for that individual.</td>
</tr>
<tr>
<td><strong>Examples</strong></td>
<td>Hallucinations, delusions, depression.</td>
<td>Lack of work adjustment skills, social skills.</td>
<td>Unemployment, homelessness.</td>
<td>Discrimination and poverty.</td>
</tr>
</tbody>
</table>

The notion of recovery was echoed in the professional literature such as the policy documentation of other countries, including the United Kingdom (Ramon et al. 2007). It gained momentum due to a perceived failure of services and society to support social inclusion successfully and the aforementioned longitudinal studies which demonstrated that some people with mental health problems can indeed recover (Ciompi, 1980; McGlashan, 1988).

This section has described the origins of the concept of recovery in mental health. This approach is based on a social model and supports an individual’s potential for recovery which is seen as a personal journey. However, this idea is not fully embedded in public consciousness and is still poorly understood. The reasons for this may be related to a lack of shared definition of recovery and this will be explored in later sections. In addition, sociologists have called for greater understanding of the social construction of recovery, enhanced integration with identity research and improved understanding of how recovery is stratified which is likely to have implications for improving health services for the most vulnerable (McCranie, 2011). The remaining sections of the chapter will explore what recovery is and how it is experienced by those with mental health problems before turning to critique the concept and explore its applicability.
2.6.3 What does recovery mean to people with mental health problems

Anthony (1993) argues that recovery is a deeply human experience and likens it to the experience of significant life events such as bereavement or other forms of tragedy. In line with these experiences, recovery does not mean that the illness or significant life events never happened but that the individual learns to cope with it and move on with their life in a way that is meaningful to them. The language used in Anthony’s paper is reminiscent of the work on biographical disruption discussed previously within the chapter (Bury, 1982).

Since the late 1980s and early 1990s, the concept of recovery has been found recurrently in policy documentation, mission statements of individual trusts and statements from clinicians and service users alike (Jacobson, 2001). The notion of recovery has generated divided opinion, with some viewing it as a simplistic concept and others perceiving it to be revolutionary in nature (Bonney and Stickley, 2008). This varied use of the concept of recovery has led to some confusion about its meaning. Recovery has been described as something that is experienced personally by users themselves. It is also described as a set of values, a movement, a philosophy, an approach, and as something that mental health services strive to promote and facilitate through policy and behaviour. Whilst predominantly focusing on psychosis, there is a relevant and emerging literature on recovery from depression which be explored in more depth later in the chapter (Ridge and Ziebland, 2006). This eclectic interpretation and use of the concept, means that it is often poorly understood by people on the ground (e.g. service users and front line staff, Jacobson and Greenley, 2001). Additionally, it has been argued that the rhetoric about the concept of recovery far outweighs actual knowledge about what recovery means for individual people in different situations and different communities (Pilgrim, 2009). However others have argued that the wide and vague definition of the concept has contributed to its use in different areas allowing recovery to be discussed as a process, as an outcome or both (Mueser et al. 2006). This section will outline and critically assess current research on the meaning and experience of ‘recovery’ as both an outcome and a process.

**Recovery as an outcome**

Recovery defined as an outcome has been associated with more scientific definitions of recovery coupled with attempts to quantifiably measure recovery and produce an evidence
base (Bellack, 2006). However, these studies have drawn comment for their focus on the biomedical and their lack of incorporation of the voice of service users. As a result, there have been some qualitative studies which have endeavoured to define a recovery state in a less traditional scientific way.

There have been a number of attempts to measure recovery quantitatively through the development of scales and questionnaires (Corrigan et al. 2004; Gifford et al. 1995). Researchers involved in constructing these measures report difficulties in conceptualising recovery and in ensuring the validity as an independent variable because it appears to conflate with, or is closely related to, a number of variables and constructs used in studies (Corrigan et al. 2004). The measures are also quite labour intensive in terms of administration (Corrigan et al. 1999).

Quantitative studies such as the ones described above have been criticised for excluding the voices of service users and for being too simplistic or biomedically focused. This has lead researchers to explore the notion of recovery as an outcome by utilising qualitative methods.

In an attempt to address some of the criticisms with quantitative studies, researchers have attempted to utilise qualitative methodology in an attempt to incorporate the voice of the service user. For example, Liberman et al. (2002) considered that an individual could be perceived to be ‘recovered’ if the criteria below were met consecutively for two years.

- **Symptom remission** – e.g. the absence of clinically significant positive and negative symptoms;
- **Adaptive work and social functioning** – e.g. full or part-time involvement in either work or school or social activities for those of retirement age;
- **Independent living** – e.g. without supervision or total reliance on disability allowance.
- **Having regular social activities with friends or family;**
- **Participation as a citizen** (e.g. voting, self-advocacy etc) (Ng et al. 2008).
These criteria were derived from a literature review and then tested with service users participating in focus groups. This definition contains strong biomedical elements and has been criticised by users and professionals alike for what are seen as the use of arbitrary criteria (Bellack, 2006).

Studies have examined the available literature on recovery and identified some key themes. Insight or the ability to have awareness that one is suffering with an emotional illness was identified as a key theme within the literature and that this was strongly related to treatment compliance and trajectory of the illness (Greenfield et al. 1989; Young and Ensing, 1999).

Regaining a sense of ‘self’ appeared as a salient to be a theme in the literature around recovery facilitated through the successful retrieval of hope (Young and Ensing, 1999). This is reminiscent of Bury’s work relating to illness as a biographical disruption12 and the importance of hope has also been identified within the data from physical health conditions (Barnard, 1995; Mattingly, 1998). In line with work in the physical health field, significant others can impact on personal hope for the future (Mattingly, 1989). In recovery research specifically hope has been identified as critical in the recovery journey through its contribution in providing ‘turning’ points in an individual’s trajectory (Hobbs and Baker, 2012). However, there is no integration about these individual observations within the current literature. Empowerment or self efficacy facilitated by developing individual coping mechanisms is also identified as relevant to enacting recovery in the literature. Social support and access to a supportive social environment in which to recover are also identified as important (Young and Ensing, 1999).

Recovery as process

Given that recovery is portrayed as a personal journey which is likely to be fluid, non-linear and develop over time, it is potentially more important to consider recovery as a process. Most researchers in the field now accept that a thorough understanding of recovery must be firmly based in the lived experience of recovery (Slade et al. 2012). There have numerous attempts to provide models of the process of recovery (Jacobson and Greenley, 2001; Jensen and Wadkins, 2007; Leamy et al. 2011; Ralph, 2000).

---

12 A sense of self and how this is perceived by participants seems central to literature on both physical and mental health conditions (Charmaz, 1991; Davidson and Strauss, 1992).
The components of recovery as a process include internal and external factors and are summarised in table 3 (Jacobson and Greenley, 2001; Ralph, 2000).
Table 3: Models of recovery as a process

<table>
<thead>
<tr>
<th>Internal factors</th>
<th>Ralph, 2000</th>
<th>Jacobson and Greenly, 2001</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Awareness of the impact of illness</td>
<td>Attitudes, experiences and processes of change within individuals</td>
</tr>
<tr>
<td></td>
<td>Insight into the need for change and how this can be achieved</td>
<td>Hope (believing recovery is possible, a focus of strengths and looking forward)</td>
</tr>
<tr>
<td></td>
<td>Determination to make changes</td>
<td>Healing (defining and striving towards a self apart from illness(^{13}) and obtaining a sense of control over the effects of mental illness e.g. successful symptom management),</td>
</tr>
<tr>
<td></td>
<td>Spirituality</td>
<td>Empowerment (relating to autonomy and having the knowledge and self-confidence to act in an autonomous manner),</td>
</tr>
<tr>
<td>Self managed care (extension of internal factors)</td>
<td>User involvement in care</td>
<td>Connection (in this sense re-relating to the external social world)</td>
</tr>
<tr>
<td></td>
<td>Responsibility for care</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>External factors</th>
<th>Links with others</th>
<th>The circumstances, events, policies that facilitate recovery:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Support from friends, family and medical professionals</td>
<td>Human rights (specifically relating to stigma and discrimination),</td>
</tr>
<tr>
<td></td>
<td></td>
<td>A positive culture of healing (relating to tolerance, safety, respect and shared decision making),</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Recovery oriented services</td>
</tr>
</tbody>
</table>

| Empowerment       | Determination and links with others              | None                                                          |
|-------------------|--------------------------------------------------|                                                               |
|                   | Advocacy                                         |                                                               |
|                   | Consideration for what happened to self and others. |                                                               |
|                   | Social empowerment (ability to find safe, appropriate and affordable housing, roles in employment or the community) |                                                               |

\(^{13}\) It has been reported that those suffering with mental health problems often report a ‘loss of self’ following diagnosis and that recovery in this sense can redefine the self so that illness only forms a part of the self rather than the whole self. This is further complicated by the stigma (both real and enacted) experienced by those with mental health problems (Estroff, 1989; Scrambler, 2004).
Andresen et al (2003) identify five stages of recovery from a review of published accounts of recovery: moratorium; awareness; preparation; rebuilding and growth. This interpretation seems to rule out a full return to the former self and on many occasions users felt as though the experience of mental illness had, in fact, made them a better person.

Within this paper these five stages of recovery were mapped against previous attempts to identify stages of recovery (see Table 4 below). Their analysis identified four key processes; finding hope (considered the catalyst for recovery), re-establishment of identity; finding meaning in life; and taking responsibility for recovery. The setting of new personal goals was described as pervasive in the personal accounts and an idea that acted to link the four processes.

**Table 4: Comparison between different stages of recovery undertaken by Andresen et al. 2003**

<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>Moratorium</td>
<td>1. Crisis Recuperation</td>
<td>1. Initiating recovery</td>
<td>Meaning of illness</td>
<td>1. Overwhelmed by the disability</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. Why me?</td>
<td></td>
<td>What now?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Awareness</td>
<td>1. Awareness of a more active self.</td>
<td>1. Initiating recovery</td>
<td>Meaning of illness</td>
<td>1. Overwhelmed by the disability</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. What now?</td>
<td></td>
<td>What now?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preparation</td>
<td>2. Taking stock of self.</td>
<td>2. Decision Rebuilding Independence</td>
<td>2. Struggling with the disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. Putting self into action.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rebuilding</td>
<td>3. Improving quality of life</td>
<td>3. Regaining and moving forward</td>
<td>3. Living with the disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>4. Appealing to the self</td>
<td>3. Regaining and moving forward</td>
<td>3. Living with the disability</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: Andresen et al. 2003

In a recent systematic review and narrative synthesis which undertook to bring together previous frameworks and models of recovery, 13 characteristics of recovery and five recovery processes of recovery were developed (Leamy et al. 2011). The 13 characteristics of recovery were as follows:
Recovery as:

- an active process;
- an individual and unique process;
- a non-linear process;
- a journey;
- a series of stages or phases;
- a struggle;
- a multidimensional process;
- a gradual process;
- a life-changing experience;
- process without cure;
- as aided by a supportive and healing environment;
- something that can occur without professional intervention;
- a trial and error process.

Source: Leamy et al. 2011

The five recovery processes were identified as connectedness (social support and enmeshment with local community), hope and optimism for the future (belief and motivation for change and having relationships that inspired hope), identity (rebuilding positive identity and overcoming stigma), meaning of life (spirituality, meaning roles and rebuilding lives) and empowerment (personal responsibility and control) (Leamy et al. 2011). The study also found that participants from Black and Minority Ethnic (BME) groups focused more within the recovery process on spirituality and stigma.

One of the most difficult tasks associated with recovery is reforming a sense of identity that includes both the self prior to mental illness and the new self whilst allowing for future hope and development. Again this echoes the work of researchers in the field of physical health who explored the notion of illness as biographical disruption. However, this hope for the future needs to be accompanied by opportunities which are often not afforded to
individuals with mental health problems (Slade et al. 2012) and also implicates social networks which can be less in evidence for those with mental health problems (Forrester-Jones et al. 2012). The wider community are an untapped resource (Wisdom et al. 2008) and reconnecting with others and reconnecting with times (e.g. having hope for the future) is relevant for maximising the likely success of recovery. The discussion about time is reflective of some work on chronic physical health conditions (Charmaz, 1991).

Individual accounts of recovery suggest the process of recovery is not an easy one (Leamy et al. 2011). The shift from a paternalistic relationship with service providers and changing from assuming a passive role in interactions with health professionals to a more active one is likely to be fraught with difficulties. Service users have reported the difficulties experienced in recovery journeys including taking on responsibilities and planning adequate coping strategies (Leete, 1989). However, this notion of the mental health service users as an active ‘consumer’ or what has been described a ‘prosumer’ (e.g. service users as professionals within the health service) is widespread (Frese and Davis, 1997). These ‘strategies’ have been explored in a fairly recent qualitative study which lead the researchers to coin the phrase ‘personal medicine’. This referred to self-motivated, non-medical self care strategies which served to decrease effects such as symptomology and increase wellbeing. The study demonstrated that there were two types of strategies; those that gave meaning to life (e.g. valued social roles and activities including employment and volunteering) and specific self-care strategies (e.g. exercising, collecting items, fishing, and puzzles). However, it is interesting to note that participants often did not share these techniques with medical professionals nor were they asked about them (Deegan, 2005). Understanding these techniques and their relationship with traditional treatment may serve to further develop the understanding of self-management and self-care.

The stages of the progress of recovery discussed so far have been useful in advancing our understanding of the experience service users have during the process of recovery. However, what these models fail to demonstrate is how these stages impact on each other and the mechanisms at play in each of these stages (Noiseux et al. 2009).
Recovery and depression

The literature cited within this chapter so far has mostly focussed on literature in the field of psychosis. However, there is an emerging literature on recovery and depression which is the most common mental health problem and the leading cause of nonfatal disease burden (Üstün et al. 2004). These studies have demonstrated some overlap to the aforementioned models and specifically that recovery from depression is considered a long-term process whereby “people attribute meanings to depression, getting better, and the self, and use tools to minimise depression and aid recovery” (Ridge and Ziebland, 2006, pp. 1050).

Furthermore, the centrality of restoring a notion of self in the process of recovery has been highlighted (Chernomas, 1997; Fullagar and O’Brien, 2012). For example, studies have identified that when those with long-term physical conditions experience mental health problems this may be related to their sense of identity being overwhelmed by physical illness (e.g. becoming a ‘diabetic’) further implicating a sense of self within the study of recovery (Goldman and Maclean, 1998). It may be that these notions of recovery from depression are closer to perceptions of recovery and management of long-term physical conditions and therefore merit consideration within the thesis.

There is also a much wider literature on the co-morbid relationship between depression and long-term physical conditions. However, as stated previously the focus of the thesis is on recovery and long-term physical health conditions without the presence of mental illness and what may or may not be unique about that.

This section has explored the concept of recovery from mental health. This was undertaken to allow a comparison with the findings from this study exploring physical illness but also to provide a sense of continuity with physical illness. However, it should be noted that it is often the case that physical problems occur together with mental health problems and therefore it is difficult to split the mental health effects from the physical effects. This is particularly true of people suffering from comorbidities (Gask et al. 2011; Lau, 2005) and those who have chronic physical conditions but have not formally been identified as having a mental health problem but experience some signs of distress or mild depression (Gask et al. 2011). Whilst this thesis focuses on recovery from long-term physical illnesses without the acknowledged present of mental illness, these issues relating to comorbidity are
nonetheless important and any findings will be discussed in light of this research data in the discussion chapter.

Central to most models of mental health recovery was an acceptance of the condition, redefinition of identity or self, finding hope for the future, and re-finding a valued role within society (including employment, helping others etc). Some of these findings find resonance within the literature already described from the experience of physical illness literature. For purposes of clarity and ease of understanding, this section separated recovery as a process and recovery as an outcome though even amongst the papers included in this review there was some, often substantial, overlap. In reality, it is likely that recovery is both these things due to its breadth and complexity (Ramon et al. 2007). In more recent usage, recovery is often defined as a process and then utilised as an outcome (Resnick et al. 2005).

A summary of the aforementioned studies attempting to outline what recovery means and how it is experienced by those with mental health problems has provided a useful understanding of the components of recovery and the stages the recovery passes through. The models discussed include some shared facets but also offer distinctly unique elements within each. Table 5 below attempts to build on the comparison table derived by Andreson et al. (2003) and incorporates the other studies which it was not possible to include in this chapter. The additional studies included in this chapter have been mapped onto the stages proposed in this model. However, there may be an argument for adding an additional stage to the end of the model, that of aspirations and hope for the future or one related specifically to adaptation. The importance of the acceptance or acknowledgement of mental illness was echoed in other studies examining the process of recovery (Jensen and Wadkins, 2007). The next section will outline the application and utility of recovery based approaches to treatment to identify any barriers or facilitator to its use for those with physical conditions.
Table 5: Comparison of stages of recovery between studies incorporating and building on those identified by Andresen et al. 2003 in table 4

<table>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Moratorium</td>
<td>1. Crisis Recuperation</td>
<td>Why me?</td>
<td>1. Overwhelmed by the disability</td>
<td>Experience of mental illness</td>
<td>Descent into hell</td>
<td>Loss of self</td>
<td></td>
</tr>
<tr>
<td>Awareness</td>
<td>1. Awareness of a more active self</td>
<td>1. Initiating recovery</td>
<td>Meaning of illness What now?</td>
<td>Igniting a spark of hope</td>
<td>Duality of ill and well self</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rebuilding</td>
<td>4. Appealing to the self</td>
<td>3. Awakening Building healthy Interdependence</td>
<td>2. Regaining and moving forward Reconstructing identity</td>
<td>3. Living with the disability</td>
<td>Discovering keys to wellbeing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Growth</td>
<td>3. Improving quality of life</td>
<td>4. Living beyond the disability</td>
<td>Capacity to manage unequal interplay between external and internal forces. Seeing the light at the end of the tunnel</td>
<td>Striving for normalcy. Specific concerns about parenting Hope (for the future) and reconciliation</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
2.6.4 The impact of the recovery movement and recovery-based practices

Evaluation of recovery based services

The recovery approach has been used widely across the world and has found success in its implementation (Salyers et al. 2009). Recovery programmes for severe mental health problems in the USA, which involved teaching service users how to plan and achieve individualised recovery goals and providing them with the skills to manage their illness independently, have demonstrated positive changes in illness self-management, self efficacy, coping strategies, levels of hope and knowledge (Mueser et al. 2006). Assisting patients to learn to live with their condition has led to patients reporting fuller and more satisfying lives, an increased knowledge about the condition, increased progress towards personal goals, and a reduction in the symptoms under consideration (Chadwick et al. 1996). This finding has been echoed internationally (Hasson-Ohayon et al. 2007).

Services based on a recovery model have been well received by service users who appear to value and engage with the model and can recognize recovery focused service changes (Marshall et al. 2009). Health care professionals have also been shown to view recovery positively as a philosophy of care (Cleary and Dowling, 2009). However, other studies have suggested that service users have expressed caution about recovery based services and felt any change associated with them would be superficial, would not instigate changes in deeply held beliefs and the power differentials existing between service users and the professionals that treat them (Deegan, 1997). Other service users report the potential to feel threatened when engaging with a service overtly claiming to be recovery focused when concomitantly experiencing feelings of pessimism about the possibilities of recovery. In this sense the concept of recovery was seen in a potentially oppressive way for those with mental health problems (Roberts and Wolfson, 2004).

This section has demonstrated the utility of recovery based approaches but not in the traditional sense of controlled trials. Despite the richness of this research along with its utility and impact, it is often criticised in terms of the relevant importance when compared with other sources of data by those within services and academia (Ramon et al. 2007). It has been argued that without the use of randomised control trials, any factors identified can only claim to be relational rather than causal in their relationship (Liberman et al. 2002).
However, a move towards more traditional evidence based research with its focus on clinical trials may threaten the richness and ownership of the research. It has also been noted that it may be that evidence-based practice and the research associated with it may not be compatible with recovery values (Farkas et al. 2005) and studies would need to place further emphasis on patient reported outcomes or subjective outcome criteria (McCabe et al. 2007). At the very least, these outcomes along with patient narratives should be held in the same value position as more ‘rigorous’ forms of research.

Given the highly personalized nature of recovery already discussed there is likely to be great heterogeneity in the experience of recovery. Furthermore, little is known about the impact of issues such as race, gender, ethnicity and other social patterning on the experience of recovery (Hopper, 2007; McCranie, 2011). It is likely that notions of recovery will differ between different cultures and communities of interest and this would need to be fully considered before developing and applying a model of recovery (Ng et al. 2008; Jensen and Wadkins, 2007). It is likely that any application of the notion of recovery to another field would need to consider these barriers and facilitators to the utilisation of recovery based approaches.

**Barriers to recovery based services**

As the previous section demonstrated some studies have found a positive application of recovery based approaches within treatment services. However, others have highlighted barriers to recovery based services. This section will explore these barriers in more detail as they may have resonance if this notion of recovery is applied to chronic physical conditions.

The knowledge and awareness of the notion of recovery outside of mental health services is considered relatively low. This has been attributed to the stigma attached to mental health problems and a subsequent unwillingness for information about personal recovery to be divulged (Frese and Davis, 1997). Stereotypes about those with mental health problems are likely to further exacerbate these issues, particularly with conditions such as schizophrenia. This potential stigma to the whole notion of recovery because it emanates from the mental health field may be one reason for the lack of integration between the fields of physical and mental health discussed in chapter 1.
Despite the increased usage of the notion of recovery within policy documentation (Department of Health, 1999b; Sainsbury Centre for Mental Health, 2001), some components of recovery do not appear aligned to the aforementioned, often rigid, service goals of adherence and risk minimisation inherent within treatment services (e.g. social inclusion, the refutation of health professionals’ ability to define illness and individual responsibility for recovery, Pilgrim and Ramon, 2009). Other studies have shown that despite the increased use of the notion of recovery, these ideals are still not embraced by staff working within mental health services (Rush, 2004) and that staff would rather rely on traditional biomedical methods of treatment and service provision (Repper, 2000). These tensions have also been echoed in primary care (Lester et al. 2005). It may also be that these diametrically opposed standpoints become further distanced as patients advance further down the road to recovery and independence and within the current climate of financial cuts and budget restraints. It may be that these tensions are relevant but less pronounced within physical health treatment services given the reduced emphasis on social control, risk minimisation and coercive treatment14 when compared with mental health services.

This section has provided a summary of some of the available literature on recovery in an attempt to improve the understanding of the concept of recovery and what it means to service users. The notion of recovery has gained popularity internationally and is now considered a well conceptualised and multi-faceted concept. Service user accounts have developed the understanding of recovery as a personal journey which involves learning to live with or coming to accept the condition. Health professionals can be involved in, but are not necessary, for the recovery journey. The notion of recovery is supported by studies which have demonstrated the resilience of those with mental health problems. However, the chapter has also highlighted that the notion of recovery is not fully embedded in public consciousness and is often poorly understood by service users and staff working within services.

14 It is important to make clear at this point that the nature of coercion is likely to vary between types of mental illness. For example, coercion can range from involuntary detainment of patients under the mental health act (which is relatively rare) to more subtle forms of coercion for those who suffer with mental health problems in the community with common mental health disorders such as views about whether their doctor wants them to take antidepressant medication.
The most important use of this chapter will be to provide a basis for the subsequent comparison to be undertaken with the data collected in this study. Whilst the recovery approach is by no means a panacea and without flaws, it offers individuals the opportunity to find the person within their mental illness and get back some semblance of normality and find roles within society that they value. There are a number of key points to consider or test with patients with chronic physical health conditions highlighted in figure 5.

Figure 5: Key points highlighted within the recovery in mental health section

- Recovery is a multi-faceted and complex concept in itself.
- Recovery is not a cure. Instead if refers to a highly personalised process of accepting and adapting to the illness.
- The course of the illness can have a significant impact on outcomes and appear related to a personality factor, an illness factor and an age factor.
- Recovery requires a shift away or a shift in focus away from the traditional biomedical model of treatment and service provision but it may be that this is different for different types of illness.
- In line with data from the physical health field, the impacts of mental health problems are severe and enduring. It appears the illness has a significant impact on individuals' sense of self and identify which needed to be overcome or managed in order for recovery and hope for the future to be achieved.
- Service users appear enthusiastic in terms of providing narratives and their stories about the experience of mental illness and recovery.
- Hope is an important concept within the literature on recovery and can often act as a catalyst for recovery.
- Recovery needs to address both the needs of the patient but also the needs of the person with mental health problems in an holistic manner.
- Any recovery based approach needs to incorporate the community and the roles an individual has within that community (e.g. parent, grandparent etc).
- Narrative accounts have been useful in developing models of recovery and as a source of information and hope for clinicians and other patients.
- It is likely that notions of recovery will differ for those with different conditions and for those from different communities or cultures of interest which would need to be explored. This should be considered by attempting to produce any model of recovery to be applied universally.
- Stigma can be a power barrier to individual recovery.
- A limited number of studies have examined the facilitators and barriers to a recovery based approach. It is likely that any application of the notion of recovery to another field would need to examine the barriers to a recovery based approach.
2.7 Summary

The literature cited above demonstrates that the experience of illness is well documented but that the experience of recovery and prognosis for long-term conditions out with mental health is not. This is likely to be an important part of the illness trajectory and may have implications for patient experience and self-management. The focus on disruption is perhaps unsurprising given the often debilitating impacts of chronic illness which may result in a focus on the present and the past. It may be that perceptions of recovery are related to the experience of illness as disruptive and this would need to be explored with those with chronic conditions.

The chapter has also introduced the concept of recovery from the field of mental health as a possible sensitising concept which may facilitate the illumination of this hitherto underexplored element of the chronic illness experience. Studies examining recovery as an outcome and seeking to operationalise and measure recovery have been useful in developing our understanding of recovery. Recovery in mental health research is now considered to have ‘come of age’ because the insights of individuals with mental health problems are now the focus of research (Slade et al. 2012). However, the chapter has also considered barriers to implementing recovery type approaches.

Understanding expectations and perceptions of recovery and prognosis is likely to be important in terms of comprehending, if and how, individuals engage with self-management and treatment or not. Furthermore, different patients are likely to use experiences to construct expectation and perceptions of recovery in different ways in line with the studies reported in this section.
CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

3.1 Introduction

In this chapter I outline the methods employed, describe the rationale relating to how these were applied to the research questions, and reflect on the process of undertaking the research. A table detailing the timeline of this research study can be found in Appendix 2.

3.2 Research questions and aims

The principal aim of the thesis was to investigate experiences and perceptions of prognosis and recovery for those with long-term physical health conditions such as diabetes, heart disease and arthritis. The research questions intended to address this were:

- What are patients’ perceptions and experiences of prognosis and recovery and how do they impact on living with and managing a chronic physical condition?

- Do perceptions and experiences of prognosis and recovery change over time, and if so how and why?

- How applicable are the concepts of ‘recovery in’ and ‘recovery from invalidation’ found in the mental health literature to those with long-term physical health conditions?

- How do social factors impact on perceptions and expectations of prognosis and recovery?

- What are the similarities and differences in notions of recovery and prognosis for different conditions (e.g. explore the similarities and differences with the mental health literature and any variation between different physical conditions)?

- What are the factors that are perceived to promote or inhibit ‘recovery’ from chronic physical health conditions?

The research commenced with a substantial exploratory period including a synthesis and critical review of the available evidence about recovery from chronic illness (mental and
physical) and literature from the wider subject area including the experience of illness which is detailed in chapter 2.

### 3.3 Research design

The current thesis sat within the remit of two larger studies (see appendix 3). As a result, the research design had, to some extent, already been agreed prior to my involvement in the study. However, the design used (qualitative) and methods (semi-structured interviews) to be employed fitted well with the research questions I sought to address.

The underlying method employed in the study was narrative inquiry (NI) incorporating a cross case thematic analysis combined with other methods to address the research aims. The study was split into two phases (figure 6). The first phase incorporated the secondary data analysis of two existing subsets of interviews to explore whether patients with long-term physical conditions readily discussed recovery in narratives about their health and illness(es). Phase two utilised findings from phase one and undertook primary data collection to actively elicit and explore perceptions and expectations about prognosis and recovery.

Phase 2 of the study utilised longitudinal data collection incorporating baseline and 12 month follow-up interviews. This timescale complied with recommendations made about longitudinal qualitative research (Saldana, 2003). Longitudinal methods are characterised by the integration of temporality into the design which gives rise to a focus on change over time with the inclusion of multiple reference or time points (Thomson et al. 2003). Thus using multiple interviews within the narrative methodology framework allowed stories about recovery and prognosis to emerge from multiple tellings over time and enabled the researcher to build rapport with interviewees. This method gives interviewers the opportunity to gain feedback on previously obtained information (McLeod, 2003; Reinharz, 1992) and allows the trajectory of the illness experience over time to be explored with the identification of any key stages or transitional periods. The detailed methods associated with each phase are presented in figure 6.
The current study drew from several different qualitative methodological approaches in an attempt to draw strengths from each. Recently, this adoption of a number of methodologies within one study has received support due to its ability to gain a richer understanding of the research topic, particularly in areas which deal with real world complexities (Mingers, 2001). The general approach undertaken was a qualitative, narrative approach incorporating...
a cross case thematic analysis with the use of ‘recovery’ derived from the mental health field as a sensitising concept (Blumer, 1969).

There exists a large and complex debate in the literature relating to whether, and how, the social world can be explored using different research methods (Guba, 1990). Whilst drawing on a number of different qualitative methodological approaches, this study was aligned to a constructionism epistemology which states that social phenomena and the meanings associated with them are constructed by the social actors surrounding them (Crotty, 1998). This approach allows for changes emergent from a changing social context. A constructionist approach refutes an objectivist epistemology, aligned with quantitative research, which states that reality exists independently of consciousness. It is more plausible in relation to the research problem on which this thesis focuses, to assume that any meaning or understanding relating to recovery and prognosis is, at least in part, socially constructed rather than something that exists in the world independently of the people in it. However, it should be noted that whilst social constructionism is described here, it may be more accurate to suggest that the study is positioned on the spectrum somewhere in the middle ground between constructionism and subjectivism. Subjectivism as an epistemology suggests that meaning is not created from an object or phenomena but is created solely by the individual (Crotty, 1998). For example, meaning can be derived from anywhere other than the object (e.g. notion of recovery) including religious beliefs, past experiences etc. The meaning people ascribe to recovery and prognosis are likely to come from both these sources therefore the study will explore both the impact of the object/phenomena and also the more subjectivist origins of meaning.

### 3.5 Research approach

The methodological approach to the study was qualitative because it was considered the most appropriate way to elucidate individual perspectives relating to prognosis and recovery due to previous research on the experience of illness (Charmaz, 1991; Frank, 1995; Frank, 2010). Qualitative research has been described as an attempt to ‘understand the world from the subject’s point of view, to unfold the meaning of people’s experiences, to uncover their lived world prior to scientific explanations.’ (Kvale, 1996, p.1). The techniques associated with these approaches aim to provide a holistic account and critical understanding of
individual’s views and actions within the social world they inhabit and are particularly suited to exploring complex concepts and those that may change over time (Pope and Mays, 1995). These methods also provide an in-depth understanding of social phenomena whilst taking into account the influence of researchers’ perspectives (Snape and Spencer, 2003). These characteristics make qualitative approaches particularly relevant to a study of recovery and prognosis. The research aims and objectives cited previously are also aligned to a qualitative approach due to their focus on meaning and understanding. Positivist strategies would have been unlikely to address the complex process of recovery and research in the mental health field and beyond supports this (Slade et al. 2012).

### 3.6 Methods

#### 3.6.1 Phase 1 – Secondary data analysis

Secondary data analysis is defined by the fact that the researcher undertaking the analysis was not involved in the original data analysis or that the research questions were not initially asked of the original data. Hakim (1982) presents the following description of secondary analysis which is fitting for the current analysis:

“Any further analysis of an existing data set which presents interpretations, conclusion of knowledge additional to, or different from, those presented in the first report on the enquiry as a whole and its main results” (Hakim, 1982, cited in Grinyer, 2009, p1).

Secondary data analysis is most commonly associated with quantitative data (Hinds et al. 1997). However, the use of secondary analysis with qualitative data is becoming increasingly popular and reflecting this, the Economic and Social Research Council (ESRC) now recommends that potential applicants only undertake new field work if they can demonstrate that there is no duplication of existing archive materials (Irwin and Winterton, 2011).

Secondary data analysis is considered useful as an exploratory analysis prior to completion of primary data collection (Hinds et al. 1997). The value of revisiting previously produced data and prioritising a concept that was present in the original data but not the focus of the study has been well documented (Bishop, 2007) and has been used to study experiences and health contexts (Emslie et al. 2006; May et al. 2004). The interviews relating to the secondary data analysis were semi-structured in nature and, by virtue of this type of
interview; the data generated was rich and detailed. This meant that the data were considered suitable for secondary data analysis (Thorne, 1994).

The above discussion infers that the secondary analysis researcher can be different from the primary analysis researcher. However, these researchers can be one and the same or, as in the case in this study, it may be one of the researchers is involved in the wider research team. I personally undertook four of the second set of interviews (Whole System Demonstrators Project) and was part of the research team involved in the Participation in Healthcare Study but did not undertake any of the interviews included from this subset of data.

Advantages and disadvantages of qualitative secondary data analysis

There are a number of advantages and disadvantages associated with secondary data analysis. Undertaking secondary data analysis is a less expensive and time consuming method than primary data collection (Boslaugh, 2007; Hakim, 1982). For this reason, it is an attractive proposition for students and small research projects. The debate about the value of secondary data analysis is ongoing. However, more recently researchers have advocated the value of secondary analysis and its use (Boslaugh, 2007; Mason, 2007). This represents a move away from a critical focus on the limitations of the method and a focus instead on the types of analytical approaches used within the method in order to advance the use of secondary analysis techniques (Mason, 2007).

The main disadvantage associated with secondary data analysis is that the researcher was not present at the time the original research was undertaken (Boslaugh, 2007). This may mean that the context cannot be fully appreciated by the secondary data analyst. However, I was involved with both research studies as part of the wider project team and personally undertook some of the interviews. As a result, I was more able to appreciate some of the factors relating to context (e.g. inclusion criteria, geographical locations etc). The remaining subsets of interviews that were utilised in this study had previously been undertaken by a researcher who worked within the department therefore it was possible to have conversations about how the interviews were conducted. However, some data relating to condition and the time since diagnosis were not collected. This did not cause too much concern due to the exploratory nature of the phase and because the focus was on whether,
and if so how, participants talked about recovery and prognosis in their narratives about long-term physical conditions rather than focusing on the similarities and differences between different groups of individuals.

This study attempted to address the disadvantages discussed above through the combination of phase 1 with the primary data collection in phase 2 of the study. Phase 1 was a useful process as little was currently known about perceptions and expectations about recovery and prognosis from the point of view of those with long-term physical conditions. This phase was able to look at how matters relating to recovery and prognosis were implicit in narratives about the experience of chronic illness. The findings from phase 1 fed into the design of phase 2 to ensure that the right questions were being asked. The linkage between phase 1 and 2 attempted to maximise the study’s capacity to reveal patient narratives relating to prognosis and recovery and enhance the validity of any data obtained.

3.6.2 Phase 2 – Narrative inquiry

Phase 2 comprised primary data collection through qualitative semi-structured narrative interviews incorporating a cross case thematic analysis to look for commonalities across individuals. In terms of narrative and thematic analysis, the use of both has been advocated due to its ability to illuminate additional levels of detail (Coffey, 1996). This phase was specifically designed to elicit narratives relating to prognosis and recovery which is one of the main features that separates it from phase 1 of the study.

Origins of narrative inquiry

NI arose to give a voice to the marginalised within society and challenged realism and positivism (Reissman, 2008). It allows individual stories to be explored in context and in depth to gain a thorough understanding of individual experience. It has been proven particularly useful within the field of health (Hall, 2011). Narrative researchers often argue that their methods can access feelings and assumptions that have organised an individual’s life which are tacit and difficult to access by traditional interview techniques and less susceptible to conscious manipulation by the interviewee (Wengraf, 2001). This has the potential to make them a useful way of elucidating knowledge and experiences relating to prognosis and recovery. The use of narrative inquiry has spread across the different epistemologies and can now be found in a number of different theoretical perspectives
including post-modernism and ethnography. As a result, varied approaches are available which fall within the narrative family with a commonality of interpreting texts which are considered in a storied form (Reissman, 2008).

Narrative approaches differ from each other in a number of ways including how they treat or deal with language with some narrative investigators focusing more on language form than others (Reissman, 2008). For example, to study the form of narrative, long texts are often broken down into coding units. The focus of the narrative analysis undertaken within this study focused instead on the content rather than form and structure of narratives. A thematic analysis of narratives akin to grounded theory and ethnography was combined with a close analysis of individual stories. The post-modernistic roots of narrative inquiry encourage researchers to eclecticism and cross analytical boundaries as well as tailoring methods to individual research (Reissman, 2008; Coffey and Atkinson, 1996).

*Types of narratives*

Patient narratives relate to the stories patients tell about the events and experiences surrounding their illness and are characterised by the temporal organisation of events. These narratives are accounts of the illness experience structured and told to an interviewer (Radley and Billig, 1996). Subsequently it is likely that they will be a mixture of fact and fiction which led Bury to assert that these should be called ‘factions’ (Bury, 2001). Narratives are context dependent, can take many forms, and will serve a number of purposes for the individual concerned. Different types of narratives are described below.

Williams (1984) distinguished between two forms of narratives; routine and reconstructed. The latter is the most pertinent in the study of the experience of illness and relates to the way in which perceptions about illness can be understood in the wider context of everyday lives.

Hyden (1997) suggested a classification of narratives based on the relationship between narrator, narrative and illness:

- Illness as narrative;
- Narrative about illness;
- Narrative as illness.
The concept of ‘illness as narrative’ relates to the individual recounting their personal experience whereby the illness, narrator and narrative are one and the same. ‘Narrative about illness’ demonstrates an individual’s perceptions relating to illness. These do not have to be biographical accounts and a health professional talking about a patient’s illness would be an example of a narrative about illness. ‘Narratives as illness’ are identified through the narrative or lack of an adequate narrative being symptomatic of an underlying condition.

Most of the work using patient narratives to explore the experience of illness has used the ‘illness as narrative’ form (Hyden, 1997). These narratives have been sub-classified into a number of different types (Bury, 2001, see table 6 for more details).

*Table 6: Classifications of patient narratives*

<table>
<thead>
<tr>
<th>Type of narrative</th>
<th>Any further sub classification</th>
<th>Key Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contingent</td>
<td>No</td>
<td>Demonstrate beliefs about the origins and causes of disease and the immediate effects of the illness.</td>
</tr>
<tr>
<td>Moral</td>
<td>No</td>
<td>Demonstrate changes between the person, illness and identity which allow the ‘moral status’ of the patient to be re-established/justified or social distance maintained.</td>
</tr>
<tr>
<td>Core</td>
<td>Yes; Epic or heroic; Comic or ironic; Disembodied or romantic; Didactic; Stable; Progressive; Regressive.</td>
<td>Demonstrate the linkages between individual experience and the wider social/culture factors.</td>
</tr>
</tbody>
</table>
Bury (2001) identified the epic/heroic, comic/ironic, disembodied/romantic and didactic sub-types of core narratives and referenced Robinson (1990), who described stable, progressive and regressive types. A progressive narrative is one that demonstrates a step towards a goal which is valued personally by the individual, a regressive narrative is one that moves away from the valued goal and a stable narrative demonstrates no shift in the direction towards the goal.

Frank (1995) made reference to three types of narratives, which illustrate socially acceptable or culturally available versions of how individuals live with their illness; ‘restitution story’, ‘quest story’ and ‘chaos story’. The restitution story appears to represent the traditional biomedical concept of recovery, which Frank holds as the most socially acceptable story similar to the ‘living in the future’ narrative identified by Davies (1997). In contrast, quest stories incorporate the disruptive consequences of illness and are assertive seeking to tackle the illness and suffering directly resulting in the central character being portrayed as a ‘hero’ within the narrative. This concept of a ‘hero’ fighting against a disease such as cancer can be found frequently in the popular media’s accounts of illness, but which some argue could put social pressure on individuals to hide elements of the illness or disguise the anger and futility associated with a diagnosis (Broom, 2001). The final narrative described by Frank is the ‘chaos story’, which is perceived to be the least socially accepted. These narratives reflect the inability of an individual to control their disease or suffering. Chaos is not only identified by the death of the person concerned but also by rage, depression and anxiety (Sandaunet, 2008) and has been aligned to ‘living in the empty present’ narratives (Davies, 1997; Ezzy, 2000). Nettleton (2006) has used these to describe the experience of those with conditions of long duration without a diagnosis.

Narrative typologies are not mutually exclusive and two or more may occur within individual stories and are affected by social context. For example, it appeared that the women using self-help groups for breast cancer, out of consideration for other users in the group, were unlikely to make the ‘chaos’ elements of their stories visible and that the group situation gave rise to more socially appropriate and acceptable ‘quest’ type narratives (Sandaunet, 2008).

A study with HIV positive men contrasted narratives which paralleled Frank’s three types and are summarised in table 7 below. Linear restitution narratives were characterised by ‘an
attempt to narrate and live a normal life’ in spite of the condition and were oriented towards the future (Ezzy, 2000, p611). Linear chaos narratives were ‘characterised by expressions of depression, anger, isolation and social dislocation’ and included elements of denial, a lack of planning for the future and focused on the loss of an ideal life (Ezzy, 2000, p611). Polyphonic narratives contained many voices and were characterised by ‘overlaid, interwoven and often contradictory stories and values’ (Ezzy, 2000, p613). Most importantly, these narratives reflected an acceptance of mortality and an acknowledgement of the uncertainty of prognosis.

Table 7: Ezzy’s theory of time and narratives

<table>
<thead>
<tr>
<th>Linear narrative</th>
<th>Polyphonic narrative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Davies (1997)</td>
<td>Living in the empty present (short-term planning for the present)</td>
</tr>
<tr>
<td>Living in the future (involves secular long-term planning and attempted colonisation of the future)</td>
<td>Living with a philosophy of the present (short-term planning for the future and increased communal orientation e.g. reflective of some new age beliefs)</td>
</tr>
<tr>
<td>Frank (1995)</td>
<td>Chaos narrative</td>
</tr>
<tr>
<td>Restitution narratives</td>
<td>Quest narratives</td>
</tr>
<tr>
<td>Marcel (1962)</td>
<td>Concrete hope</td>
</tr>
<tr>
<td>Despair</td>
<td>Transcendent hope</td>
</tr>
</tbody>
</table>

Source: (Ezzy, 2000)

Advantages and disadvantages of patient narratives

The use of patient narratives in health research has increased rapidly over recent years (Frank, 1995; 1997; 2012b; Mattingly, 1998; 2010; Williams, 1984). Narrative interviews are considered the best way to reveal rather than marginalise individual experience and to allow participants to develop their own thoughts and share their experiences (Frank, 1995; 2010). For example, narrative methods have been used in emancipatory ways and are considered empowering for those taking part by giving the opportunity to voice or express new ‘selves’ which were previously untellable (Pavlenko, 2002). Narratives can illuminate aspects of the individual experience of illness on the continuum of the illness trajectory making it particularly relevant to recovery given the indication from the mental health field that recovery is a personal journey.
The advantages of narrative methods overcome some of the criticisms associated with qualitative interviewing highlighted by feminist researchers who challenged the power imbalance in the structure and conduct of research (Reissman, 2008). For example, studies utilising cross-gender interviews found that women were more comfortable being interviewed by other women (McKee and O’Brien, 1993). It appears these critiques depend on who is eliciting the narrative and could be extrapolated to other relationships including medical professional/patient or academic/non-academic. It is also worth noting that narratives are created for a given audience at a specific moment in time and will use taken-for-granted discourses and values operating within a specific culture (Reissman, 2008). As a result, the narratives produced in this study required close interpretation or analysis.

Participants in this study were asked to describe the past when producing narratives. It is likely that this prior past experience will need to be reinterpreted to reflect current identities as individuals seek to make meaning from it (Carricaburu and Pierret, 1995). This is particularly relevant for the individuals included in this study because of the biographical disruption associated with chronic illness (chapter 2, Bury, 1982). In addition, some participants will have lived with their condition for some period of time and subsequently been exposed to a number of professional practices and competing targets/agendas on which judgments will have been made and which were explored.

### 3.7 Ethics

#### 3.7.1 Ethical approval

*Phase 1*

The transcripts included in phase 1 of the study came from two projects; the first was the participation in healthcare study which gained ethical approval from Bolton Research Ethics Committee in September 2007 and Research and Development (R&D) approval from Salford Royal Foundation Trust. The second project which provided transcripts for the secondary data analysis came from the Whole System Demonstrators project which gained ethical approval from Liverpool Research Ethics Committee.
Phase 2

The current study sat within the remit of two wider projects. The first explored participation in healthcare and gained ethical approval from Bolton Research Ethics Committee in September 2007 and R&D approval from Salford Royal Foundation Trust. The second project was the Greater Manchester Collaboration for Leadership in Applied Health Research and Care (CLAHRC). The aim of this project is to support patient self-management and improve quality of care for people with vascular disease by developing and evaluating patient centred interventions. This project gained ethical approval from Greater Manchester Central Research Ethics Committee in September 2010 and R&D approval from Salford Royal Foundation Trust.

3.7.2 Ethical considerations

Phase 1

There are ethical considerations that need to be kept in mind when undertaking secondary data analysis. Discussions were held with the principal investigator on each study to ensure that secondary data analysis of the type required in this study fell within the scope of the initial ethical approval. After discussions with the principal investigator and my supervisory team, it was considered that this was the case as ethical approval had been granted for the studies to investigate the experience of chronic illness and I was working as a part of the research team on each project. Whilst perceptions about recovery and prognosis were not the analytical focus of the study, it is possible that they formed part of the narratives around the experience of chronic illness and this study could illuminate and expand on the analysis already undertaken.

Phase 2

Ethically, the minimum requirement that any study should adhere to is that participants should not be changed for the worse following their involvement in the study. The aim of this study was to produce narratives about their health and explore expectations relating to recovery. As a result the principal aim was not to intervene or change participants in any way.
In line with ethical guidelines, informed consent within the current study was an ongoing process throughout the course of the study (World Health Organisation, 2012). For example, participants were told that participation was voluntary and given the opportunity to leave the study at all points of the research, in line with ethical guidelines. One participant agreed to take part in the study but then was not at home on two occasions when the interview was arranged thus exercising his right not to take part. Participants were also consulted about the audio-taping of interviews and told they could opt to not have their interview recorded if they wanted. This happened on one occasion and detailed field notes were taken instead during the interview.

3.8 Recruitment and study participants

3.8.1 Phase 1

Phase 1 comprised a qualitative re-analysis of two existing datasets. The first came from a study into participation in healthcare and consisted of 14 semi-structured interviews with patients who had a number of long-term conditions including diabetes and heart disease. Participants were sampled purposefully from chronic illness registers from consenting GP practices and invitation letters were distributed to eligible patients. Exclusion criteria included those receiving palliative care or those considered by practice staff to not be able to provide informed consent. If participants were interested in taking part, they returned a consent form in a self-addressed envelope and a researcher followed this up with a telephone call to arrange a suitable time and date for interview.

The second subset of interviews came from a study exploring the potential of technology to support self-care at home for patients with diabetes and chronic obstructive pulmonary disorder and consisted of 35 interviews. These participants were sampled from a randomised control trial assessing telehealth and telecare equipment. Those patients who had indicated that they were willing to take part in a qualitative arm of the study were invited through a letter and information sheet to take part in an interview. Participants were sampled purposively to include a range of chronic conditions, ages, locales, genders and illness severities. The letter was followed with a phone call from the researcher to establish
whether participants were willing to take part. If so, a convenient time and date was arranged with them.

The total set of interviews used in phase 1 comprised 49 interviews with patients. The geographical locations of the interviews were Greater Manchester, London and Cornwall.

**3.8.2 Phase 2**

In terms of sampling, the key to the approach was aligned to the aims of qualitative research which assert that enough in-depth data should be gathered that can illuminate patterns, concepts, categories, and dimensions of the given phenomena (Glaser and Strauss, 1967; Strauss and Corbin, 1990). Often narrative studies have small sample sizes given the in-depth nature of the analysis. Given the finite resources available in the current study, a purposive sampling strategy was employed over two waves. It was initially envisaged that the study would include between 30 and 40 participants due to the scope of the research question and the experience of the researcher. In actual fact 32 interviews were included. The first 19 participants were mainly older and retired. Consequently, the next wave of recruitment purposively sampled younger participants who were employed. Recruitment ended when consensus (between myself and my supervisors) was reached that no new themes were arising from the data (e.g. that data saturation had occurred). This sampling strategy reflected the eclectic methodology of the study. For example, rather than focusing on a smaller number of interviews as narrative studies incorporating an analysis of the form and structure of language would, a larger sample was selected due to the focus on thematic analysis of the content of the interviews. Therefore the study incorporated some of the techniques associated with grounded theory, e.g. data saturation. To summarise, the sample was deemed to be adequate because it was small enough to allow the individual deep analysis of individual interviews which is considered the ‘raison-d’être’ of qualitative research whilst also being large enough that it appeared no major new themes were arising from the data (Sandelowski, 1995).

For the first wave of recruitment, two practices in the Greater Manchester area were approached and recruited into the study. Patients were sampled purposively from the chronic illness registers held within each practice. Particular conditions were not selected as the focus of the study was on the diversity of illness experience associated with chronicity
given the social and cultural differences between participants (Mattingly, 2010). This generic philosophy has been supported by recent self-management programmes such as the EPP (Sanders et al. 2008). Those who were not suitable were excluded. The exclusion process was done by a member of the practice staff in collaboration with the researcher and criteria included the terminally ill and those deemed unable to give informed consent to take part in the study for reasons such as severe dementia. As a result of this sampling strategy, 50 letters were distributed to patients from each practice. Twenty potential participants responded to the letter and 19 interviews were arranged and conducted (one participant was not home on two occasions when interviews were arranged). All 19 participants interviewed agreed to be followed up after one year to explore any longitudinal differences in the data.

For the second wave of sampling, participants who had taken part in a previous study (CLAHRC) and had agreed to be contacted for further research were approached. As previously discussed the database was purposively sampled to select those who were younger (60 or below) or who were currently employed to address the limitations of the sample from the first wave of recruitment. A total of 13 participants were selected in this way and all agreed to be followed up after 12 months. Further details can be found in table 8.
Table 8: Description of study participants

<table>
<thead>
<tr>
<th>ID No</th>
<th>Gender</th>
<th>Age</th>
<th>Married</th>
<th>Employment</th>
<th>Identified others?</th>
<th>Interview undertaken</th>
<th>Relationship</th>
</tr>
</thead>
<tbody>
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<td>1</td>
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<td>80</td>
<td>Yes</td>
<td>Retired</td>
<td>Yes</td>
<td>No – husband too ill</td>
<td>Spouse (F)</td>
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<tr>
<td>2</td>
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<td>Yes</td>
<td>Yes</td>
<td>Spouse (F)</td>
</tr>
<tr>
<td>3</td>
<td>F</td>
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<td>Yes</td>
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<td>-</td>
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<td>No suggestions</td>
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<td>-</td>
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<td>Retired</td>
<td>Yes</td>
<td>Yes</td>
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<td>Retired/LT sick</td>
<td>Yes</td>
<td>Yes</td>
<td>Spouse (M)</td>
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<td>12</td>
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<td>Retired</td>
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<tr>
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<td>Yes (for second time)</td>
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<td>27</td>
<td>M</td>
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<td>31</td>
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<td>33</td>
<td>F</td>
<td>38</td>
<td>No</td>
<td>F-T Employed</td>
<td>No suggestions</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Key: F-T – full-time; P-T – part-time; L-T – long-term; M – male; F - female
As a result of the two waves of recruitment, 32 service users with long-term physical health conditions were recruited to the study. Once individual patients had been selected, they were asked to identify other key stakeholders relevant to their care and condition who may have been able to provide insight into the illness trajectory and any notions of prognosis and recovery. These could have included healthcare professionals and/or family and friends and were identified through consultation with the participant. (see figure 7). Table 8 displays information about each participant included in the study and the interviews with other key stakeholders involved for each individual participant.

Figure 7: Participant journey

Only two participants had pre-existing relationships with each other in addition to being at the same GP surgery. ID14 and ID 17 were married but were interviewed separately. The researcher was not known to any of the research participants prior to the interviews.

Out of the 32 interviews undertaken, only nine participants identified someone else who they suggested for inclusion (table 8). All those identified were spouses. The remaining 23
were either living alone or did not think it appropriate for their spouse or anybody else to be approached. Seven of the nine identified were approached and consented to take part (see table 8). One participant (ID 18a) said his wife was too busy to be interviewed and an interview was arranged with ID 1a but on the day of the interview her husband was too unwell for her to participate and when contacted subsequently she did not wish to take part. These ‘significant’ others were asked to produce narratives about the original participants’ illness, prognosis and recovery in a similar way to the individual participant. A flow chart detailing all the participants included in phase 2 of the study can be found in figure 8.

*Figure 8: Schedule of interviews and participant attrition over the 12 month study*

<table>
<thead>
<tr>
<th>Time point (months after recruitment)</th>
<th>Participants</th>
<th>Significant others nominated by participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Participants (n=32)</td>
<td>Spouses (n=9)</td>
</tr>
<tr>
<td><strong>Attrition due to:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Death (n=2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uncontactable (n=1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recent cancer diagnosis (n=1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Husband too ill to take part (n=1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Participants (n=26)</td>
<td></td>
</tr>
</tbody>
</table>

### 3.9 Interview process and consent

#### 3.9.1 Phase 1

Interviews were undertaken at participants’ homes at a time convenient to them. The interviews were audio-taped with participants’ consent and transcribed verbatim. Transcripts were anonymised and quotes produced with an ID number and pseudonym to identify the participant concerned. Interview schedules for the studies included in phase 1 can be found in appendices 4 and 5.
3.9.2 Phase 2

The interview schedule from the wider project (participation in healthcare) was redeveloped in conjunction with the principal investigators and my supervisors to ensure it met the aims of both studies. This resulted in a revised schedule which started with a narrative section relating to the experience of illness and including prompts relating to recovery and prognosis before going on to a semi-structured format which aimed to address the wider research project’s aims (as detailed in appendix 4).

Interviews were offered at a location and date convenient for the participant. Participants were asked if the interview could take place in a quiet location, free from interruptions and background noise and they were asked to keep an hour and half free for the interviews. All interviews were undertaken in participants’ homes and, on average, lasted approximately an hour (ranging from 30 minutes to one hour and forty minutes in length).

To start the interview, the process of consent was undertaken with the participants (information sheets can be found in appendix 3 and consent forms in appendix 6). The researcher described briefly what the interview would involve in an attempt to combat any pre-held expectations on the behalf of the interviewee. Participants were then prompted to produce narratives about illness trajectory, prognosis and recovery, which formed the basis of this phase. This was undertaken using a technique common in narrative inquiry and involved the use of an open question which can be found below:

“Can you tell me what has led you to where you are now in terms of your health?”

Prompts were made in relation to prognosis, recovery and hopes for the future if these were not readily discussed. Other issues relating to participation in healthcare were then discussed and a full copy of the full interview schedule can be found in appendix 4.

The interviews were deemed to be ‘in-depth’ due to the fact that the interviews aimed to explore the complexities of the phenomena under examination and to see whether there were more realities under the surface of the data through some probing and the follow-up interviews. By their nature semi-structured interviews are less confined than more formally structured ones and require more improvisation on the part of the interviewer. However, they still require a great deal of preparation to be done prior to the interview. The interview schedule was drafted a number of times in consultation with the project supervisors. One
key feature of this drafting process was to ensure the language was simple and easy to understand in a bid to minimise any ambiguities. In addition, consensus between myself and my supervisors was reached that the questions and prompts in the schedule were all necessary to address the aims and objectives and that there were no omissions in the schedule. For the second phase of the sampling, the schedule was revised to incorporate specific prompts relating to employment and its impact on the experience of illness.

In order to further enhance the interviewing, Kvale’s (1996) qualification criteria for interviewing were adhered to as closely as possible and can be found in figure 9. The only criterion omitted was steering as this was not consider aligned to the narrative approach utilised in the study.
Data collection began in March 2010 and was completed by January 2012. Attempts were made to follow-up participants at 12 months. During the 12 month follow-up, participants were shown the narrative emplotment (see section 3.10.2 for more detailed information) produced after the initial interview and asked to comment and reflect on it. They were prompted to discuss their experiences over the preceding 12 months and discuss hopes and aspirations for the future (see appendix 7 for follow-up interview schedule). The follow-up interview schedule was drawn up after analysis had been conducted on phase 1 data and the baseline interviews.

The interviews were audio-taped with participants’ consent and transcribed verbatim. Transcripts were anonymised and participants were provided an ID number for purposes of...
identification. There is some debate as to the best way to transcribe research interviews. Some would argue that it is important for the researcher to transcribe their own interviews in order for them to stay as close to the data as possible (Fraser, 2004). However, after discussions with my supervisory team and considering the number of interviews undertaken it was deemed more appropriate to obtain the services of transcription service (although I did transcribe two of the follow-up interviews). The company used was recommended to me as they had been used by other researchers within the department and adhered to standardised conventions of transcribing (Silverman, 1993). In addition, in an attempt to address critiques that transcripts are subjective representations of qualitative interviews (Green et al. 1997), I briefed the transcription organisation as to the nature of the transcripts and the type of transcription required and also checked interviews against the original tape recordings and was satisfied with the quality of the verbatim transcripts provided to me (Fraser, 2004). The company made me aware of any issues with individual transcripts and clearly marked any parts of the interview that it was not possible to transcribe.

3.10 Data analysis

The approach was broadly narrative in its approach utilising cross case thematic analysis. The overall aim of the analysis was to develop a model of recovery and prognosis that was found in accordance with the data that the interviews produced about reality. As with any other theory in the social sciences it is a composition of explanatory concepts aimed to produce a simpler representation of the wider, more complicated social reality (Crotty, 1998; Silverman, 1993). As already stated, the sensitising concept of recovery derived from the field of mental health described in chapter 2 was used as a framework for the analysis.

Narrative analysis is concerned with the details of narratives, how and why people produce the narratives they do (Reissman, 2008). Despite being focused on the details of individual narratives, narrative analysis can generate concepts that are derived from the data and the fact that they are individually focused does not mean that the results are ungeneralisable (Reissman, 2008). Due to the relatively large number of interviews, it was deemed within this study, to be appropriate to utilise narrative thematic analysis which focuses on ‘what’ is being said rather than ‘how’ things are being said (Reissman, 2008).
The field of narrative inquiry is broad and has a number of different strands including realist, postmodernist and constructionist strands. As a result there is some diversity in the literature about how to undertake analysis on narrative data. Reissman (2008) produced a useful classification system on narrative analysis and the different ways in which to undertake the analysis. This will be used to illustrate to the reader how data were analysed.

3.10.1 Phase 1

Transcripts were first entered into the qualitative software package (atlas.ti) which was used predominantly as an organisational tool. The data were then subjected to thematic content analysis akin to grounded theory to see if patients readily discussed recovery or prognosis in their interviews. As such, the analysis was predominantly inductive. Any elements of the transcripts that were directly, or could be deemed connected to recovery or prognosis, were coded accordingly as well as any other potentially relevant data. Sections of the transcripts were analysed thematically to identify any potential themes that arose from the data. Once a list of themes and categories had been generated these were re-analysed to identify duplication (example codes are provided in appendix 8). Any codes identified in this respect were collapsed (for example the codes ‘revalidation of previous identity and routines establishment’ and ‘re-establishment post diagnosis’ were collapsed into the super code of adaption). Next the themes were ordered hierarchically where appropriate and written up with direct quotes from the data to support them. Key findings that were identified were then fed into phase 2.

Drawing on the work of Reissman (2008), narrative data analysis was categorised along a number of dimensions; definition of narrative, how the narrative was represented, the unit of analysis, focus and the attention to contexts (see table 9). A further category ‘time’ was included to differentiate between the phases as phase 1 was undertaken on single interviews and phase 2 was longitudinal in its design.

It was not possible to consider the local context in phase 1 to a great extent as the interviews had been undertaken by another researcher and field notes were not available. However, consideration was given to any societal contexts where possible and appropriate.
### Table 9: Phase 1 narrative approach

<table>
<thead>
<tr>
<th>Phase</th>
<th>Definition of narrative</th>
<th>Design</th>
<th>How the narrative was represented</th>
<th>Unit of analysis</th>
<th>Attention to context</th>
</tr>
</thead>
</table>
| 1     | Segments of text related to perceptions of recovery | Single interview | Lengthy interview excerpts; transcribed verbatim. | The narrator’s perception of recovery and prognosis. | Local: Minimal  
Societal: Some |

#### 3.10.2 Phase 2

The analysis in phase 2 of the study incorporated both inductive and deductive approaches. Analysis was inductive because I was interested in exploring participants’ perceptions about recovery and prognosis which arose from the data but also deductive because the analysis used the framework of recovery from mental health to guide the analysis of the data.

All interviews were audio-taped with individual consent, transcribed verbatim by professional transcribers and entered into the Atlas software package. Transcripts were checked for accuracy upon their return. Only one participant declined to have the interview audio-taped and instead notes were taken during the interview. Detailed field notes were also taken after each interview was completed (example available in appendix 9).

Data analysis was carried out concurrently with data collection in line with the constant comparative method (Charmaz, 1995a) so any issues that emerged post interview could be explored in an iterative manner during future analysis and demonstrated an element of a grounded theory within the approach to analysis (figure 10).
Once transcripts were received from the transcribers these were read and re-read to ensure I became familiar with the data. Initial thoughts and analyses at this stage were also documented. A spreadsheet was developed containing information and characteristics relating to each participant and narrative type in order to display the data in a different manner and help contextualise any codes identified. Data from these different sources were combined and conceptual themes were developed. Emerging themes were discussed with my supervisory team. Codes were further analysed and classified hierarchically under three main headings. Concept diagrams for each code were developed in Word (see appendix 10). Themes were presented along with supporting quotations from the raw data with some characteristics from the Excel spreadsheet for contextual reference.

To summarise, this research was influenced by grounded theory in that the codes and themes were derived from interviewees’ accounts of their experiences, even though its concerns were structured around revealing perceptions relating to recovery and prognosis. Analyses were further shaped deductively through the use of the theoretical framework derived from the study of recovery from mental health.

In line with phase 1 the narrative methodology utilised for this phase can be found in table 10.
Table 10: Phase 2 narrative approach

<table>
<thead>
<tr>
<th>Phase</th>
<th>Definition of narrative</th>
<th>Design</th>
<th>How the narrative was represented</th>
<th>Unit of analysis</th>
<th>Attention to context</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Extended account of the interviewee, the story of illness and expectations for the future.</td>
<td>Initial interview and 12 month follow-up.</td>
<td>Lengthy interview excerpts; transcribed verbatim.</td>
<td>The narrator’s perception of illness trajectory and perceptions about recovery and prognosis.</td>
<td>Local: Some Societal: Some</td>
</tr>
</tbody>
</table>

In addition to the narrative thematic analysis, narrative emplotment of individual interviews was undertaken in line with the work of Lapum *et al* in 2010. Two central themes that underpin this methodology are temporality and contextuality, which point to how stories are context based and are likely to change over time and within different situations (Lapum *et al*. 2010). In order to understand why and how stories are being told in specific ways, the current study explored narratives over time from the viewpoint of the participant and also explored the narratives of significant others involved in the participants’ daily life and care. Narrative emplotment, which comes originally from literary theory, and as a result focuses closely on plotlines (Lapum *et al*. 2010). This allows the person providing the narrative to describe how characters, events, and outcomes are related at different stages of the illness trajectory. The key stages of the narrative and the main characters involved at each stage were also explored over time. This narrative approach requires that the researcher focuses and engages with the story being told and resists the immediate analysis of the information during the interview. Only after each interview was completed and when the interview had been transcribed, was the story narratively mapped. This involved extracting hard datum about facts, events, times and critical incidents from the narrative along with some inferences about level of functioning and key actors at each time point. These maps helped to summarise individual stories for analysis; to compare the narratives of different participants and to explore narratives from the same participants at different time points (see appendix 11 for an example).

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15 The narrative emplotment described here is different from that employed by Mattingly which is more therapeutic in nature and which refers to how allied health professionals such as occupational therapists make coherence from, or sense of, a sequence of events that have occurred to patients using narratives often in a very subtle way (Mattingly, 1998).
3.11 Data quality

Perhaps the biggest criticism levelled at qualitative data is that it is under-theorized. Specifically this relates to assertions that assume interviews are a simple way for researchers to view social realities and that any data can simply be extracted and quoted directly (Wengraf, 2001). It has also been noted that research about how to actually undertake methods of qualitative data collection is currently scarce (Wengraf, 2001). In order to address these criticisms, this section will focus specifically on the reliability, validity and credibility of the qualitative data collected during the study.

3.11.1 Validity

The validity of data refers to the ‘trueness’ or ‘trustworthiness’ of the data or its ability to reflect the reality it is seeking to explore. Traditionally, in scientific enquiry validity is tested through the replication of the study under consideration. However, this is unlikely to be possible within the social sciences and especially with qualitative research interviews due to the specific, context dependent nature of the study design (Bloor, 1997). In order to use qualitative interview data to make assumptions about the realities outside of an interview (which researchers invariably do) careful attention needs to be given to the context (both individual and societal) in which interviews are based and for the researchers in question to make explicit any assumptions on which the data collection and analysis are based (Bloor, 1997). The chapter will now move on to discuss specific threats to validity posed by this study.

3.11.2 Narrative specific validity concerns

The narratives used in this study required participants to recall the past and consider the future. These differ from more structured interviews, akin to stimulus response models, which keep participants more ‘on-track’. Narrative methods therefore, whilst producing rich in-depth data, also open themselves up to a different range of problems and possibilities. Narratives need to be treated with care as they do not give access to ‘real’ past events or allow the researcher to ‘test’ whether assertions made about the future actually transpire (Mattingly, 2000; Stanley, 1993). This is likely to be especially pertinent to the current study due to its focus on recovery and prognosis which is predominantly ‘future’ focused. However, what these interviews will provide is access to socially constructed narratives
produced in response to a specific context. However, this disparity between actual lived experience and any narratives about them should not be ignored (Mattingly 2000; 2010). All narratives were also produced collaboratively with the researcher undertaking the interview and this should be kept in mind during the study and the subsequent analysis.

The co-construction of narratives between the interviewer and interviewee (Bury, 2001) means that interviewers must be aware of the previous knowledge and experience that they themselves bring to interviews and try to understand how this may affect their interpretation of the data and conduct during interviews. However, this type of prior knowledge may not be entirely unyielding and it may be that previous experience can be impacted upon by the research process resulting in learning and development for the individual researcher (Wengraf, 2001).

3.11.3 Strategies for addressing validity concerns

This section documents the strategies employed within the study to address issues relating to validity. Wengraf (2001) advocates for the operationalisation of the research problem and research questions prior to undertaking any research. In addition to this, theory questions relating to the conceptual framework in which the research is based should be clearly differentiated from the interview questions. Furthermore, data from the interviews undertaken should serve as indicators for the concepts in the research questions developed. The research questions and associated aims and objectives were verified with my supervisors prior to starting the research to ensure they were operationalised sufficiently.

Two common approaches to address the validity of qualitative interview data are triangulation methods and member validation. Triangulation is commonly used within sociological studies as a way of addressing validity issues and is frequently described as a ‘catch all’ solution. However, it has been argued that this method has not been fully understood (Bloor, 1997). The type of triangulation most commonly used within social sciences is the triangulation of different methods or the between method triangulation (Denzin, 1989). Data which is corroborated by two different data collections methods is subsequently deemed to be more ‘valid’. Whilst acknowledging the usefulness of using more than one type of research method, Bloor (1997) questions whether using this type of strategy and the finding of corroboratory results means that the data is fully valid. One of
the main objections to this type of triangulation is the difficulty in comparing data from two different sources adequately. Given the finite resources available within this study, this type of validation was not deemed feasible to be included in the study. However, data from phase 1 and phase 2 (incorporating primary and secondary data collection) were combined in an attempt to see if issues of recovery and prognosis were coherent in discussions about long-term physical conditions.

Member validation is commonly used within sociology in an attempt to validate findings. At its most basic level, it involves showing interviewees details of the analysis or interview summary in order for them to confirm that the interpretations or summative work has been done accurately. Validation of interpretations has been criticised for reasons which are mostly extensions of the aforementioned issues of self-presentation and the context dependent nature of interview situations. As a compromise, in this study the summative narrative emplotments produced after each initial interview were shown to participants in the follow-up interviews to enable them to check for accuracy. Furthermore, interviewees were asked at the follow-up interview whether they would like to receive a copy of the abstract of the study once complete. Detailed field notes were taken after each interview to supplement the verbatim transcripts derived from each interview. The production of a ‘paper trail’ (e.g. narrative emplotments and detailed field notes) resulting from the research process should increase the readers’ ability to trust that the data and analysis accurately reflects, and is a true summary of, the interviews undertaken. An example of narrative emplotment can be found in appendix 11 and field notes in appendix 9.

3.11.4 Reliability and generalisability

The reliability of data refers to the ability of the data to be consistent across different context and across different times. The fact that the interviews were followed up at 12 months to test the data obtained in the first interview (through presentation of summative narrative emplotments to participants) and to enable journeys, trajectories and unfolding truths to be explored over time should increase the likelihood that the results can be extrapolated to extra-interview realities.

Generalisability within the natural sciences is often argued with the defence of statistical significance, power calculations and detailed sampling strategies. However, this is not
possible within qualitative research due the time taken to undertake individual interviews. Within social sciences arguments are made instead for commonality (Al-Busaidi, 2008). Within this study commonality is inferred by the fact that all participants had a chronic health condition and were sampled from the same GP practices. To some extent, the sampling strategy also tried to identify what is known as ‘deviant cases’ because after the initial wave of sampling the majority of participants were not employed either because they were retired or not in work because of long-term sickness. Younger participants who were currently employed were then actively sought to test out emerging theories.

3.11.5 Credibility

As qualitative analysis is interpretive in nature, credibility refers to the interpretations made about the data (Green and Thorogood, 2005; Miles and Huberman, 1994). In order to address some of these issues, emerging themes were discussed with my supervisors who both had experience undertaking qualitative research in the health sciences. Discussions were undertaken which provided the opportunity to develop concepts and promote credibility. This input was helpful to ensure that the concepts and themes derived from the data were rooted in the raw data itself.

In this section a number of different issues relating to the reliability and validity of the data have been discussed. There are no ‘hard and fast’ rules that guarantee validity, reliability, generalisability and credibility and this is left to the discretion of the individual researcher concerned. However, the issues appear to be well summarised in a diagram developed by Wengraf (2001) which can be seen in figure 11. Throughout the research process attention was given to these issues and the diagram served as a useful point of reference.
Figure 11: Briggs-Wengraf model of components of the interview situation

Source: Wengraf, 2001

3.12 Researcher Reflections

3.12.1 Research design

It should be acknowledged that I currently work, and have worked for a number of years, within social science and health services research. It is therefore highly probable that I have been affected by what has been coined the dominant paradigm (Kuhn, 1970). This may have impacted on the choice of narrative interviews as the method for the study. On reflection, however, whilst acknowledging the aforementioned limitations of qualitative data, I cannot envisage how an alternative method would have worked any better than the one utilised in the study. I also felt that the process drafting the interview schedule served the project well in that it appeared the prompts and interview questions within the schedule related well to the central research aim and the individual objectives.
3.12.2 Recruitment

One of the most difficult aspects of the study design was the recruitment of GP practices. This part of the process was also extremely time-consuming. The making of initial contact with practice managers, through to obtaining the support of GPs, and eventually attending the GP surgery to undertake the mail out was never a straightforward process and often involved a lot of chase-up phone calls and numerous visits to the surgeries. This is perhaps understandable given that taking part in research cannot be expected to be a priority for busy GP surgeries especially when, as in this study, they are not paid for their involvement.

3.12.3 Data collection

My prior experience may have served me well for conducting the interviews. I was not a totally novice interviewer and had developed some skills over my time as a researcher that I could incorporate into the data collection. This centred on empathetic close listening skills and paying close attention to the narrative as it developed. However, I had not undertaken narrative interviews before and initially found it difficult to try and leave participants to develop narratives of their own accord. This became easier over time and was facilitated by the constant reviewing of transcripts as they were received and the taking of detailed field notes. I also undertook a practice interview with a willing volunteer. The lessons advocated by narrative researchers were also useful and included the use of eye contact, non-verbal sounds, allowing pauses and silences and trying empathetic and un-intrusive mirroring (Wengraf, 2001). This iterative approach to interview data collection also helped explore any missing probes or a lack of flexibility on the part of the interviewer.

I felt that I developed relationships with participants over the course of the study which were conducive to the interview process. I was not consciously aware of a power imbalance between myself and interviewees that impacted on the interview. The narratives produced by different participants varied in their scope and nature and some individuals were much more attuned to the production of individual narratives. Others needed further prompting to elaborate and produce further narratives on given topics.

The majority of interviews were undertaken with minimal interruptions as requested but for one participant their young daughter was present because the childminder had cancelled at short notice. I suggested the interview be rearranged but he was keen for the interview to go
forward as he worked full time and consequently thought it would be difficult for him to rearrange. This did make the interview more difficult as the child interrupted and distracted the interviewee on a number of occasions. Further prompts were required for this participant to remind him where he left off prior to the distraction. In a minority of cases, interviews were disturbed by phone calls but this did not disrupt the flow of the narratives to any great extent. Apart from that the only other interruption during interviews was one noisy pet.

In one of the baseline interviews, the interviewee became upset during the interview when talking about a stroke and its subsequent impact. My reading around, and prior experience of undertaking qualitative interviews, helped me to deal with this difficult situation. The interview recommenced after giving the participant a short break and him expressing that he wanted to carry on with the interview despite offers to cut the interview short.

### 3.13 Summary

This chapter has outlined the theoretical position, methods utilised in the study along with concerns about the quality of the data. The next five chapters will present the findings that were revealed utilising the methods and techniques outlined in this chapter.
CHAPTER 4: PHASE 1 RESULTS – INSIGHTS ON PERSPECTIVES OF RECOVERY AND PROGNOSIS FROM SECONDARY DATA ANALYSIS

4.1 Introduction

This chapter presents the findings from the secondary data analysis in the format of recurrent themes occurring across cases. Quotes are provided to support themes and the letter R denotes the interviewer within excerpts.

In undertaking the secondary data analysis, it was apparent how participants often used narratives or stories when talking about their health. For example, in the following quote the participant clearly sets the scene for further components or ‘episodes’ in his story.

“They’re very, very good there [GP Practice], excellent. I’ll tell you as the story unfolds, anyway.

Phase 1, ID D16

Narratives were often fairly elaborate, well constructed and incorporated wider aspects of lives than just current health problems. The quote below illustrates this as the participant starts talking about current health difficulties which she then links back to earlier stages in her life including getting callipers and being evacuated in the second world war.

Well I do get pains in my legs, but it's more in the right one but that's the weak leg anyway. I was born with the (inaudible 00:07:09)...the wrong way around, they had a name for it but I've forgotten what it's called.

R: Right.

And I had that in splints and leg irons or whatever you call it. Callipers.

R: Callipers, yes I know what you mean.

And er, gradually over the years, got evacuated in 1940...

R: Yes.

..only up the road here, (inaudible 00:07:40)...

R: Oh yes, I know where that is yes.

Then I got double pneumonia there...
R: Oh dear.
...playing in the pond looking for frogspawn...

*Phase 1, IDA05.*

These narratives were provided by respondents despite the more structured approach to interviews within the primary studies which often restricted participants’ ability to produce longer, more flowing narratives. This gives some indications of the value to patients and researchers of using narratives and that ‘storytelling’ is an everyday feature of interactions between social actors as highlighted by the narrative analysts discussed in chapter 2 (Frank, 1995; 2010). This supported the appropriateness of the planned focus on narrative data collection for the primary research to be undertaken in phase 2 of the study.

The above examples illustrate the way in which participants outlined stories of their experiences and I was able to identify sections of the transcripts that could be considered related to prognosis and recovery. After this preliminary tranche of the data, wider topics were then identified which were thought to relate to a recovery approach to chronic illness management. What follows is a thematic analysis of patient narratives about living with chronic physical health conditions and the themes that were common across cases.

### 4.2 Themes related directly to recovery and prognosis

#### 4.2.1 Dynamics of hope and acceptance

Participants who were interviewed rarely spoke directly, or in great depth, about recovery and prognosis when talking about chronic conditions. This is perhaps unsurprising given the chronic nature of their illness which merited their inclusion in the studies. The focus of the data was the current impact the illness had on their day-to-day lives. However, participants did make passing references to their hopes (or lack of them) for the future. Themes included acceptance of chronic conditions, clarity and realism of information relating to prognosis, hope and the impact of negative prognoses.

There were no references made to a desire for total restitution or biomedical recovery when talking about long-term conditions such as Diabetes and Chronic Heart Disease (CHD). Some individuals made direct references to this not being possible and it appeared that this
was something that had been accepted. It was also possible to identify narratives of decline within the data.

There's nothing no medically that they can do really, not to relieve it. If I have a shunt put in to relieve the pressure, it won't do anything, it might stop it getting worse, but it won't bring back you know, the loss of feeling in me hands or the loss of use of me legs, it won't bring it back, it will just be as it was like, you know. It might stop it going further a little bit, but that's about it, so you know, it's a road of no return really."

Phase 1, ID 31

Biomedical recovery or restitutional recovery (discussed in chapter 1 and 2) could be seen in discussions about conditions such as curable cancers or more trivial problems such as throat infections or common colds.

Again, it's recuperated. I thought that's lovely, because radiotherapy I had bread and milk for breakfast and soup for dinner or tea for a month, because I couldn't swal.

R: I see.

It destroys part of your gullet see, and that's got to recuperate as well.

R: Yes, yes.

And it probably destroys part of the good lung, there was only one good lung there at the time, you know. Must do.

Phase 1, ID 24

There were also passing references made to prognosis. It appeared that, in the most part, clarity and realism of prognosis was important to participants along with trust in the medical professional giving the prognosis which echoes previous research (Hagerty et al. 2004). However, this was not universal and despite being in the minority clarity was not always welcomed. This was particularly apparent when the message was not what the patient wanted to hear and could be seen to impact on the relationship between patient and health professional.

I had another one in between once and I didn't like her very much. She told me about six times in one appointment that I was going to have a heart attack, if I didn't get my diabetes down, so, don't like her very much.

Phase 1, ID 42

This seemed to relate to a discrepancy between a previously envisaged and a hoped for future being directly contravened by an anticipated shift caused by diagnosis. This future
sense of self with the illness was something participants appeared keen to move away from and found difficult to accept.

It's denial in a way I suppose, that ain't going to happen to me, I am not going to get run over by that bus am I, you know. It's that attitude I think, not nothing special, it's just I can't see meself being like that anyway and I think that sometimes you can put things off but like that can't you, sometimes you know, you can; Francis Chichester you know, went round the world, sailed round the world, first one to do it, he had cancer when he left, but he didn't have it when he came back and it's that sort of, mind set or situation I suppose I don't know. If you don't give in to it, you don't, you know, you might not get it like you know, and that's all you can do isn't it you know.

Phase 1, ID 31

The above quote also highlights tension relating to hope, which has been highlighted previously (Barnard, 1995; Mattingly, 1998) and particularly within American studies of cancer. It appears from the wider literature that clinicians are aware of this tension but feel they have a responsibility to provide hope for the patient as part of their role (Delvecchio-Good et al. 1994). This need to provide hope for patients seems to resonate with quest narratives or a ‘fight’ or ‘war’ against cancer and, in this sense, practitioners feel the need to ready the patients or troops for the subsequent battle (Delvecchio-Good et al. 1990; Frank, 1995). This use of military metaphors has been challenged previously because of its ability to become oppressive to patients and contribute to their exclusion and isolation (Sontag, 1990). This study adds to the current literature by extending these themes into chronic physical conditions such as diabetes and CHD.

Occasionally, there was a perception that giving a negative prognosis could actually have a detrimental impact on illness trajectory and that deteriorating health was associated with the prognosis rather than the actual illness. This may reflect previous literature which has documented the perceived ‘magical power’ of being labelled with a condition and its negative impact on future prognosis (Sontag, 1990). This has the potential to disrupt the careful dynamic of hope that would enable participants to accept and live with their condition found previously (Barnard, 1995).

But no, it was only diagnosed in March and the funny thing was that I went downhill from there.

R: Right.

I think because of actually...

R: March of 2008 you are talking about it?
Yeah, because of knowing sort of, mentally knowing what this thing was, you know, I've sort of, like gees couldn't get ahead of it.

**Phase 1, ID 31**

There were sections of text within the data relating to recovery more akin to the mental health literature that could be inferred from the transcripts. The data was categorised into the following main themes: the relationship and impact of diagnoses to constructions of prognostic trajectories, adapting to the physical and social consequences of illness and fluid rather than determined illness trajectories.

### 4.2.2 The relationship and impact of diagnoses to constructions of prognostic trajectories

For those interviewed, the diagnosis of a chronic condition had caused them significant disruption and uncertainty. For some this change was very sudden and represented a rapid shift from the identity of a healthy person to an ill one which has resonance to the concept of biographical disruption discussed in chapter 2 (Bury, 1982).

More than anything that does worry me. Once, once you've had a heart attack and you know, before I had my heart attack, I was a very healthy person, I used to ride me bike backward and forward to work.

**Phase 1, ID 4**

The aforementioned uncertainty was exacerbated by a perceived lack of information about prognosis and chronic illness management at the time of diagnosis for some participants. The notion of uncertainty as a form of disruption is a common theme within research on the experience of chronic illness (Bury, 1991). This issue of information in relation to recovery and prognosis will be discussed in more depth in chapter 5.

You just can't tell somebody one day, you're diabetic and um, they've got to work out themselves what they can eat, what they can't eat, what they can do, what they can't do, you know?

**Phase 1, ID 18**

In a minority of cases participants felt that had clear direct information about prognosis. For these patients, an honest and direct approach was appreciated and helped them make some of the changes necessary for adequate chronic illness management. However, it should be acknowledged that clarity of prognosis was not always welcomed as discussed on page 105.
Other chronic illnesses such as COPD and lung cancer were often intertwined with moral narratives about personal responsibility for ill health as in the issue of smoking below.

_I was just going over to the shops to get some more tobacco. She said, ‘Keep your money in your pocket because if you get any more tobacco,’ she said, ‘you’re gonna be dead inside twelve months.’ I said, ‘Bloody hell.’ I said, ‘Now you’ve scared me, you know.’ And I think, honestly, it’s something like that, you know, somebody telling you dead straight, and you sort of think to yourself, ah, I wonder. You know, so you give it a try and then you think, I don’t really need a smoke anyway._

**Phase 1, ID D09**

Some respondents had a clear perception of how their quality of life could be improved. In this way ‘recovery’ was directly related to the impact conditions had on their day-to-day life. The quote below highlights one modest ambition, that of being able to go for longer without having breathing problems. For this participant, recovery appeared related to the setting of realistic goals that seemed achievable, to enable them to make the most of their time left. The goals he reports were centred on a very specific aspect of living in the here and now and preventing deterioration in the future reminiscent of Barnard’s work on hope (Barnard, 1995) and the notion of transcendent hope (Marcel 1962, cited in Ezzy, 2000).

This echoed research described in chapter 2 in the recovery in mental health field which demonstrated the utility of individualised goals (Mueser et al. 2006) but differs from mental health findings in that the focus in these goals relate to a reflexive calculation of ‘time left’ along with the slowing of time and minimisation of disruption to the status quo.

_So my problem is, you know, I want to go longer without having this breathing problem all the time._

_R: Mmm, do they give you...?_

_If the doctors could do anything like that for me, you know that would be great._

**Phase 1, ID 1**

Despite these recovery states outlined by patients, these had often not been brought up with medical professions in line with research discussed in chapter 2 (Deegan, 2005). Only one participant acknowledged that issues wider than health should be brought to the attention of the medical professional within consultations and accepted responsibility for this.

_I’ll be honest to a certain extent it's our own fault, because we don't see a doctor a lot, and they don't actually know how much struggle we've got, do you know what I mean, nobody knows what we go through, it's off the record sort of thing, but I can't even go_
to the toilet anymore on my own do you know what I mean? I can go to the toilet, but I can't even clean myself up afterwards um, and you are the only person to know...

Phase 1, ID 46

It was not clear from the transcripts why participants did not raise these issues with health professionals. However, there were indications that this may be because of perceptions that consultations were not focused on recovery (or the future) and that participants were concerned about overburdening health services but this would need to be explored in more depth in phase 2 of the study.

Well, I go to t' doctors and he says, ‘Are you all right, _____?’ And I don’t, try not to go all t’ time. Because I think you can become a thingy, drain on the surgery if there’s a lot waiting and you don’t really want anything, do you. I just, if I need owt I take my prescriptions.

Phase 1, ID 10

Previous research from the mental health field has indicated this may also be related to a fear of disapproval (Deegan, 2005) but this was not apparent within the current data. This is an important issue that is likely to have implications for practice and was explored in more depth during phase 2.

4.2.3 Adapting to the physical and social consequences of illness

Given that some of the respondents included in the study had been living with their long-term condition for a number of years, there appeared to be a lot of data reflecting adaptation. The notion of adaptation was prominent within the data and may resonate with the focus of interviews but it did appear to be more than just this. Specific elements of adaption included other family members or friends taking on tasks for them, individuals learning to cope without being able to drive, or learning to do tasks and activities at a lower level or frequency. There was no sense from the data that participants were trying to recapture the past which has been found previously (Charmaz, 1991) but instead appeared to have adapted to their changed role and identities (Charmaz, 1995b). The quotes below demonstrate the adaption narratives participants included when they talked about their chronic condition.

Well you know everything's slower, I walk slower, I, you know, my housework takes me longer, everything takes that little bit longer.

Phase 1, ID 4
I already know what, how it's going to affect before I start my day. So I start to plan my day and stretch things out a bit so they last a bit longer.

R: Yes.

Take my time over everything, so I'm not sat on the couch all day see.

**Phase 1, ID 45**

...we move about as much as we can. Yeah we do, we still do our own [housework], we do it between us.

R: Yeah.

You know, I'm, it's a bit difficult for me with the vacuum, so Vince, I mean I do, do it, but Vin usually does the vacuuming and he dusts the place...

**Phase 1, IDA03A04**

It seemed that in some cases patients lowered their recovery expectations gradually over the course of living with, and adapting to, a chronic condition so what they perceived as a state of recovery was not static but instead evolved alongside their changing expectations and circumstances.

### 4.2.4 Fluid rather than determined illness trajectories

The majority of participants spoke of an illness course that was fluid, which is likely to impact on perceptions relating to recovery and prognosis. Often people reported that they had asymptomatic periods interspersed with times of crises in line with data from the physical health field (Charmaz, 1991). For others though these peaks and troughs could be less marked.

In line with findings from the mental health field, illness trajectories were often described as a journey and participants made reference to staying on the ‘correct path’ during illness. Often participants made reference to wanting more input from professionals to help them to stay on this path and seldom took responsibility for this themselves. This paternalistic attitude towards recovery and chronic illness management was apparent throughout the transcripts. It is likely, as in previous research that the language associated with recovery and any metaphors used will be important in understanding conceptualisations of recovery (Sontag, 1990). This will be explored in more detail in later chapters when recovery is discussed directly (e.g. phase 2).
I thought, personally I thought it [monitoring technology] may give me a bit more backup, and let me know where I am going wrong. Which I feel probably will be a good thing and then also on the other hand as I just said, will keep you on the straight and narrow a bit more. You know that someone is checking it, I think the nurse is going to be there and if I've got three or four high readings over a week, then she is going to pull me up and say, 'Why? What are you doing?' Then you know that you can say to her, 'well, I am doing so and so' and she can say, 'you are wrong you should not be doing that' or 'you should not have had that.'

**Phase 1, ID 28**

### 4.3 Factors likely to impact the propensity to engage with a ‘recovery’ based approach to chronic illness management

Whilst participants did not regularly discuss prognosis and recovery directly, there were elements of their narratives around chronic illness from which one could infer a number of factors that may be related to the adoption of a ‘recovery’ based approach. These factors were separated into micro/individually based factors and macro/context based factors. These will be discussed in turn next.

#### 4.3.1 Micro/individual factors

Micro factors relating to individual agency were implicated when considering a recovery based approach to chronic illness self-management. These include competing priorities and agendas, perception of wellness, social comparison, and the perceived role of patients and health professionals within the health service.

**Competing priorities/agendas**

Competing priorities and agendas often came up in accounts as distracters to the establishment and maintenance of illness routines and regimen. In this respect, it is possible that these could impact on the adoption of, or interest in, a recovery based approach to illness management. The distracters were varied and included looking after grandchildren, pets or caring for partners or spouses who were not well. Notions of juggling and prioritising have been found in previous research exploring chronic physical conditions and their management (Charmaz, 1991).
Often participants talked about how their health took a ‘back seat’ when spouses or close family members became ill. It appeared that this habitual behaviour was hard to change even once the family member concerned had recovered or passed away.

_The only thing was um, now it's my husband now, has been diagnosed with Parkinson's._

_R: Right._

_And um, I’m busy checking that he takes his medication._

_R: Yeah._

_And sometimes; I get up to go and take the injection, but I get sidetracked._

_R: Right._

_And then I think to myself, have I taken it?_

**Phase 1, ID 77**

The majority of participants in phase 1 were retired and therefore it was not possible to explore how employment impacted on illness routines and regimen and consequently on notions of recovery. This fed into the design of phase 2 of the study.

**Perception of wellness and visibility of illness**

Adopting a recovery based approach to chronic illness management requires an acceptance of the condition and a thorough consideration of its impact along with a realistic interpretation of the future. It appeared from the data that patients were often reluctant to do this. Acknowledging illness and accepting support was something individuals appeared to shy away from as it had the potential to make participants feel ‘iller’. There was a keenness to create distance between themselves and any negative stereotypes or stigma associated with an ill persona. This has previously been found to be a common feature of narratives from older and deprived individuals (Sanders et al. 2002). This has clear implications for health promotion and health education activities and would need to be addressed with these participants before activities could be effective.

_R: Um, in terms of assisting you in your day-to-day living?_

_No._

_R: No._
I would, I would feel crippled then, so I don't want it.

**Phase 1, ID 61**

Participants appeared to want to hold onto this perception of wellness for as long as possible. This was more easily achieved with conditions such as diabetes, especially when they were asymptomatic, and for those at the early stages of the illness trajectory.

*R*: With diabetes you don't feel ill...

...until it is actually done some serious damage inside...

... I used to smoke, I do still drink, but I used to go out all the time with my friends in the pub...

*R*: Yeah.

...never give it a thought, oh, diabetes, oh, I'll be alright, I'm taking all me tablets.

**Phase 1, ID 74**

References to stigma, albeit in directly, were found regularly in the data which had the potential to impact on perception of wellness and the visibility of the disease. This related to a wide range of issues including eating habits for diabetes, stigma associated with ageing, mental health, and the general stigma associated with having a chronic health condition. The issue of stigma is particularly important within the field of mental health will be explored in more depth in later chapters within the thesis (chapter 8).

Well I had to write a food diary, and she is sitting there reading, I bet she thought, 'God, greedy cow.' And she said, 'Right stop that, stop that, stop that', and oh.

**Phase 1, ID 74**

And I've got a disability sticker obviously.

*R*: I see.

'Cause then I'm walking about; which I don't use...

*R*: Oh right.

...because I hate people, people to think I'm disabled.

**Phase 1, ID 61**
Social comparison and justification as normative markers of prognosis

Those participants included in phase 1 often appeared to use social comparison to normalise their situation in their own minds or to distance themselves from felt or enacted stigma. This relates to the section above on perceptions of wellness and again is not a new theme within the literature (Rogers et al. 2009b). Participants with one condition compared themselves with others who had more than one condition and those with physical conditions compared themselves to those with dementia or other neurodegenerative conditions. This internal hierarchy constructed by participants was commonplace within the data and could potentially reduce the likelihood of focusing on ‘recovery’ or on an ideal ‘recovery’ state.

But as I say, I'm not like, I'm just, more or less, all I have really is diabetes, he has everything, you know.

Phase 1, ID 1

Erm, I enjoy that very well, the Age Concern. I mean there’s people a lot, I don’t know whether they’re worse than me but they look it. But I’m all right mentally, you know. (laughs) I can have a bit of fun there, you know.

Phase 1, ID 13

Rehearsing future expectations of illness progression

Interviews analysed during phase 1 of this study highlighted the importance of expectation in the experience of illness which is also likely to impact on the perception of prognosis and recovery. Findings relating to expectations could be classified into three main areas; familial, medication and ageing.

It appeared that previous familial experience founded a great deal of individuals’ expectations for the future especially amongst those who had received limited information at diagnosis.

I’ve come to terms with it, put it that way.

R: Right okay. Did you find that...?

I used to worry, ”Is it was going to be my last day or what?”

R: Right, your heart?

And um, if I go out am I going to come back?
R: Did you go through...?

Just thinking of what my Dad went through.

Phase 1, IDA05

Expectations about what medication could do for underlying conditions impacted on an individuals’ likelihood of engaging in, or taking responsibility for, self-management strategies such as diet control. This was particularly pertinent in those with diabetes especially if participants were asymptomatic. For example, the quote below shows how this participant felt that taking medication for diabetes meant that they did not have to take responsibility for their own self management and in this case this related to the dietary changes necessitated by diabetes. This appeared to have been strongly impacted upon by the asymptomatic nature of the condition.

It was quite helpful. I mean, it's just one of those diseases where you don't feel ill...

R: Yeah.

...until it's too late, when you've done a lot of damage to your; I just thought, oh, I'm taking tablets it's alright, I can have a sweet, I can do this because I feel fine, blood sugars are fine...”

Phase 1, ID 16

One interpretation of this finding is that the recent advances in medication associated with biomedicalisation has given individuals a perceived sense of security and this combined with limited symptoms often meant that lifestyle changes were not made until a later stage of the illness trajectory. The propensity to take responsibility for managing conditions will be explored in more detail in a later section and phase 2 of the study.

4.3.2 Macro/context based factors

This section explores the macro factors implicated when considering a recovery based approach to chronic illness management and looks specifically at the relationship with health professionals in the NHS and the perceived role of patients within the health service.

Barriers to recovery in clinician-patient relationships

The principles of recovery in mental health (described in chapter 2) imply that in order to adopt a recovery based style of management, patients would need adequate relationships with health professionals to enable them to discuss recovery ideas or plans with them.
However, it appears that in the majority of the interviews that this was not the case and this related to a perceived lack of patient centeredness within consultations and paternalism within relationships with health professionals.

The quote below highlights the impact of a lack of patient centeredness within consultations which seemed to result in a lack of disclosure and discussion about regimen and routines. This has the potential to be a barrier to a recovery based approach and may also mean that recovery plans and hopes for the future are undertaken by the patient in an ad-hoc way without input from health professionals. This is something that will need further exploration in phase 2 of the study.

Yeah, not so much the nurse but the doctor um, I wouldn't say that she understands me, no, um, and I wouldn’t say she really listens to me. She knows, I think she knows, she's probably heard it over and over again from different patients, the same things, so I always feel as though she’s, she's looking at something else, or doing something else when I'm trying to explain about...

**Phase 1, ID 009**

Utilising a recovery based approach to condition management would require a patient determining what the most important areas or symptoms were to target for improvement. In this quote below, that patient talks about trying, on a number of occasions, to speak to the doctor about her dizziness which she felt caused her most difficulty on a day-to-day basis. However, during these attempts she felt that the health professional was dismissive of this symptom and instead focused on other more medicalised issues. She felt unable to challenge this due to the perceived status of the doctor and, as a result, allowed him run the consultation and determine what needed to be discussed.

*B: They seem to latch on to insignificant things and the important things, like the dizziness, they just dismiss as, 'Well I don't know what that is,' as unimportant.*

**Phase 1, ID 59**

This paternalistic relationship with health professionals was rife within the data and appeared related to the degree of personal responsibility individuals took for their own health.

*No. They want to do their own job, I'm only a layman, I don't know what they're doing. They know better than me, so leave them and let them get on with it.*

**Phase 1, ID A05**
But of course, that come just after Christmas and I’d been out, of course, like everybody else, trying to enjoy myself, and I did have a little bit extra to eat and a little bit extra to drink, which is what you do at Christmas and the holidays, consequently my blood sugar was up a bit so I got a telling off for that, you know.

**Phase 1, ID D09**

There was a sense within the data that some conditions could be attributed to the natural ageing process and therefore should have been expected which has been found previously (Hinojosa *et al.* 2008; Sanders *et al.* 2002). What is particularly interesting for the study of recovery and prognosis was that this perception was often attributed, correctly or not, to the medical profession which participants did not feel able to contest.

A: *Once they said, 'Oh, something you may have to put up with it, because, what can I say, sometimes when you get that age.' That's what he said, didn't he?*

B: *Yes.*

A: *You see, but he's not worried about that I can't use the arm, he said; that's the remark he made really didn't he?*

B: *Yes.*

A: *He said...*

B: *'I think he was having a bad day.'*

A: *...'Oh, certain age of people go through that...'*

B: *'You'll just have to put up with it.'*

**Phase 1, ID 21**

This perceived lack of ability to challenge medical professionals extended to the decisions made about their condition. This is reflected in the following quote from an ex-nurse. She talked throughout the interview about her good relationship with her regular GP but was anxious when she had to see a different one as she found it more difficult to engage with them. As a result she adopted a passive role within these consultations. It seems likely then that the continuity inherent within relationships with health professionals may impact on the propensity to engagement with a recovery based approach.

*I always dread telling any new GP; in case they think oh God she knows it all. I don't usually tell GPs what I used to do.*

**Phase 1, ID 164**
However, sometimes relationship with doctors characterised by high continuity as well as developed relationships made it more difficult to bring up new issues or get one’s point of view across.

*Um, well you more or less know what you've got to do over the years you've been going. More or less straightforward; go in; sit down, "How are you? What you been doing? What you been up to?"

The doctors say, "Have you any problems? How's your chest? Are you bringing anything up?"

*R: Right.

This is normal conversation.

*R: Okay.

*Takes your blood pressure whilst he's talking to you...

*R: Right.

...you know. That's about the only time he'll bring it up or whatever else he's got going through his mind he wants to ask...

*R: Yeah.

...and I just answer it whatever it is...

*R: Okay.

...or give correct answers as best as possible.

**Phase 1, A05**

However it was interesting that participants often acknowledged that relationships with health professionals had improved over their lifetime with current relationships representing a significant improvement from those in the past.

...remember, as a lad, the old Jewish doctor we had in Cheetham, (Higher Broughton?), you were frightened to death of him. 'Ah, young man.' He was like a headmaster. 'How are you?' 'Yes doctor.' You just spoke when you were spoken to. Now it’s a freer exchange, I think, it’s a different ball-game, isn’t it now.

**Phase 1, ID D14**

However, this ‘freer exchange’ in the health professional/patient relationship was not universally valued across the sample.

*No, no. In fact I sometimes say, I get too much. The classic is, before I had my heart bypass, once again, the doctor a lovely man, but, and I suppose this is what they do. I remember years ago when you went into hospital, the doctor wouldn't tell you anything.*
But now I think you are given too much of an overload of information and he’s telling me how they are actually going to perform this op on me.

**Phase 1, ID 52**

It is worth at this point bearing in mind that the patients included in this study were all recruited from GP practices in deprived areas (based on Index of Multiple Deprivation (IMD) scores) and this paternalism may be reflective of this. However, this would need to be explored in more detail during phase 2 of the study. As discussed previously it was not clear from the transcripts what, if anything, patients did to deal with concerns about consultations of this nature or how this impacted on their illness management. It did appear however tentatively though that this paternalism and perceived lack of patient centeredness had the potential to negatively impact on future access of health services.

*R*: Have you been back to your doctor or consultant about the fact that you feel the knee isn’t quite right?

*I haven’t been back to the doctor’s since; when I had a problem, my legs swelled and they thought it was thrombosis and I had to go and have scans, and they still insisted that it was thrombosis and it wasn’t. Four scans I had, then it went away.*

**Phase 1, ID 66.**

**The role of patients at the interface with the health service**

There were a lot of narratives within the data that appeared to represent patients describing themselves in a ‘good patient’ or ‘bad patient’ role found previously (Lally, 1989). These narratives represented an ideal type or model patient and may be reflective of public rather than private accounts of experience (Cornwell, 1984) and resonate with orthodox (medically legitimated) as opposed to unorthodox accounts of illness (self legitimated (Britten et al. 2002). In this study, being a ‘good patient’ involved adhering to access requirements and not breaking the rules established by the surgery or within their relationship with health professionals. Often these routines had developed over time and were well established. Adhering to rules, for example relating to access, had often served them well in the past in terms of getting appointments and it appeared patients were not willing to change these habits. The patient role, as described by participants, appeared quite pervasive and stable even when the patient was no longer in contact with health services. It is likely then that
individuals’ perceptions of their roles as a patient and the perceptions of the role of health services may impact on perceptions relating to recovery and prognosis.

Well, you’re sat there and they give you a card at reception and you wait for your number coming up. In my case, they shout for you in the treatment room.

R: Right.

You go in the treatment room and have a sit down and have a natter. Then she’ll take me blood pressure...

R: Yes.

...and she’ll see how I’ve been feeling and whatever, and then I have to blow down this machine and see what your lungs are up to.

Phase 1, ID A05

Being a ‘good patient’ was often closely related within the data to being a passive or trusting patient and adhering to what was told to them by medical professional reflecting the aforementioned paternalism. This passivity, however, often had detrimental effects on patients illustrated in the quote below.

A: Er, no, not really. The only time I was, as I say, he put me on these tablets and I was on ‘em for .. I dunno, what was it? For my breathing, it was, really bad. I think I’d been on ‘em, oh, I took the lot and I really got bad, and I had to phone up and make an appointment and I went over, and it’s my own fault cos I said, ‘Oh, I can’t take, I’m bad.’ He said, ‘You are bad.’ He said, ‘Show me the (…).’ So he brought the tablets up on .. ‘Oh my God.’ He says, ‘How long you been like that?’ I said.. He said, ‘Have you finished ‘em all?’ I said, ‘Yeah.’ ‘Oh,’ he said, ‘Didn’t you read the leaflet?’

B: Which we didn’t.

R: Ah right.

A: I didn’t read the leaflet.

Phase 1, ID D06

This passivity is reflected well in the following quote whereby the participant is asked by the interviewer how he feels his diabetes treatment is progressing. It appears that he misinterprets the question and responds in terms of how he thinks his doctor feels his diabetes is developing. This passivity reflects no real sense of ownership over conditions or responsibility for them. What he refers to as ‘swimming’ is a symptom currently causing him difficulty but which had not been addressed by the GP. He is quick to skim over this in his narrative and it appears this mirrors his perception that the GP has skimmed over this within consultations. His partner is quick to refocus him within the interview on the more
medicalised symptoms which may be reflective of their experience of the consultation process. This directly contravenes the notion of recovery inherent in the mental health literature.

R: What would you say is the most serious or the most um, awkward of your conditions that you have? Is it the diabetes or...

A: It is the diabetes, yes and because of that I feel very giddy all the time. My head spins, you know? These last few days I've been quite steady...

R: Yes.

A: ...but once I start feeling giddy it's there every day...

R: I see.

A: ...and it does worry me...

...R: And how do you feel that your diabetes is progressing?

A: He's quite pleased with it.

R: Yes, other than this swimming...?

A: Yes, that's right. Even he can't pinpoint what it is, but the actual diabetes side of it, he's quite pleased with it.

B: Yes, the blood sugars have at long last evened out haven't they?

A: Yes, yes.

Phase 1, ID 59

Avoiding being a burden to self, others and society

The notion of burden was commonly found within the transcripts analysed. It appeared that participants as well reporting the burden of illness upon themselves, often felt as if they were a burden on friends, family and health services as a result of their condition. The burden of chronic illness is well documented (Illsley, 1981) and it appears that there are moral elements to how the boundaries of relationships are negotiated by chronic illness sufferers and those around them (Finch and Mason, 2004). In addition, burden has been linked to a lack of treatment adherence (May et al. 2009) and is therefore likely to have clear implications for recovery and prognosis.

Participants frequently reported not wanting to worry or concern family members about their health. Some felt spouses and/or close family members were already worried enough
about them or had their own health problems to worry about. It would be interesting to explore the perceptions of these spouses and close family members to compare their views with those of individual patients.

Yes, oh no he don’t like that, you know but um, he’s my carer at the end of the day and some days when I’m really bad, you know, but then again I don’t like to worry him because he gets very worried and he can’t sleep and you know...

**Phase 1, ID 170**

Burden is a theme commonly found within the literature on physical and mental health conditions (Freund and McGuire, 1995; Gallacher *et al.* 2011; Maurin and Boyd, 1990; Reeve *et al.* 2012; Wiener, 1967). Burden was particularly marked within participants’ relationships with their own children and most significant amongst women. It appeared that in order to fulfil their role as a parent, individuals should be looking after their children and not the other way around.

I never, do you know what I mean, I should be helping the girls, not the girls helping me, so therefore in that way, they would, I know they would do anything for me, but I’ve never, we always managed to scrape through, haven’t we?

**Phase 1, ID 46**

Being a burden on health services is related to the previous section concerned with the role of patients within health services. Participants often appeared concerned about the amount of money that appointments or procedures cost the NHS and did not want to take ‘more than their fair share’ of resources. They also tried to distance themselves from those they felt unfairly overused the health service. This notion of patients rationing the use of health services is not new (Rogers *et al.* 1999a; 1999b) and may also reflect the dependent status chronic illness patients are ascribed within recent health policy documents (Illsley, 1981). In this sense, it appeared participants were protective over the limited resources within current healthcare providers, even on rare occasions, to the detriment of their own health. It may be that this perception is socially patterned and this would need to be explored in more detail in phase 2 of the study. Those with longstanding relationships with individual GPs often acknowledged the amount of work they did for the community and were concerned that they may overstretchesing themselves and in this sense were keen not to overburden them further.
I probably will, you know, but sometimes, I go to my doctor’s and sometimes he looks
tired. I think sometimes they’re overworked. You know, I went once and it was, he
fit me in at the evening, and to be truthful, I thought he should’ve gone home and gone
to bed.

R: He’d had a long day, had he?

He looked really tired, you know.

R: Oh right. Okay. So getting information is difficult then, about things like the strokes.

I dare say if I asked for it, you know, perhaps if I was to ask for different things I would
get them, but sometimes I think you’re a bit lazy in asking for information.

Phase 1, D02

4.4 Summary

The aim of this chapter was to examine if narratives about recovery and prognosis were
apparent in interviews relating to the experience of illness. Key themes identified from the
secondary data analysis relating to recovery and prognosis were reported and separated into
those that were directly or non-directly related to recovery and prognosis. These themes are
summarized in figures 12 and 13. As figure 12 demonstrates, it is likely that these factors
are interdependent and dynamic in nature as well as socially patterned. Given that the focus
of the interviews included in this phase were not focused on recovery, it is perhaps
unsurprising that the data relating to these issues was sparse. However, this was anticipated
during the design of the study and it was always envisaged that these emergent themes
would be translated into phase 2 of the study to enable them to be further explored. These
emergent themes are summarised in figure 13. There were a number of links with data from
this chapter to the findings from the mental health field presented in chapter 2 including
issues of burden, stigma, the importance of personalised goals, the notion of illness as
personal journey, passivity in relationships with health professional and the importance of
acceptance. These will be picked up and examined in more detail with direct comparison
with models from the mental health field in chapter 8.
Figure 12: Meso, macro, and micro factors affecting adoption of a recovery-based approach to chronic illness management

MACRO LEVEL
- Relationship with health professional (paternalism, continuity etc)
- Perceived role of patient within health services
- Burden

MICRO LEVEL
- Perception of wellness
- Social comparison and justification
- Rehearsing and expectations
- Competing priorities and agendas

MESO LEVEL
- Biomedicalisation
- Policy initiatives implicating choice, autonomy, control and notions of recovery (discussed in chapter 1)
**Figure 13: Key findings from phase 1 to feed into phase 2**

- The participants who were interviewed rarely spoke directly, or in great depth, about recovery and prognosis when talking about chronic conditions. However, from what data was available it appeared participants with long-term conditions used narratives related to the concept of recovery highlighted in the mental health literature. Specifically, this related to discussions about a personalized recovery state, which does not follow a traditional biomedical recovery. However, this needed to be explored in more detail.

- The narratives about recovery appeared to indicate, although tentatively, that those with physical health problems used a notion of perceived ‘time left’ to conceptualise their hopes for the future. It may be that narratives about recovery from physical conditions are present orientated when compared to the more future orientated narratives of patients with mental health conditions. However, there was limited data within the transcripts to support this. Therefore the use of longitudinal methods and narrative emplotment in phase 2 of the study should allow this to be explored in more detail.

- It appears this recovery state is often not discussed with health professionals and may be done on a personal ad-hoc basis. The reasons for this will need to be examined in phase 2.

- It is likely that this recovery state will be mediated by a number of factors both individually and context based, which will need to be further analyzed through the longitudinal primary data collection, narrative emplotment and analysis.

- It is likely that the factors identified in phase 1 are socially mediated and this will need to be explored in phase 2. It is also plausible that these factors change over time and figure 2 will endeavour to explore this through the use of a longitudinal study design with a follow-up at 12 months.

- It was not possible in phase 1 to explore the impact of employment on perceptions and expectations relating to prognosis and recovery and this will need to be examined during phase 2.

- The notion of burden on family and friends was a key factor identified during phase 1. Phase 2 will compare and contrast the views of these family and friends with those of the individual participants.
CHAPTER 5: Exploring perceptions and expectations of recovery: the views of participants with chronic physical health conditions.

5.1 Introduction

The following chapters present the findings from phase 2 of the study which involved primary data collection in the form of narrative interviews with participants with chronic physical conditions such as diabetes, CHD and arthritis. Patients were included based on the chronic or long-term nature of their conditions. Both baseline and follow-up interviews explored individual experiences of illness with a focus on participants’ perceptions and expectations of prognosis and recovery. Where appropriate, data from the interviews with significant others (nominated by participants) supplement the individual participant data provided. This phase was informed by the thematic analysis from the phase 1 secondary data analysis presented in chapter 4.

I assigned pseudonyms to each participant to enable them to be identified throughout the course of the next four chapters and to enable the reader to see how they have responded at different time points (the letter R denotes the interviewer within transcripts). A label of affluent or deprived was also ascribed to participants. This was developed based on individual scores on the IMD 2007, discussions with practice staff at the time of recruitment, and the use of definition developed by Townsend (1987). Based on this definition and discussions with practice staff, three participants were moved from affluent (based on postcode IMD score) to deprived categories (ID3, Phyllis; ID10 Annette; ID12, Marie) as this was considered more representative of these participants.

‘Deprivation takes many different forms in every known society. People can be said to be deprived if they lack the types of diet, clothing, housing, household facilities and fuel and environmental, educational, working and social conditions, activities and facilities which are customary, or at least widely encouraged and approved, in the societies to which they belong.’ (Townsend, 1987: p.126)

5.2 Social patterning, notions of recovery and ‘habitus’.

One of the central research questions of the thesis was to explore how perceptions of recovery were socially patterned. It became apparent during the data analysis that
socioeconomic status was associated with notions of recovery and habitus (Bourdieu, 1977) and a table detailing the differences between the social classes can be found in appendix 12. Habitus relates to a set of internalised and culturally defined ways of behaving derived from everyday life. Often individuals are not consciously aware of habitus and, in its simplest form, it relates to a cognitive structure used to deal with the world by producing thoughts and actions (Bourdieu, 1977; Townsend, 2011). Habitus can be viewed as a both an individual and a collective phenomenon (Bourdieu, 1977). In relation to illness, the notion of habitus asserts that agents act within the field of health as a result of a combination of resources (capital which includes economic, symbolic, cultural etc) and a set of internalised and habitual ways of working accrued over a lifetime (habitus). The concept of habitus asserts that society is not ‘one hegemonic habitus nor a unified collection of discrete habits; all members do not fit equally’ (Frank, 2012b, p.703). In addition, how people take care of their bodies is one of the deeper manifestations of habitus (Bourdieu, 1984).

Habitus includes the notion of symbolic violence whereby dominant groups in society impose categories of thought onto the dominated groups. These notions of habitus and capital had apparent resonance within the data. It appeared that those from different socioeconomic backgrounds saw themselves differently and this appeared related to individual capital and habitus16. Often those with greater social and economic status made assertions or assumptions about those from lower classes. For example, those with lengthy educations or technical training felt they had subsequent capital which they could use within the field of health. Specifically, this related to being able to make healthier lifestyle choices, communicate in an equal dialogue with doctors and also contribute to the decisions made about their health. They also felt, in comparison with those from lower classes, that it was their right to do this and something that they felt comfortable with. In this respect, having capital in the first place made it easier to obtain more capital in the future.

Yeah, I’ve got a scientific background or mathematical background, so I understand figures and trends and things, so...I’ve got a degree in paper making er, which is a general science degree, but...

... It's the way I am; I always like to know how things work. From an early age I would take model cars apart and take toys apart and put them back together, my dad was an engineer by trade you know. You know, I learnt to use spanners and tools and that sort

16 Whilst participants are described in two groups (high/low socioeconomic class), the data did not fall perfectly into these two categories and, as some of the quotes demonstrate, there was some overlap and participants did not always express attributes of the group that they were ascribed to within the write up.
of thing since very young. I loved Meccano and Lego and I just have an enquiring mind, I just wanted to know how things work.

**ID2: Reg, male, 52 years, leg ulcers, cryoglobulin anaemia, affluent.**

I suspect that people with more money are healthier, not necessarily because they can afford better health care, but because they probably don't have bad habits. They probably don't drink excessively, they probably don't smoke excessively. They probably do exercise well and they are probably more assertive in pursuing a course of action that will give them better health care or better health. I don't think it's, you know, there's nothing to stop somebody that's less well paid from being healthy if they put their mind to it, it's a case of, I don't know, I don't know. Oh, that's a tricky one. I, intuitively I would say that people with more money probably do enjoy better health because they have other personal skill sets that lead to better health

**ID1: John, male, 80 years, stroke, high blood pressure, affluent**

To illuminate this further, the quote below is drawn from a participant considered affluent. He demonstrates clearly the notion of physical capital which relates to the ability of groups within society to consider their bodies and lifestyles as superior to others, namely those from lower class groups (Shilling, 1993) and that ‘dominance is constituted by its capacity to disregard’ (Frank, 2012b, p.703).

Most of them, you've got to look at the population out there. They eat too damned much and they drink too damned much, but if they were told not to eat as much as they do they wouldn't...

... The people that I see down at the gym they're all lean, all fit and muscular, but it's a fraction only. The majority of people out there just don't sort of, give consideration; the masses it's called.

R: The awareness you were talking about before.

I don't want to talk about a class structure, but if you were thinking about, I mean, you sociologists have got various categories of people, but the lower level they just do in fact indulge and into excess.

**ID1: John, male, 80 years, stroke, high blood pressure, affluent**

It should be noted that for the most part participants from lower social classes did not seem to readily acknowledge or recognise this perceived capital deficit. This is consistent with previous work which has found that discussions about social inequalities in health are rarely found within the narratives of those from deprived areas (Blaxter, 1997). Patients in this study were more likely to focus on individual responsibility as perpetuated in health promotion and prevention discourses. As Blaxter (1997, p.753) notes, this may reflect a ‘feeling of disbelief or unease at the notion, or a conceptual difficulty’ and further challenges the meaning of structural risk factors when considered by patients on an individual level. Later studies using open ended survey questions revealed that participants were more likely to cite place as a possible reason for health
inequalities indicating that lay understandings of the cause of illness are complicated and multi-factorial (Popay et al. 2003). However, when the same participants took part in qualitative interviews to explore these findings in more depth, they generally questioned the existence of health inequalities for a myriad of reasons. These included a distrust of statistics and the media in general, a perception of greater homogeneity within classes, a rejection of the use of labels such as ‘rich’ and ‘poor’, and an increased emphasis on individual agency (mind over matter) (Popay et al. 2003). This highlights the difference in response generated by different methods and indicates that narrative accounts provided in interviews may require participants to ‘account for themselves socially and/or morally’ (Cornwell, 1984; Popay et al.2003). It also supports the assertion that questions relating to general concepts of health can lead participants to produce narratives that echo public health strategies. Similarly, more abstract questions about health are more likely to produce holistic and often moralistic narratives (Blaxter, 1997). This may go some way to interpret the results found in this study.

When participants in this study spoke about class differences or financial differences, this related to economic capital which may enable people to buy better food or private healthcare which may speed up treatment which echoed previous findings (Popay et al. 2003). It seemed that participants from deprived areas had more fatalistic views and felt that illness could not be warded off entirely by increased financial capital, which is illustrated in the quote below and echoes previous research amongst deprived individuals (Cornwell, 1984).

*I don't think the treatment is any better [for those with more money] and their health certainly isn't; money doesn't make you healthy. Um, but it does make accessing health services, specific health services, I mean, um, I, my first wife had a triple bypass operation, now from when she first was diagnosed with angina she could probably have paid and had an operation within a year or maybe less.*

**ID15: Ron, male, 65 years, diabetes, high blood pressure, deprived.**

In terms of relationships with health professionals, those from more affluent areas appeared to find communication with health professionals easier and were more likely to view this dialogue as a right rather than a privilege. Those interviewed from more deprived areas used health services more cautiously and were fearful of wasting professionals’ time which could deter them from accessing treatment. This notion of patients rationing their use of health services has been found previously (Rogers et al. 1999a; 1999b). It seemed that those from lower social classes found some moral value in using health services as little as possible and only when they really needed to. This
lack of dialogue and reduced access are likely to impact on recovery through reduced opportunities for patients to negotiate about treatment or get their views across in consultations.

But I'm not sure with the doctors because as I said to you, I quite often feel embarrassed as if I'm bothering them, as though I am going on about nothing when they've got more important things to do. Even now after having what I've had, I think, oh, you know, some of these things sound a bit petty really.

ID14: Vera, female, 73 years, primary biliary cirrhosis, stomach cancer, deprived.

It appeared that the relationship between social patterning, habitus and recovery could increase an individual’s vulnerability in terms of chronic illness at various stages on the illness trajectory. Firstly there was a perception that the limited capital of those people in lower class positions predisposes an individual to chronic illness through unhealthy or uninformed lifestyle choices. Secondly, this lack of capital could potentially inhibit relationships with health professionals. Thirdly, those from lower classes cannot pay to speed up access to health services by paying for private treatment. Additionally, what constitutes a ‘good patient’ differs amongst different patients with those from more affluent areas considering that a good patient is an active one in relation to managing their health and interactions with health services. Alternatively, those from more deprived areas considered more negative strategies to be reflective of a good patient (e.g. not using health services until absolutely necessary). This adds to the findings in phase 1 of the study (chapter 4) which only included participants from deprived areas who considered a good patient to be associated with these negative strategies. Finally, it is likely that habitus will impact significantly on expectations for the future and in this sense on recovery.

5.3 Recovery journeys: the content and range of perceptions of recovery

This section details the content and range of perceptions relating to recovery which were apparent within the data.

5.3.1 Roller coaster rides: seeking the normalcy of living life with a chronic condition

It appeared that there was a high level of acceptance within narratives about living life with a chronic condition (Pinnock et al. 2011) in line with data from phase 1 of the
It appeared that participants had, for the most part, come to terms with the fact that they would not recover from their condition in the traditional sense of the word (e.g. biomedically). There was no sense from the data that participants were trying to not think about the future or trying to recapture or romanticise the past which has been found previously (Charmaz, 1991). Equally, there was no evidence that those with chronic conditions were pulled towards two extremes (either becoming wholly identified by the condition or by excluding the condition in its entirety (Barnard, 1995)). Instead it seemed that the majority of participants fell somewhere in between these two extremes. As a result, the illness trajectories discussed within narratives were, for the most part, regressive or partially restitutional in nature and often weaved seamlessly into their life stories (discussed in chapter 2 and 3). In this way, individuals reflected to some extent on what Frank coined memoir narratives (a type of quest narrative) whereby illness is incorporated into an individual’s life story. These narratives are characterised by the individual being distanced from the initial disruption of illness and having had time to reflect on their experience in order to form coherent narratives (Frank, 1995). However, the narratives identified in this study may be more aligned to the polyphonic ‘living with a philosophy of the present’ narratives (e.g. ‘I do sort of, live one day at a time now’ ID14, Davies, 1997; Ezzy, 2000) as most of the journeys described in this study did not progress to a fully blown ‘quest’ which these narratives coined by Frank (1995) require.

Participants conceptualised ‘recovery’ as a personal journey. However, this was often a journey that people did not want to be on and participants sometimes made direct reference to this. This notion of recovery as a journey appears to reflect a sense of purpose and reflexive monitoring on the part of participants and accordingly these narratives have some similar features to the quest narratives (albeit not to the same degree or extent discussed above (Frank, 1995)). Using the metaphor of chronic illness recovery as ‘a journey’ infers some notion of travel and similar metaphors have been used for tuberculosis previously (Sontag, 1990).

Yeah, so that’s given me confidence. Because what that tells you, even though you were immobile virtually with it in the beginning with practice and so on and so forth, so I'm anticipating that I will get better...

...It is. I just want another journey. It’s a rotten journey I don’t want it, but there we are.

ID1: John, male, 80 years, stroke, high blood pressure, affluent
The notion of recovery as a journey was raised tentatively in the phase 1 analysis (chapter 4). The longitudinal narrative data collection in phase 2 of the study allowed this concept to be explored in more detail and found that these ‘journey’ narratives as described by participants varied considerably. Journeys appeared to start from personally constructed baselines or ‘pre-illness’ selves from which individuals measured or discussed their subsequent trajectories. In this sense, individual perceptions of illness related to not feeling or being themselves. These pre-illness identities served as a comparator for all things that followed within narratives.

Journeys differed in the length and type, and also in the degree of impact the chronic condition had. For example, some participants described one major event (e.g. one illness diagnosis or crisis point within the narrative, such as a heart attack) whilst others described multiple events (e.g. heart attack in addition to stroke and arthritis). Participants also differed in the extent to which they felt they had recovered from their condition. Some displayed an almost complete return to prior functioning (progressive narratives but not fully restitutional e.g. with some residual impacts such as tiredness etc. (Bury, 2001; Robinson, 1990) whilst the current functioning of others represented a significant deficit when compared to pre-illness functioning (including both regressive and stable narratives (Bury, 2001; Robinson, 1990).

As well as referring to recovery as a personal journey, participants used other metaphors when talking about recovery. The importance of metaphors is not new and some consider them of central importance in shaping the storyline within narratives (Sontag, 1990). For example, participants talked about roller coasters and likened the recovery process to being on this type of fairground ride with the associated highs and lows. Other metaphors used in relation to recovery included the body being likened to a car which needed regular maintenance to ensure nothing went wrong in the future. This suggests links with the notion of recovery or, at the very least, maintaining health to ward off future problems which enables the individual to continue with a life they consider worth living. Using metaphors which compared the body to a car portrayed an element of disembodiment or, at least, dissociation with the body as something external to the self (e.g. a car). Military metaphors relating to battles against illness commonly found in cancer literature (and to a lesser extent in studies of CHD, Davison et al. 1991) did not appear applicable to the chronic illnesses included in this study. The metaphors
used within narratives illuminated the experience of recovery and examples are provided in the quotes below.

Not having to be on the roller coaster all the time I think, not having to... I've probably come to the other extreme now where I could do with a bit of a roller coaster, but not having to perform...

**ID 32: Jeff, male, 60 years, kidney stones, high blood pressure, CHD, angina, deprived**

But when I first had the operation and I'd been on that table and they'd done everything and put three new arteries in, then I can sit here and say, well I've had a full MOT.

**ID28: Ivy, female, 66 years, chronic heart disease, deprived**

Recovery from chronic physical conditions was not viewed as a simple, linear process. Instead recovery appeared to be a laborious, slow process and one which was often fraught with difficulties. For some participants, however, this was something that they had expected from the outset and for some participants (including the one below) they seemed to find some moral value in being able to cope.

And that was a bit of a setback to say the least. But I'm recovering.

R: You're recovering.

I've just come from the gym now.

R: I thought...

I try to go a couple of times a week and I've had, immediately after the stroke I started on physiotherapy and yeah, I'm recovering, but slowly. I expected it to be slow to be honest with you.

**ID1: John, male, 80 years, stroke, high blood pressure, affluent**

The notion of recovery as a personal journey meant that participants often felt that it was difficult to get reliable or relevant information to assist them. They felt that even if it was possible to receive such information, that it may put undue pressure on people who may not ‘recover’ in the same way or to the same extent. In this respect, there was an implicit recognition that for many, recovery was not an available option. Nonetheless this has clear implications for the health services responsible for the treatment of those with chronic physical health conditions in terms of fulfilling expectations around information provision.

Yeah. There might be, I mean, I don't know, they may have something down there I don't know, but it would seem sensible to me, if there was a leaflet, I mean, I don't know how frequent strokes are. If it was a regular sort of, if it was a sort of, regular event amongst the patients over there, a little pamphlet...
R: That would be helpful.

...one sheet sort of, saying don't worry you're going to recover and maybe everybody doesn't recover. I mean, I think it's the extent of the event that determines how quickly and how much you are going to recover.

R: Right, okay.

It would be a bit misleading to write something and say that you're going to recover.

**ID1: John, male, 80 years, stroke, high blood pressure, Affluent**

The same participant felt that he did not want to simply be told that he would recover which would make for feeling unduly pressurised and was viewed as something that would not have been useful and could potentially have been oppressive (Roberts and Wolfson, 2004).

R: Has he ever talked, did you ever bring that [balance problems] up to your GP or...?

No.

R: And is there a reason why you didn't mention that to him?

No. He's sure to say you'll recover. Everybody says you're going to recover.

**ID1: John, male, 80 years, stroke, high blood pressure, affluent**

It appeared from the data that the personalised nature of the recovery process meant that participants often learnt for themselves (through tacit knowledge) as to their own barriers and boundaries through trial and error. In this respect external information had little to offer.

### 5.3.2 The perceived tension between recovery and burden

In line with phase 1 data, participants often reported that following their diagnosis they felt they had become a burden on those around them (including friends, family members, health professionals and the wider health service). The novel contribution of the phase 2 data relates to the clarification of the nature of burden, the perceptions of significant others in relation to this burden and the social patterning of burden perception.

Some participants reported feeling that since diagnosis, relationships with family and friends, or an individual’s roles within personal communities, had changed indicating disruption to what could be described as a pre-existing ‘familial habitus’ (Pimlott-Wilson, 2011). This sense of burden related to friends and family members providing help and support in day-to-day lives which they would not have done previously. This
seemed more difficult for people who had seen their ‘pre-illness selves’ as independent and requiring little support from others. This demonstrates how past lives can be used as interpretive contexts or lenses in which to make sense of current and potential functioning.

This sense of burden described by participants incorporated both practical and emotional elements and was viewed as prospectively threatening. Participants reported not wanting to burden others by talking about their condition which gave rise to stoicism in some cases. This served to reinforce elements of identity (such as being a mother, grandmother etc), to not allow illness to take over lives entirely and to retain a sense of normalcy and equality with the non-chronically ill. It may also act (as noted in other studies) to reduce the likelihood of valued others perceiving them negatively and thus may represent a form of symbolic violence (Bourdieu, 1977; Townsend, 2011). Others may argue that given the capitalist society in which we live which focuses on and encourages consumerism, individuals may unconsciously refrain from vocalising suffering in an attempt to preserve the optimism on which these types of societies are based (Kleinman, 1988) and a sense of equality.

This sense of burden was often based on an in-depth knowledge of how others around them were likely to respond and highlighted the imperative of prioritising the maintenance of pre-existing relationships. Some participants balanced the notion of burden with an awareness of how others could be worse off than them and that negative events became more frequent as one gets older.

*It’s very hard because it’s doing nothing and doing nothing and just feel like a zombie everyday to like I am now, which is hard for other people. It’s hard for me to see other people doing my work and um, it’s a very hard thing to say...*

*...I try and not grumble about it and not, you know, er, can’t be tearful all the time because we had a friend that lost her husband and he said he could bear anything, but he couldn’t bear her tears, so I thought right, that’s taught me that if I’m ever ill I’ll you know.*

**ID3: Phyllis, female, 81 years, high blood pressure, stroke, macro globular anaemia, diabetes, deprived**

The quote below highlights the holistic and stoical attitude of considering health relative to others things in their lives. Specifically, this relates to there needing to be more to life than aches and pains otherwise individuals may consider life ‘not worth living’.

135
I don’t think people want to sit and talk about my aches and pains and, I mean, we’re all getting old, we all say it’s old age, sort of, thing...

**ID6: Paula, female, 73 years, CHD, degenerative disc disorder, arthritis, supraventricular tachycardia, affluent**

This notion of burden was echoed in the narratives produced by significant others (all spouses in this study) about their partners. For some spouses, burden was minimised within narratives but for others, it appeared that the impact was much greater than that reported by the participants with long-term conditions. This may suggest the culturally valued position of stoicism and non-disclosure for those with chronic conditions and reflect previous research that has demonstrated that participants underplay their health problems (Cornwell, 1984). It may also reflect positive self representation within the interviews or what Frank refers to as ‘passing’ or the concealing of some flaws or stigmas that could potentially threaten their sense of self. This highlights the artfulness of storytelling and the benefits of doing so for the person telling the story (Frank, 1995).

The interviews with significant others highlighted how involved and invested spouses were in the recovery process. Some spouses felt they would welcome more involvement in the medical worlds of their partners from which they often felt excluded. Spouses often talked about being reliant on their partner telling them what happened within consultations and relaying any information obtained. When significant others talked about the impact from health conditions, their comments were woven seamlessly into biographies. Other valued aspects of life were eroded simultaneously as participants aged or as marriages progressed. It seemed participants could not remove or isolate illness trajectories and management from other aspects of their lives. They also used other people as reference points against whom they compared themselves. This social comparison maintained a sense of a life they considered worth living and expands on the finding from phase 1 of the study demonstrating that social comparison not only occurs in those with the condition but also amongst others within their social network.

*Well people must, er, your marriage isn't the same. People must split up because of things like this. It must cause a rift. We're not the same are we?*

*We get on as, you know, as two people can get on. But, er, the marriage isn't, you know, as it should be.*

**Spousal interview, Lionnel, male. Husband of ID 10: Annette, female, 62 years, asthma, CHD, carpel tunnel syndrome, diabetes, high cholesterol and high BP, deprived.**
I said “We’ve had a grand life” but I says “We’re not...we’re dependent on that now” I
said, “We just love one another because of who we are”. So on a...when you’re...you
take it all together, we’re a right couple of cases aren’t we?

\textit{Spousal interview, Carl, male. Husband of Phyllis, female, 81 years, high blood
pressure, stroke, macro globular anaemia, diabetes, deprived}

Some participants saw themselves as becoming a burden on a stretched health service as
identified in phase 1. Phase 2 was able to specify that these concerns about burdening
health services centred on the limited resources which spanned primary, secondary and
tertiary care but were particularly pronounced within primary care. Participants would
cite the limited time available within consultations with general practitioners (e.g. ten
minute limit on consultations) and felt these needed to be focused on more medically
relevant discussions, e.g. medical crises, medication reviews. In terms of secondary
care, they felt services were over stretched in general, which often resulted in cancelled
appointments or lengthy delays. This focus on financial and resource issues within
individual illness narratives highlights the political-economy aspects of healthcare that
have an impact at the individual level of service use.

\textit{I don't know. I don't know, it's all [health services] now so pushed. Everyone's so
pushed. There aren't any counsellors. I know the hospice because the last five years I've
worked in the hospice. Now they do have counsellors and they are very good but the
ordinary hospitals don't.}

\textit{ID4: Anne, female, 78 years, cancer, stroke, asthma, diabetes, leg ulcers, affluent}

I had an appointment made two weeks ago and before I’d even got the letter saying the
appointment had been made I was being rung up to have it postponed, so I'm not
actually going to have the appointment that I'm scheduled to have. I think it's made for
April 22nd, and I first went to the clinic in Manchester on the 11th January, so we're
moving, you know, the sand has run through the hour glass pretty quickly and I suppose
that's just a classic of how stretched the clinics are with becoming an increasing
problem.

\textit{ID7: Andrew, male, 53 years, diabetes, affluent.}

This notion of burden again appeared related to habitus and was more pronounced
amongst those with lower socioeconomic status. Burden was also exacerbated for those
who been employed themselves, or knew somebody who had worked within health
services. In this sense, individual narratives were shaped by wider contextual factors
and, again, past lives were used to interpret current events.

\textit{No, no. I was a nurse so I know basically...}

...what it is. I just find it difficult to talk to them.

\textit{R: And why do you think that is?}
Because I know how busy they are...

...I know that they haven't time for you to go in and sit down and talk to them, because there's a queue of people waiting in the waiting room, therefore you just don't.

**ID4: Anne, female, 78 years, cancer, stroke, asthma, diabetes, leg ulcers, affluent**

Participants’ narratives incorporated references to ‘less responsible’ patients or characters who over used health services and about whom they appeared to feel indignant and morally superior to. Such characters within the stories served as negative reference points and participants were keen to distance themselves from these types of patients for what seemed to be a fear of being labelled negatively by others (including potentially the interviewer). Thus narratives held clear messages about feeling compelled to act differently in the light of avoiding being associated with these characters in order to place themselves within a group of morally responsible patients in line with data from phase 1. It appeared that the perceived ‘wasting’ of resources could potentially have relevance for individuals in terms of what could be provided to them as a result in the future.

\[\text{You know, it would save, save doctors time, save their own time, save the NHS time, which is most you know, um, I think there's a lot of, there's a lot of wasted time. Wasting appointments, wasting drugs... ...I could go on and on and on.}\]

**R:** Right. And why is that important to the NHS, why is cutting that bit out...?

Well it's money. You know, it's money they are short of money and people, you know, the people who need it sometimes don't get it. It's all these time wasters and you know, I think because it's free they just, it's just wasted, that's my opinion on it anyway...

**ID5: Moira, female, 63 years, asthma, affluent.**

These perceptions of burden appeared to impact on the expectations people had in relation to their prognosis and recovery in a predominantly negative way and related specifically to not seeking help from others. These perceptions of being a burden, particularly in relation to health service, were more common amongst those from more deprived areas. Those from affluent areas were more likely to consider access to health services as a right and something to which they were entitled (constituting part of their habitus) especially if they felt they had ‘saved’ the NHS money by going private or by limited use in the past.

\[\text{When I went in there and saw it closed on Saturday morning I was furious, if you really want to know I was livid. I felt God almighty, all these years I've paying into this damned service and the people in there, they're going in there every week, you know, and just when I needed it, it didn't, it wasn't there, but I can't understand it.}\]
5.4 **Self-defined implicit recovery goals and their manifestation**

In line with the framing of personalised notions of recovery as a journey, the majority of participants held personally defined recovery goals which they wanted to achieve over the next 12 months. One interpretation of this finding is that the need to ‘recover’ was implicitly either important for those living with long-term physical health conditions or perceived as part of reclaiming a valued sense of self (Charmaz, 1983). In this way, these goals formed manifestations of the theme of participants wanting to make the most out of their perceived time left which was raised but not explored in depth during the secondary analysis undertaken in phase 1.

There was a wide range of hopes for the future but it is important to note that a small minority of participants ignored prognosis altogether and consequently did little self management. Often for these participants, whilst they knew they had a chronic illness diagnosis (e.g. diabetes); they did not consider themselves to be ill. They placed themselves in a ‘liminal’ space between the traditional dichotomy of sickness and health (Jackson, 2005). However, they would often acknowledge that other people considered them to be ill, both within their individual networks and in the wider community. This echoed the findings in phase 1 of the study that perceptions of wellness impact on expectations for recovery and prognosis. Personal recovery goals appeared related to illness beliefs and wider aspects of patients’ lives. Consequently, habitus and an individual sense of self are relevant to understanding.

Participants sometimes made passing references to recovery goals set by others and these predominantly related to those imposed by health professionals. These were generally biomedical with participants appearing to have little ownership over, or attachment to, these externally set goals. The quote below highlights how the biological

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17 A goal was defined and identified within the narratives as any achievement or objective towards which efforts or ambition was strived. These had resonance to identity goals defined by Charmaz, (1995b) in her paper discussing adapting to impairment ‘Wishes are founded on feelings as well as thoughts. If possible, ill people usually try to turn their wishes into intentions, purposes and actions. Thus they are motivated to realise future identities, and are sometimes forced to acknowledge present ones. However implicitly, they form identity goals’ Charmaz, 1995b, p 659)
reductionism inherent within the goals imputed by health professionals which often had little meaning for the participant concerned.

_Everybody keeps telling me [health professionals] that I must get my HBA1C down to about 7½ and it’s probably hovering around about 10, but since it’s only a measure of the mean of the blood sugar because the amplitude is so big, if I drop the mean then the bottom end of the peaks or the troughs end up putting me in trouble, so to avoid that I’m obviously running it a bit higher than I ought to._

**ID7: Andrew, male, 53 years, diabetes, affluent.**

Recovery goals were reflected in the data in idiosyncratic ways and were not centred wholly on medical related matters. It appeared these were personally defined goals and not ones that had been imposed or suggested by medical professionals who were not mentioned in relation to recovery goals in any great depth. This suggests patients are not dependent on medicine in terms of recovery goals and hopes for the future and this echoed findings from phase 1 of the study. Goals appeared to be derived from a pre-illness habitus of a healthy body and formed a role for the individual in terms of self care. Specifically, they gave participants motivation and the ability to work instrumentally towards concrete goals which were meaningful to them and to enable them to make the ‘most’ out of the perceived time they had left.

There was a sense of underlying pessimism within the discourses about recovery goals alluded to by participants. Goals, for the most part, reflected incremental improvements or maintenance type goals rooted in everyday routines rather than more radical or utopian type goals. There were no references to grand hopes for the future even as a mechanism for dealing with the present which has been identified previously (Charmaz, 1991; Ezzy, 2000). Instead goals appeared related to the narrowing of lives as a result of chronic illness (Charmaz, 1983) and reflected implicitly the desire to minimise disruption and make the most of perceived ‘time left’. This separates the findings of this study from other research that has demonstrated HIV patients’ desires for a longer life (Ezzy, 2000) but supports other studies which have highlighted the importance of time within the illness experience (Rasmussen and Elverdam, 2007).

The goals described were wide ranging but included being able to go to the park with grandchildren, to being able to write better, or being able to play golf again. These goals alluded to regaining elements of a pre-illness ‘sense of self’ that was valued by participants (Charmaz, 1983). This finding echoes the sentiment inherent in Clarke et al.’s paper in 2003 that biomedicalisation has brought with it an increased sense of
individualisation and customisation of health (Clarke et al. 2003). In line with this assertion, there were a variety of norms for different people included in the study.

*Um, we used to go walk in the mountains, in the Lake District, climb the fells, (inaudible 00:17:53)... kids when they were eight, nine, ten years old. They're twenty-two now, but I'd still like to be able to do that. Last year we went to the lakes and we did some longish, four, five, six mile walks, no problem at all. Didn't find any high level ones, yet.*

**ID2: Reg, male, 52 years, leg ulcers, cryoglobulin anaemia, affluent.**

The goals described above included physical or fitness markers and in this sense represent embodied goals. In this quote the individual’s social role is linked closely with his physical fitness or physical capital (Bourdieu, 1977). He talked proudly throughout the interview about football coaching and his refereeing role within the community. In this way, his sense of self was related to status and his perceived standing in society which had been impacted upon by his physical condition. For this participant, getting on with life would involve getting back to this valued position in one form or another. In current culture, football is positively valued as a social activity and historically, like other sports such as darts, has been considered a working class or working man’s sport. One interpretation of this finding is that this participant’s (from a deprived area) symbolic capital was closely linked to his physical fitness or physical capital. Therefore illness had impacted more significantly on his existing capital and the potential to accumulate future capital than other participants (predominantly from more affluent areas) who had a greater repertoire of sources of symbolic and cultural capital (e.g. distinguished professions, education etc) to draw upon. This participant also uses mathematical expressions (illustrated below) to subjectively define fitness which was common within the data.

*Oh, I’d like to get this arm better for a start, so that I could er, write to people.*

*R: Right.*

*I can’t, I can’t use a computer.*

*R: Right.*

*Cos I can’t, I can’t put that on a mouse!!!, I can’t, I can’t put any pressure or anything with that. Erm, so I really would like to get, if I could get that better and probably be that, I mean, since I had me hip broken, I mean I was, the previous month I was still refereeing, only during matches and things, kids matches and things like that. But I was still mobile and things like that. Now I’m not even, I’m not even 30 percent now to what I was.*

**ID 17: Arthur, male, 80 years, CHD, stroke, angina, deprived**
Well, I would have thought when you recover, you more or less get back to where you were in the beginning. But in some ways, some of the things are only partial recovery, I would say maybe only 95% or maybe 80%.

**FU interview, ID12: Marie, female, 76 years, cataracts, arthritis, high BP, polymyalgia, degenerative disc disorder, deprived**

It appeared that the setting of recovery goals were not entirely divorced from the desirability of undertaking social activities which made up their life worlds. Participants demonstrated implicit rationalisations in order to accommodate and live with the post-illness self and make the most of the time participants perceived themselves to have left. Specifically, individuals appeared to display adjustment to, and prioritisation of, leisure and social activities and what could acceptably be retained in lives. In this sense, recovery related to getting back to previously desired, or valued activities, and incorporating illness as an extension of their new identity. It could therefore be argued that participants are striving for familiarities and, as a result, valuing social activities over other daily activities, e.g. employment. This rationalisation and accommodation results in illness being given less of a focus within day to day living and echoes Charmaz’s (1991) work on reconnecting and Barnard’s (1995, p.45) work on illusions as a ‘reinterpretation of reality in accord with preferences or needs’ versus denial and repression.

Well I mean in what way like, what just going in to work or going out socially like, I mean I’d go down the pub with the lads and have a couple of jars and come back and I’m quite happy like. I've got no ambitions of going abroad, I've been abroad all my life so, it’s not really bothered me like.

**ID22: Nick, male, 60 years, CHD, sciatica, high BP and high cholesterol, affluent**

Whilst predominantly pessimistic, the ambition within recovery goals varied amongst participants. This appeared to be informed by their own and other people’s experiences but also by individual habitus. For example, the participant quoted below suffered with diabetes and talked about his mother who had also suffered from diabetes. He told me that since being diagnosed his mother had declined rapidly and had died within three years. This experience had impacted on him and it appeared that the knowledge of his mother’s experience had limited the ambition inherent within his own recovery goals. The impact of expectations will be explored in more depth in chapter 6.

Socially, I would like to be just pretty much the same as I am now, which is less than what I was before, so I’ve got three active girls and I used to go out more with them. We used to go out to eat and drink socially a lot more than we do now. But you know, if it stays the same as it is now, it’s not too bad.

R: How realistic do you think that is, kind of achieving that ideal?
No idea. I think we’ve just got to wait and see. Certainly, Mother, within three years she’d gone. She just went straight downhill, you know.

**ID27: Steve, male, 65 years, diabetes, high cholesterol, deprived**

It also appeared that illness trajectory impacted on recovery goals. For example, those with only one significant event and demonstrating a partial return to previous levels of functioning (identified through narrative emplotments) often appeared to have higher levels of ambition within their goals which echoed research in the field of mental health (Ciompi, 1980). This compared to others with multiple conditions who were more likely to use chaos, degenerative narratives (Frank, 1995) or living in the empty present narratives (Davies, 1997). As a result, these individuals appeared to have reduced ambition within their recovery goals. The ambition and/or expectation manifested within individual recovery goals are also likely to be shaped by habitus and the social patterning associated with this.

### 5.4.1 How do things change over time? The stability of recovery goals

During the 12 month follow-up interviews, recovery goals appeared relatively stable. For example, for the majority of participants who had not experienced major life events over the preceding twelve months, the goals described were relatively unchanged. However, recovery goals were flexible should internal or external situations change. Recovery goals could be disturbed following critical moments or turning points in the trajectory and this resulted in renormalisation of goals. These critical moments included a diagnosis with a new condition, deteriorating illness or family problems.

*Oh it would be the same as last time with going to get quite a bit of weight off, that’s my main, but to be fair but it always has been sort of my weight going up and down over many years and I’ve only myself to blame I have to say.*

**Follow-up interview ID11: Colin, male, 53 years, CHD, affluent**

Yeah... though the prognosis from diagnosis is I think three to five years [with motor neurone disease]... so 18 months minus whichever one of those numbers you want to take, doesn’t give me a huge amount of time. So, on that basis, you know, the underactive thyroid and the diabetes is, you know...

...The focus has changed completely [laughter].

**Follow-up interview ID7: Andrew, male, 53 years, diabetes, affluent.**

In follow-up interviews, participants spoke about a number of barriers to achieving their personalised recovery goals which were both within, and outside of, an individual’s control. These included family problems including health problems, additional illnesses
or deterioration of existing ones, finances, self motivation, fate, or just general everyday life getting in the way of self-management.

You pick it up and it's, and it's all again it's all lecturing you on what you should be doing.

R: Mmm.

Yeah, in a perfect life, yeah, we would do this and we would do that but life isn't like that...

... Just everyday living you know, I mean, the fact that um, you might not have as much money, the problems you have from day-to-day um, especially in this economic climate, where everything is going up except your income...

R: Mmm.

...and oh, I can't afford that so.

**ID15: Ron, male, 65 years, diabetes, high BP, deprived.**

I suppose if I become ill and if I have to start eating foods that...that I suppose just if I have any ill health or if I stop, if the energy goes it’s...but luckily I think I’d recognise when it was happening. That’s the worst thing because in the past I’ve had hormone imbalances as well as again slows you down. That was in my late twenties and people say, “Well you are getting older”, “I’m not thirty yet”.

**ID21: Michael, male, 42 years, diabetes, deprived**

There were a range of views about employment in relation to the achievement of recovery goals. For some, employment was important in terms of reinforcing elements of identity, providing routine, increasing access to social support, and as a source of economic and symbolic capital.

I like going because it’s a way of socialising. Sometimes yeah I might be feeling crap, but I just get that, I might get that couple of hours where we’re having a laugh or you’re having a bit of a joke that you seem to just forget about it for a little bit. Yeah I’ve got my aches and pains and stuff like that, but it’s put to the back of my mind, whereas when you’re sat in the house mulling, you’re thinking God I feel tired, God, I’ve got to do this.

**ID33: Becca, female, 38 years, diabetes, heart murmur, deprived**

Well the work gives me something to get out of bed for at 7 o’clock in the morning. I get up and go to work at 8 o’clock, and now, because we’re only working across the road - we’re working at the house across the road which is handy - I don’t have to go in as early. But we still go in at 8 o’clock, put all the heating on, come over and have a brew, and then go back over at about 8.20 and start our work. And then maybe work till about half 5.

**ID29: Richard, male, 45 years, diabetes, high blood pressure, depression, irritable bowel syndrome, deprived**

However, employment could sometimes become a barrier to achieving recovery goals even within the same narratives that expressed positive elements of working. This was
because of its contribution to increasing an individual’s stress levels whilst concomitantly reducing free time for exercising and eating regularly.

*I just don’t think you get... obviously if you’re working full time, you don’t get a lot of free time. I mean, a lot of it’s work, sleep. You don’t get a lot of time to do anything else. It’s just like during the week I’m just so busy. I work eleven-eight Monday, eleven-eight Tuesday. I do eight-six Wednesday. And like last week, I had three snooker matches and a table tennis match at night. So I weren’t getting in until ten o’clock at night, eleven o’clock at night, so what else do I do? I just go to bed don’t I and then prepare for the next day like, so that’s all I’m doing at the moment, just really busy...*

**ID21: Michael, male, 42 years, diabetes, deprived**

### 5.5 Collective recovery: Who is involved and where does it occur?

In the majority of cases and in line with phase 1 data, it seemed there was a degree of silence related to notions of recovery. Specifically, this silence related to recovery goals not being raised with the health professionals responsible for their care. This issue was also highlighted in the phase 1 secondary analysis but it was not possible at that stage to identify the reasons why patients did not discuss recovery goals with health professionals. One of the aims of this phase was to try and identify these reasons and these will be discussed here as the novel contributions that phase 2 provided to the study.

Given the highly personalised nature of the recovery process, it was perhaps unsurprising that the recovery journey appeared to occur mostly within personal life worlds (Biley and Galvin, 2007). The main ‘helpers’ or contributors were friends, family members and pets, and particularly those with whom they lived. This highlights the importance of other people in the social network and how illness, and the experience of it, is often a shared or dyadic experience which has been found elsewhere (Charmaz, 1991; Frank, 1995; Mattingly, 2010). Other participants took little responsibility for recovery and this notion of responsibility will be explored in more depth in chapter 6.

*Bit different when you’re married isn’t it? You’ve got a woman there or your children who can help you. If you’re single men you’ve nobody there have you to give you a hand. I mean, I know they do a lot of stuff on their own, but just having somebody.*

**ID14: Vera, female, 73 years, primary Billary Cirrhosis, stomach cancer, deprived.**

*Glenda, she’s my boss, she obviously knows and she did a risk assessment when I went back in to work. She just grounded me for a couple of weeks, you know, so instead of going to social services offices to engage and stuff I would just go out and do that and*
just work mornings and then I’d come home in afternoon and she’d ring up and check, make sure I weren’t in office and stuff like that.

R: And what is...

We were bobbing down, you know like, and I could ring her and just say, you know.

ID31: Sue, female, 53 years, CHD, unstable angina, underactive thyroid, deprived

Health professionals played a role in terms of monitoring health on a regular basis (e.g. monitoring blood sugar levels and blood pressure and intervening at crisis points such as cardiac events) but were not seen as central to recovery. In this sense, health professionals were implicated in relation to the medical monitoring of illnesses whereas friends, family and pets played a bigger role outside of traditional health services.

However, it should be noted that a small number of participants did report that family members could be a hindrance to recovery. For example, the woman quoted below was keen to reintegrate back into her activities within the community after surgery for stomach cancer. However, her husband was concerned that she would be overdoing it so discouraged her which caused tension between them. This quote illustrates that even the most well intended intrusions by loved ones can be perceived negatively if not explicitly invited. This story appears to reflect the wider disruption to selfhood she is experiencing as a result of illness.

Yeah because, my husband, he got be really worried when I came out of hospital and I said to him, 'I'm going to go on.' 'Oh you can't be doing that.' I said 'Well I've got to, I can't just be sitting about because even in the hospital I was walking,' I had me walk up and down the corridor that way, that way two or three increasing it two or three times and exercising me legs, some people didn't get out of bed.

R: No.

But they said you know, 'Try and move about,' which I did I got in a routine of walking up and down.

R: Mmm.

And then he was saying, 'What do you want to go to those meetings for?' I said, 'If I sit here you've got more time to think, haven't you, about what's going on and make yourself feel ill.'

ID14: Vera, female, 73 years, primary biliary cirrhosis, stomach cancer, deprived.
5.5.1 Recovery goals and aspirations: the limited role of health professionals

For the most part, the production and maintenance of recovery goals was very much perceived to be the realm of individual participants and their family and friends. As discussed earlier in the chapter, participants had often not raised recovery hopes and goals with the health professionals responsible for their care. This issue was raised in phase 1 but it was not possible to identify within these transcripts why this was the case.

Phase 2 built on phase 1 of the study and found that, on the whole, participants had not discussed recovery hopes and goals with medical professionals because they felt it was their own responsibility to set and work towards these goals. Whilst health professionals could contribute in the form of diagnosis and medical advice, the majority of patients felt that they were ‘experts’ in their own bodies and took responsibility accordingly. Others felt they were not given permission to participate within the medical consultation (Protheroe et al. in press).

This was not the case for all participants and it appeared from the data (albeit in a minority of cases) that some participants would have welcomed discussions with medical professionals about their recovery goals. However, they did not feel that the medical consultation in general was the correct arena in which to bring up recovery hopes and goals. It appeared that participants felt the focus of medical consultations was on illness, particularly medicalised symptoms or on talking about giving up things that were bad for them, e.g. smoking or poor eating habits. The first quote below demonstrates how some participants did not feel that GP’s had time to discuss anything other than specific medical conditions within consultations. The second quote is taken from a participant who had only discussed hopes for the future with health professionals if they related to stopping what he considered unhealthy behaviours.

*R: Would you like the opportunity to speak to your GP about things like that?

Well it might be nice sometimes, you know, if you go feeling pushed and someone says, ‘Well how are you coping and everything?’ But no, if you go in with a sore throat that's what's treated.

*R: Right so it's very focused, again to the medical condition?

Yeah. They haven’t time to do the rest.

ID4: Anne, female, 78 years, cancer, stroke, asthma, diabetes, leg ulcers, affluent
R: Have you spoke to your doctor about that, about things you could do to help you achieve that, has he ever mentioned anything?

Not particularly apart from, like I say, giving up unhealthy things really.

**ID22: Nick, male, 60 years, CHD, sciatica, high BP and high cholesterol, affluent**

Furthermore, some participants were often conscious of the limited amount of time GPs had to spend with patients and subsequently did not feel that talking about recovery goals and aspirations were the best use of this limited time and this links back to the aforementioned notion of burden. In this way the ceremonial ordering of consultations were pre-set and often difficult to manoeuvre for a number of reasons (Goffman, 1967). Others, albeit a small minority, felt they may be ridiculed by health professionals for raising recovery type concerns as the term had no place in the vernacular associated with chronic conditions. As a result, patients often withheld personal, existential issues from the health professionals treating them. An example to support this is provided below of a female participant whose biggest concern was her limited mobility. When I asked whether she had raised this with her doctor or any other health professional she said she thought they would laugh at her for having such grandiose ambitions for the future.

Well they must know, mustn't they? You see, when I started; I wasn't fat like this, but every time I went to the hospital, 'You haven't put weight on have you?' because immediately if you put weight on they wonder how your health is, this is at the hospital. So of course I just went on eating what I wanted, if I wanted a piece of cake or a biscuit, I'd have it, and feel well on it, even though I was with this. But um, no.

R: Is that something you'd bring up with your doctor, about how important it is to be walking a bit more, or you don't really think it's his place to know that kind of, thing?

Well I think he'd laugh at me, don't you?

R: Why do you think that?

Because she's never heard of somebody walking.

R: Right.

See I haven't, have you?

I haven't. I've seen them walking a lot better and I must admit, I've walked a lot better, I've walked with sticks, but now I can't. Maybe my age has got something to do with it, er...

**ID3: Phyllis, female, 81 years, high blood pressure, stroke, macro globular anaemia, diabetes, deprived**

Despite this withholding of personal information, the majority of participants talked about the potential value of holistic treatment or patient centred care. Reasons for this
value echoed the definition developed by Little et al. (2001) but focused mainly on the communication component as opposed to the partnership and health promotion elements. In this study this related specifically to the potential impact personal problems can have on health conditions and improved relationships and trust between patients and doctors. There were concerns amongst a minority of patients, however, that they would not want the doctor to know about some personal problems such as drug or alcohol abuse in case it had a negative impact on them in the future.

So I had a diabetic appointment yesterday and obviously they’ve upped the insulin you know, it was put on me sort of thing, but again it’s just for that reason you know, she asked me what my daily routine was, you know, that sort of thing and I thought well that’s it. There’s nothing personal about it, it’s not ‘How are you feeling?’ ‘How is it affecting your life?’ you get none of that.

**ID33: Becca, female, 38 years, diabetes, heart murmur, deprived**

I’d be very wary of talking to them about er, if I had had an alcohol problem for example, because they er, which I don’t. Um, because I know from, not from my personal experience but the er, experience of other people who have come forward and said, you know, I have this problem. And I’d have a slight question mark over whether the, er, you know, once that’s on your medical record. It’s a bit like the HIV test, you know, can cause you all sorts of problems.

**ID11: Colin, male, 53 years, CHD, affluent**

The apprehensions raising concerns with health professionals could be further exacerbated in relationships with health professionals that fell at each end of the continuity spectrum. For example, those seeing a doctor for the first time often felt nervous about bringing up new concerns. Conversely, some people who had long-standing relationships with doctors felt that it was hard to challenge the existing relationship within consultations as their meetings had become highly scripted and followed a set agenda. This meant for some patients that they felt doctors made incorrect assumptions about them and they felt entrenched in a ‘sick’ type role.

However, other patients with long-standing good relationships felt that continuity improved their relationship as the doctor knew them better and therefore had a better sense of their lives around them. It also meant they did not have to repeat their ‘health stories’ and decreased the ‘medical veil’ associated with health professionals. Others appeared to value the fact that they shared the same social circles with doctors or

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18 This study developed a definition based on three elements: “communication” which included listening, exploration of concerns and requirements for information, doctor-patient relationship and clear explanation. Second was “partnership” which included specific aspects of communication that related to finding common ground – exploration, discussion and mutual agreement about patients’ ideas, the problem and treatment. Finally, there was health promotion, including how to stay healthy and reduce the risks of future illness’ (Little et al. 2001, p3)
undertook the same social activities. The quote below demonstrates how the patient believed that proposed treatment was more likely to be appropriate because the doctor knew him well.

Why is that continuity important to you?

Erm...I think because he knows you know where I’m at, he knows I like sport that...that I want to sort to do sporting things again and that I want to walk, and he’s said...he actually said you’re just the kind of guy that this operation will benefit. You know so I thought that’s quite reassuring isn’t it.

**ID18: Barry, male, 69 years, high blood pressure, high cholesterol, long-standing back problem (clodication), deprived.**

It did appear that this difference in continuity perceptions was related to social class. For example, more affluent participants were more likely to describe shaping the consultation with health professionals to best suit their own needs and therefore valued long-standing relationships with health professionals who knew them well. However, those from more deprived areas demonstrated more paternalistic relationships with health professionals and, as a result, were more concerned about raising new issues or disrupting the status quo within consultations. This appeared related to the perceived difference in symbolic capital between patient and GP within the health field (Bourdieu, 1977). This seemed particularly marked for those from more deprived areas. In this way, participants from more affluent areas appeared to be able to customise their own case management within health services much better than those from deprived areas whose care appeared more reactionary (Protheroe *et al.* in press).

### 5.5.2 What happens when recovery goals are raised with health professionals

A minority of participants had brought up recovery hopes and goals with health professionals. For the most part, these participants felt doctors had their own view on prognosis (predominantly degenerative) and, as a result, had been dismissive of their hopes and instead attributed symptoms to the normal process of ageing or symptoms of their chronic condition.

That's, that's mainly what’s stopping me from doing things, 'cos I can control my asthma, but I can’t control this pain and this is bothering me.

*R:* And have you brought that up with your GP, have you told them?

Yeah and they just said, 'You've just got to face up and live with it.’ That’s all you get the view of every doctor.

*R:* Is just live with it?
Yes, you've got to live with it.

R: Right.

**ID 10: Annette, female, 62 years, asthma, CHD, carpal tunnel syndrome, diabetes, high cholesterol and high BP, deprived.**

It appeared from the data that these patients did not accept these explanations from health professionals which echoes previous research (Busby et al. 1997) but nonetheless did not raise the concerns again in the future. This reflects tensions between professional perceptions of disease and lay experiences of illness highlighted in previous literature (Kleinman, 1988) along with power relations and notions of expertise. Social patterning may again be implicated in relation to these tensions. The following quote demonstrates how the participant did not accept the doctor’s response to his concerns about diabetes treatment but this was particularly because he put the responsibility on him to lose weight himself. This has implications for the limits of shared decision making assumed to prevail in chronic illness policy documentation.

*I did tell him that I was feeling lethargic and tired all the time and he just said it’s one of the symptoms of diabetes and that’s it basically.*

R: Right.

*He didn’t say there’s something you can do. He probably did say something about losing a bit of weight. But I thought... I can’t see that being the answer, although I’m sure it would help.*

**ID29: Richard, male, 45 years, diabetes, high blood pressure, depression, irritable bowel syndrome, deprived**

### 5.6 Summary

The secondary analysis undertaken within phase 1 of the study and reported in chapter 4, highlighted a number of areas for further exploration in phase 2 of the study. The results of this further exploration and other novel contributions of this chapter are summarised below:

- Phase 1 highlighted the experience of recovery as a journey and this chapter has supported those findings and identified the range of journeys experienced by participants and the factors that affect them.

- Phase 1 highlighted a key issue of burden within the experience of chronic illness. This chapter has built on those findings and the novel contributions of phase 2 data relates to the clarification of the nature and impact of burden, the
perceptions of significant others in relation to this burden and the social patterning of burden perception.

- Phase 2 of the study identified that narratives often included personalised recovery goals which often reflected a reconnection with valued activities. This has links to the theme of participants wanting to make the most of their ‘perceived time left’ highlighted in phase 1. This notion was not developed in depth during phase 1 given the limited data and was identified as an area for further analysis in phase 2. These often pessimistic goals were directly related to acceptance of the condition and elaborated on how participants intended to make the most of this perceived time left. There were also some overlaps within the findings to quest narratives (Frank, 1995) and ‘living in the philosophy of the present’ (Davies, 1997) but these seemed to represent an additional type of narrative because there was some consideration of the future but this was very much related to minimising disruption and making the most out of perceived time left.

- In line with chapter 4, these findings have clear links to the models of mental health recovery discussed in chapter 2 particularly in relation the orientation of narratives, the experience of time, and the centrality of hope within narratives. Whilst there was not scope within this chapter to compare the findings with these directly, this will be undertaken later on in the thesis within chapter 8.

- Phase 1 identified that participants often did not bring up recovery hopes with health professionals. However, there was not sufficient data to understand the reasons for this. This chapter has developed this understanding by identifying the reasons for this from the point of view of those participants included in the study.

- This chapter also explored the impact of employment on recovery which it was not possible to do in phase 1 given the sample which was predominantly older and retired participants.

- Throughout the chapter, the concept of habitus was a useful tool in exploring how notions of recovery were socially patterned. Those participants from more affluent areas appeared to have a greater repertoire of access to all types of capital whilst those from more deprived areas demonstrated an over-reliance on
physical capital. The chapter also highlighted the different stages within the illness trajectory where these relationships can increase an individual’s vulnerability in terms of chronic illness. Narratives were used in an attempt to gain richness within data whilst also attempting to tie them explicitly to the social and cultural space (habitus) inhabited by participants to address some of the aforementioned critiques of narrative approaches.

Two themes underlined all the above findings within the narratives and these were that of individual responsibility for, and expectations of, recovery. For example, the recovery goals reported by participants were impacted on by the individual responsibility participants took for their conditions and the ambition inherent with these goals were often related to individual expectation. It is to these two dominant themes that the next chapters turn to in order to explore them in more detail.
CHAPTER 6: EXPECTATIONS, RESPONSIBILITY AND THEIR RELATIONSHIP TO RECOVERY AND PROGNOSIS

6.1 Introduction

The previous chapter explored the personalised experience of recovery as a journey for the participants included in the study. This chapter will build on the previous one and explore two dominant themes within the data, the extent to which participants took responsibility for their recovery and their expectations related to it.

6.2 The experience of recovery and notions of personal responsibility

This section explores the extent to which participants talked about and gave meaning to taking responsibility for recovery and self management as well as their relationships with health professionals. This is particularly relevant given the lexicon of biomedicalisation discussed in chapters 1 and 2. This includes the notion that health has become a social and moral responsibility for patients (Clarke et al. 2003) which implicates active and responsible self-management. It appeared from the data that these wider and societal changes had impacted on individual narratives and that there was a wide range of views on responsibilisation within the data. For example, at one extreme participants were highly motivated and took full responsibility for their recovery and self management whilst at the other participants took little responsibility and expected health services to do this for them.

6.2.1 Recovery, health beliefs and high personal responsibility

The initiatives described in chapter 1 demonstrate how policy makers are increasingly encouraging patients to take responsibility for their own health by leading healthy lifestyles and encouraging active participation in their own health care (e.g. Expert Patient Programme, Desmond Programme and use of assistance technologies). This shift in a collective responsibility at state level for health to the onus being placed on the individual or community plays a central role in modern health promotion and has been echoed across most western societies (Crawshaw et al. 2004; Michailakis and Schirmer,
Furthermore, research has demonstrated that to be an active participant within care, patients with a chronic illness need to take personal responsibility for self-management (Audulv et al. 2009). However, this focus on the individual has given rise to concerns that it may result in victim blaming (Lupton, 1993) and instead calls have been made for strategies encouraging individual change within the context of broader social responsibility (Minkler, 1999).

At one end of the responsibility spectrum, participants described themselves as highly motivated and viewed recovery as their personal responsibility. These participants were adept at mobilising resources to support them and whilst health professionals could play a role in recovery, they saw themselves as ultimately having control over it, at least at a rhetorical level. One reason for this could be the findings described in chapter 5 whereby some participants appeared protective over what they perceived to be the limited resources of health services and this appeared, to some extent at least, to be due to an underlying assumption that wasting resources might impact on what would be available to them as individuals in the future.

Yeah. I mean most people would. Right, you don’t need a health professional to say where do you want to be, right, unless you’re talking about your medical needs, right. I mean you live your life the way you live your life, right. So if you want to be in a certain position in twelve months time, then get off your arse and do it; don’t talk about it, do it.

ID25: Thomas, male, 41 years, diabetes, deprived
These participants with high levels of personal responsibility used health services as a source of information and as access to diagnostic tools. Ultimately though, they wanted to project a narrative of having ownership over their own illness and recovery. For example, participants cited examples of sourcing their own physiotherapy appointments, seeing alternative therapists for conditions and setting clear goals for the future. These strategies were more easily achieved for the affluent because they could opt for private medical care if they felt NHS treatment was not good enough or that they would have to wait too long for it. This reflects the notion of customisation associated with biomedicalisation (Clarke et al. 2003) but also indicated that patients saw general practitioners as holders of social power which could legitimise health problems and provide access to specialist treatment.

This was the, er, doctor that told me it was pleurisy, so um, that’s when I went back to see Dr Scott after that and, um, he arranged that you know, Dr Fitzpatrick would take me on and fit the pacemaker for me, but I had to have it done as a, privately, because I don’t have healthcare they cover, so that was very expensive.
R: Why did you have to have it done privately, sorry?

Um, well because my next appointment was July...

R: Right.

...and I thought, I can't cope for two months like this.

**ID6: Paula, female, 73 years, CHD, degenerative disc disorder, arthritis, supra-ventricular tachycardia, affluent**

I said to these guys here, I think I should have some physiotherapy, so they sent me to BUPA, which is a sort of, an out-station here, a BUPA out-station just across the road and they deal with; they don't do physiotherapy there, but they do sort of, orthopaedics and things of that nature. So they sent me down to the Alexandra and I went there for three sessions and I saw a young lady there who gave me certain exercises to do, which I could do at home here and I've binned those and now I'm doing my own.

**ID1: John, male, 80 years, stroke, high blood pressure, affluent**

What was crucial for the second participant above was that he used the techniques obtained from the physiotherapist and adapted them to fit with his daily routine (e.g. local gym) after his contact with the physiotherapist had ended. Other participants failed to utilise and sustain techniques provided by allied health professionals. This could be attributed to a lack of individual responsibility which often impacted negatively on illness control and subsequent impact.

Patients who took a high level of responsibility for their recovery also actively obtained information from sources such as the internet, newspapers, friends and colleagues. This information was used in a myriad of ways from informing lifestyle choices to validating diagnoses and advice from medical professionals.

I just logged into Google and put this, there's, there's, er, EMS. There's an acronym for this, MCGN [mesangiocapillary glomerulonephritis] I think it is...

R: Right.

...er, and, don't quote me on that by the way, I typed, typed that in and it, it actually...

...and I put that in and it came out with exactly what, what Dr Metra had told me...

R: Yeah.

...so I just said, well, he seems to know what he's talking about so.

**ID2: Reg, male, 52 years, leg ulcers, cryoglobulin anaemia, affluent**

However, some participants did highlight that despite an increase in available information relating to their condition over recent years, there was a limit to the usefulness of it. For example, they often questioned the validity of information available on the internet and also described the danger of what they described as becoming ‘over
knowledged’. For some, these reasons were enough to discourage even the most active self managers from seeking too much information from these types of sources.

The snag with the Internet of course is like the snag of modern day life, it’s just complete and utter information overload and how difficult it is to actually assimilate, you know, when you hit a search and you end up with 864,000 sites to go at, how the hell do you choose the one, do you just choose the one on the front page? It would be much better actually if somebody decided to design a browser that produced the results as an official representation, which I thought would be rather a clever representation, I saw somebody suggesting that if you had the search results laid out like a street map of a town and the tallest buildings were the most frequently visited, you could instantly see the layout of the land rather than, you know, you only see ten sites on page one don’t you and you know that there’s another zillion pages to arrive. No, no, I’m not a technophobe, but blimey I’m not sure that, and it’s changed our lives completely in the last few years. I mean, I was a great believer in using yellow pages, now I would just go straight to an Internet search and do it that way.

ID7: Andrew, male, 53 years, diabetes, affluent.

6.2.2 Recovery, health beliefs and limited personal responsibility

At the other end of the responsibility spectrum were the patients who had paternalistic relationships with health services and appeared to take little personal responsibility for recovery. One example of this type of patient is Frank (quote below) who had smoked for over thirty years and since being diagnosed with COPD had not stopped. This was despite his doctor telling him that smoking one more cigarette had the potential to kill him. Smoking appeared so ingrained into his identity that it seemed he could not consider giving up. He took little responsibility for smoking and instead felt that health services should be able to ‘clear out’ his lungs like they had done with his arteries during an operation for CHD. The quote below highlights an inherent presumption that technological advancements in one area can be used in another. This ultimately reflects another belief that there was little he could do to improve his own situation through efforts at lifestyle change and exercise. This participant had high expectations that health services technologies could be used in an all encompassing way but these high expectations limited the input of action on the part of an individual.

Eh, well I should think this day and age, eh, they could, I asked them I said can you clear my bronchial tubes out? She said I don’t think so. But surely they do the heart. Don’t they? Well they’ve done my heart. I had a heart attack and one of the doctors put stents in.

R: Right.

Now why can’t they do the bronchial tubes the same?

ID20: Frank, male, 75 years, COPD, CHD, back problems, deprived
Participants generally acknowledged that paternalism in relationships with health professionals had diminished over recent years. However, it still appeared commonplace within the data and particularly for those from more deprived areas. These relationships with health professionals appeared related to habitus and the internalisation of cultures and experiences obtained over the life course constrained relationships with health professionals. It also reflects Clarke’s assertion that biomedicalisation can further exacerbate health inequalities through the stratification of resources (Clarke et al. 2003). Whilst in Clarke’s (2003) paper this stratification related predominantly to health insurance or a lack of health insurance, this data suggests that stratification can persist despite a national health service, due to individual habitus and income.

*Er, some yeah, I'm sure. But I think there's a; my parent's generation, um, just accepted anything they were told and if the doctor had told them then that was that.*

**ID11: Colin, male, 53 years, CHD, affluent**

*Er, you get the younger doctors now who are quite prepared to come and explain everything to you. Years and years ago the doctor was God, and they didn’t explain what they, what was wrong with you, they just told you, erm, ‘we're going to do such and such a thing,’ and that’s it. You know, and you didn’t have any choice.*

**ID 17: Arthur, male, 80 years, CHD, stroke, angina, deprived**

It appeared that class relationships in society were replicated in medical consultations and this related specifically to capital differences (Kleinman, 1988). Those from more deprived areas felt less able to question their doctor in relation to decisions about chronic conditions and this appeared related to habitus (Protheroe et al. in press). It seemed that participants used reasons of deficiency to make sense of these differences. For example, affluent participants would cite prior experience within scientific fields as reasons why they felt able to challenge medical professionals which again highlights the importance and central role of habitus. These participants felt that a lack of this type of upbringing amongst others would limit their ability to do the same. In this way participants with higher socio-economic status referred to symbolic and cultural capital which they can draw upon even when physical capital had been diminished (e.g. with illness). It may also relate to the perceived power balance between patients and health professionals within the health field and specifically to symbolic capital.

*Yeah, I've, I've always been active, I've always wanted to do things, I've never sat back and taken a back seat you know... so you know, I will monitor the bloods, I will get the blood test results as well...*

*...Yeah, I've got a scientific background or mathematical background, so I understand figures and trends and things, so...*
... I can understand trends, statistics, analysis and things, so I can have a look at things and see what’s going on.

**ID2: Reg, male, 52 years, leg ulcers, cryoglobulin anaemia, affluent.**

Furthermore, those from more affluent areas had what appeared to be a ‘healthy distrust’ in health professionals compared with the participants in phase 1 (from more deprived areas). While they would defer to health professionals in a crisis, it appeared they acknowledged the limitations to one person’s skills and experience and tried to get second opinions often in a confirmatory way. In addition, they actively sought out consultations with professionals they considered to be leaders in the field or in a suitable position of authority. Others felt that since they had been living with their condition for long periods of time, they knew their body better and considered themselves ‘experts’ in their own condition.

Well the turnover of staff and the conflicting advice didn't exactly fill me with a huge amount of confidence. You know, some of these people, okay, they're trained in the disease but they haven't been a diabetic for thirteen years and sometimes you get left with a distinct impression you know more about the condition than they do, which is a bit arrogant I suppose but that's the feeling I've been left with and that's why I've sort of, stuck with the surgery.

**ID7: Andrew, male, 53 years, diabetes, affluent.**

Well I mean, he follows what is recommended by the pharmaceutical company doesn't he? He has no input in it. He has the ability to monitor, he'll ask you how you feel and he'll ask you, he might even, I'll ask him and I intended doing in about another, at the end of six months I will ask him for another series of tests.

**ID1: John, male, 80 years, stroke, high blood pressure, affluent.**

The participants who reported paternalistic relationships with health professionals often did not actively seek information about their health conditions. Instead they preferred more passive approaches such as being given leaflets from the health professionals.

I don’t use the Internet.

R: Is the any reason why you don’t use it?

I don’t have a computer for a start but I don’t think I would be, I think sometimes you can know too much you know, you can look into things too much and um, think that you’ve got things that you haven’t got maybe...

...Um, yeah, or leaflet form or um, you know, if I was really needing to know something you would probably just make an appointment maybe and see the nurse or a doctor and discuss it with them maybe, you know if you had a worry or thought things like that.

**ID5: Moira, female, 63 years, asthma, affluent.**

R: Okay. And do you expect your opinions about your illness or your health problems to be taken into account when you’re speaking to the doctor?
Erm, my opinion, no, I tell them the symptoms and then it is up to them.

R: Right.

Erm, I’m not a doctor, erm, I know some medical things but I’m not a doctor.

**ID16: Margaret, female, 73 years, osteoporosis, high blood pressure and high cholesterol, affluent**

Those who were more actively engaged in their healthcare disregarded using leaflets as a sole source of information and generally considered them to provide only superficial levels of information.

I have picked up leaflets in the pharmacy and the information that they give is very helpful. It's probably a little bit too superficial, but you know, it's a general piece of information it's not really, you know, I suppose if you wanted more specialist information you wouldn't expect to get it in a leaflet you have to go and do the research, so, you know, but yes I've picked them up before now and read them...

...Yeah, I mean, every piece of the jigsaw helps make the picture a bit clearer doesn't it and they're [leaflets] certainly a piece of the jigsaw.

**ID7: Andrew, male, 53 years, diabetes, affluent.**

In extreme cases information provided by health professionals in terms of self-management was compared to a lecture and an attempt at social control which was not received well. This was particularly pertinent if patients’ lives were chaotic and lifestyle changes would exacerbate an already stressful home life situation. These social pressures appeared to demoralise participants in terms of recovery hopes and goals.

... the attitude you got from the people that were running the [smoking cessation] clinic were, they'd never smoked, the two nurses that were running it had never smoked and they were head mistressy pointing the finger at you, you're a naughty boy, um, and yes it will be hard, but with all this help you can... And I thought no I can't be bothered I went twice.

**ID15: Ron, male, 65 years, diabetes, high BP, deprived.**

And I got stomach ulcers in my thirties, so again that was a big thing because that was a diet thing, it was no fried food. And I remember the doctor giving me the lecture, “If you drink; stop, if you smoke; stop”, and all this and it's like, what's left. But I did try and do it and I did drive my mother crackers saying, “I can’t eat this, I can’t eat that”.

**ID26: Lynne, female, 62 years, stomach ulcers, diabetes, high blood pressure, high cholesterol, thyroid problems, deprived.**

For some of these patients, this had led to collusion with the medical professional in that both parties knew that the patient was undertaking action not best suited to their self-management but they both accepted this and the health professional no longer challenged them on it.
Um, the two doctors, one my, the doctor I see regularly, my own doctor um, she doesn’t mention it [stopping smoking] at all now...

...She's just sort of, said, 'Fair enough, I've tried with you and nothing is going to work, so I might as well not keep on at you...

...because all you’ll do is get annoyed and then you won't come.' The other doctor that runs the diabetic clinic, he just mentions it every time um, I go to see him. 'Are you still smoking?' 'Yeah.' 'Well you've got; why don't you try and stop again?' It doesn't matter how many times I say 'I am too old now' and he leaves it, he doesn't push it too much because he knows he is fighting a losing battle.

ID15: Ron, male, 65 years, diabetes, high BP, deprived.

There was a sense within the data from a minority of participants that attempts from health professionals to engage with patients about self-management were seen as a ‘tick box’ exercises and something that the doctor had to do to meet external targets and priorities. In this sense, the contact did not reflect any concern for the individual patient and, as a result, they were less inclined to engage with it.

Only initially, when they were asking what I actually consume in a week. And they were telling me what I can now consume in a week, which we had a bit of a laugh about. But that was the only time that we’ve discussed it. Now they just check up are you still complying - you know, they just tick all these boxes.

ID27: Steve, male, 65 years, diabetes, high cholesterol, deprived

6.3 Expectations related to recovery and prognosis

This final section in the chapter explores the second dominant theme within the literature, that of expectations. Expectations have been explored in relation to a number of areas including prescribing (Britten and Ukoummune, 1997), satisfaction, cause, and outcomes (Britten et al. 2002).

It has been demonstrated that understanding lay beliefs is important in understanding why some groups of patients do not engage with self-management, health education or health promotion/prevention activities (Blaxter 1997; Busby et al. 1997; Kaptein et al. 2010; Pill and Stott, 1982; Smith et al. 1999) and because they are associated with health outcomes (Dalbeth et al. 2011). However, these studies have tended to focus on participants who are healthy and yet to develop illness (Smith et al. 1999) and little is currently known about patients’ expectations for the future and ongoing experience of those with existing chronic conditions which is what this section sought to address.

Despite participants feeling that the quality of information given on prognoses had improved over recent years, there was still a feeling that patients did not get a lot of
information at the time of diagnosis which echoed previous literature (Charmaz, 1991; Murray et al. 2002) and the findings from phase 1. This meant that there was a lot of perceived uncertainty especially around conditions such as diabetes and COPD although participants were clear that their conditions would not completely get better (Murray et al. 2002; Pinnock et al. 2011). This reflects the aforementioned discussions around liminality and also highlights a theme of learning to live with uncertainty. This applies to professionals’ predictions about prognosis that are, or are not, picked up by patients but also to patients and professionals own uncertainties about the future. It appears then that in terms of the prognoses for chronic conditions there may be shared notions of not knowing what the future holds for a patient which contravenes traditional medical prognoses. Training for uncertainty has been highlighted previously as a critical part of medical education (Fox, 1957). However, further research with health professionals would be required to ascertain if these uncertainties reflect their own views or are being imposed by patients onto them as well as whether these uncertainties result from personal limitations or medical limitations (Fox, 1957). This has implications for future research which will be discussed in chapter 9.

The impact of uncertainty appeared greatest at the point of diagnosis and seemed to reduce as participants lived with, and adapted to, their condition (Pinnock et al. 2011). However, further in-depth research into specific conditions would be required to identify any differences between conditions (see chapter 9).

R: What do they say about prognosis?

Well um, I'd say it doesn't get better. I'm not too sure um, if it's caused by the fact that you're body is not producing enough insulin then it will never get better.

R: Right.

Not at the moment, if it's just that the insulin that you are producing is enough but it doesn't work properly, which I think is the correct thing it could well get better...

R: Right.

...well not cured, but it could get better.

R: Mmm.

Um, and part of that is of course weight.

ID15: Ron, male, 65 years, diabetes, high BP, deprived.
When participants talked about asking medical professionals directly about the prognosis for their condition, this had generally not been a positive experience. Prognosis in terms of operations, particularly in relation to heart disease and cancer appeared to be much clearer.

And I asked Dr Jones, what’s, um, the sort of, prognosis and she said it will get worse as I get older and I said, 'Well, what’s the treatment?', and she said, 'Well, there isn’t any'. It’s just painkillers, stronger and stronger pain killers and, er, I’ll end up taking morphine.

**ID6: Paula, female, 73 years, CHD, degenerative disc disorder, arthritis, supraventricular tachycardia, affluent**

...and then it [diabetes] got progressively worse, but the doctor had already told me that it would get worse as the years went by and that I would probably end up having to take insulin.

**ID15: Ron, male, 65 years, diabetes, high BP, deprived.**

Patients often accepted that, given the nature of their condition, the provision of clear and useful information related to prognosis was not possible. Sometimes questions about prognosis were misconstrued as questions relating to treatment and how often patients were required to see health professionals.

I’ve never had anybody sat me down and say you will never have anything again. But I have had, but the doctor has said to me very clearly you are, as far as your heart’s concerned there’s nothing that should restrict you doing anything. And that’s how it should be. So that’s what I take as a prognosis.

**ID 32: Jeff, male, 60 years, kidney stones, high blood pressure, CHD, angina, deprived**

R: In terms of, when you diagnosed with the, um, for needing the pacemaker, did you discuss prognosis at all?

Er, yes, and he also um, put me on a website, an arrhythmia website where it literally tells you; I’ve got diagrams of the operation and how they do it and all the rest of it.

**ID2: Reg, male, 52 years, leg ulcers, cryoglobulin anaemia, affluent.**

One participant felt that had she been given information about prognosis this would have had a detrimental effect on her recovery. This lady was within the minority within the data. She had very limited expectations for the future and this impacted negatively on her self-management and engagement with recovery type activities.

Well I don't think doctors will do that anyway.

R: And why is that do you think?
Well because if they told me I’ve got ten months or a few weeks, I would go down wouldn’t I?

R: Right.

I mean, it’s logical that, isn’t it? I had; my daughter's husband, he had um,... you know, what that is, that’s asbestosis...

...And he was told he can live ten months and he did live ten months, you know, but he had a; it wasn't a happy time. 'Oh it’s the last time I’ll see tulips, the last time I’ll see daffodils,' it is not a good thing I don't reckon.

ID3: Phyllis, female, 81 years, high blood pressure, stroke, macro globular anaemia, diabetes, deprived

As a result of the perceived uncertainty in relation to prognosis, participants appeared to rely on other sources of information on which to base their expectations about recovery. This led to a wide range of views on the future ranging from very low expectations to very high expectations. It seemed from the data that information on which to base expectations came from a number of different sources including; their own and others experiences, expectations relating to ageing, and their relationships with health professionals. As Frank outlines, individuals form narratives using elements of other stories available to them and these sources can provide both advantageous and disadvantageous types of ‘companion stories’ (Frank, 2012a).

6.3.1 Expectations relating to prognosis and the impact of the experience of others

Participants often reported that their expectations about prognosis came from their own or the experience of others. This included people that they knew personally, such as friends and family members but could also include people they had heard about from others or read about in the media. This information informed their perception of prognosis which echoes the work of Davidson et al. (1991) on lay epidemiology and the notion of ‘candidacy’. In this way individual realities are shaped by the stories or narratives that are available to them (Frank, 2012a).

And the constant thing I’m aware of is the fact that my father died in his early fifties from a heart attack, but of course in them days there wasn’t the treatment. My oldest half brother on my father’s side, died in his early fifties. I have got another half brother in Canada, who is from my father’s side, who is in his late fifties, and has a lot of health problems, but he is seriously overweight.

ID30: Ken, male, 54 years, CHD, diabetes, deprived

I remember a lad, you know, a few years ago, he was in a wheelchair, he had one of his legs cut off, right. That was part of his diabetes. But he wasn’t helping himself, right, he was in the pub on a daily basis, drinking cider, which is high sugar content, and brandy
and coke. Right, so he was overloading his system with sugar, right, he wasn't taking his medication, right, and he died, right, an early death.

**ID25: Thomas, male, 41 years, diabetes, deprived**

The experience of others as with the Davidson *et al.* study (1991) could serve as enhancing one’s own expectations for the future. For example, if a person saw a friend or family member coping well with their condition or self-managing in a positive manner this could serve as an inspiration to the individual concerned. This echoes Frank’s notion of narratives as variations of familiarity and the need for characters to be portrayed as role relevant and the notion that the horizons of the story generally reaffirms shared horizons (Frank, 2012a).

*My eldest brother is 73 and he’s walking and running five mile every day. That’s what I want to be in.*

*R: To aspire to.*

*Yes, so that’s where I want to be.*

**ID 32: Jeff, male, 60 years, kidney stones, high blood pressure, CHD, angina, deprived**

Additionally, the experience of others could serve to normalise symptoms and difficulties associated with the vicissitudes of living with a chronic physical health condition and providing a basis on which to carry on normally. However, it should be noted that for some participants, positive perceptions derived from the experience of others could further enhance individual disruption if their condition did not develop in the same way. Despite one participant not feeling overly concerned about a diabetes diagnosis because her mother was well adapted following her diagnosis, she found her own diabetes much harder to manage, which was exacerbated by the direct comparison with her mother’s experience. This illustrates that despite expectations already in place, the reality for this participant was something entirely different and in line with previous work this discrepancy between expectations and reality can be worse than having no existing story/expectations at all (Frank, 1995).

*At the beginning I’ve got to say it didn’t really bother me, because my mum’s diabetic and I thought to myself I’ve seen how my mum, she’s insulin as well, and she had a rough six months and then they got on top of it and they got it under control and all that lot, and it’s part of her every day. She’ll have a good day, a bad day, and you know, she’ll feel a bit light-headed and that, but nothing that took over her life. So then I thought, oh well, I could live with that.*

**ID33 Becca, female, 38 years, diabetes, heart murmur, deprived**
The experience of others could potentially serve as an insight into where participants did not want to be in terms of their health condition. This was particularly salient immediately after diagnosis and particularly for diabetics. For example, it appeared there was a perceived internal hierarchy amongst diabetic patients. At the top were those with limited impact and who controlled their condition through diet and at the bottom of the perceived hierarchy were the patients who needed to take insulin and/or whose diabetes was poorly controlled. Those just taking oral medication fell somewhere in the middle of these two. Often those with diet controlled diabetes reported visceral fears about needing to take insulin in the future. This also expanded into other conditions and the quote below demonstrates one participant’s fears about having to take stronger or higher doses of medication in the future for her blood pressure like some of her friends had needed to.

Well just the same as now really in the sense that, keep on, I’d be happy, I mean I’m glad I don’t have to go up to a high level of tablets, I mean, you know, a lot of, a lot of people are on these sort of tablets. I’ve got friends who are on much higher, one friend in particular who has had a much, much higher dose and still doesn’t seem, he still doesn’t seem to be sorted, his blood pressure is still yo-yoing up and down and everything so I just really want to maintain the same, you know, go on the same in the sense that I know I’ve got to go on taking them, I don’t want particularly want to take any stronger ones or any different ones and I just want them to go on working the way they are.

ID19: Helen, female, 64 years, high blood pressure, back and hip problems, affluent

Social comparison was a constant reference point for people within the data as in research discussed previously (Bury and Holme, 1991; Pound et al. 1998; Rogers et al. 2009b; Sanders et al. 2002) and within phase 1 of the study (page 114). This phase built on the data from phase 1 and showed that this comparison was so strong that often participants expressed not wanting to go to groups with people who had similar conditions because of the threat of social comparison which might result in negative comparisons with others. Despite groups serving a normalising process for symptoms and the experience of illness, these groups also had their downsides. For example, participants did not want to be faced with people who were coping much better or much worse than them. Those managing much worse and with worse symptoms served as foresight as to what might happen to them and this was something some participants often did not want to know about. Conversely, participants did not want to see people managing their condition particularly well as they felt this might make them feel inadequate in relation to their own self-management.
I’ve also found that it’s impacted on, and I think it’s the tablets more than anything else, the blood pressure tablets and all the rest of it, that have an adverse effect on your sexual life, on your libido. And again I’m not given to talking to people generally, but some other chaps I’ve met through this, that have said they’ve had similar problems.

**ID 32: Jeff, male, 60 years, kidney stones, high blood pressure, CHD, angina, deprived**

I am probably being slightly head in the sand, in a sense; I’ve never been so I’ve got no opinion to proffer one way or the other. I just don’t really want to. I suppose it’s a fear of finding oneself depressed at the thought of how well other people are coping with their condition and you’re not doing desperately well, on the other hand you might be pleasantly surprised at how well you’re coping with the condition because everybody else seems to be doing rather badly. That’s not really a comparison I really want to put myself through because it’s very subjective.

**ID7: Andrew, male, 53 years, diabetes, affluent.**

### 6.3.2 Prognosis and ageing

Participants often attributed health conditions to the natural or normal progression of ageing and this was unsurprisingly more common amongst older participants. This echoes previous work discussed in chapter 2 which found that biographical disruption following illness was less marked amongst older participants who were more likely to consider that their health problems were a normal part of the ageing process and reflects the notions of biographical flow and continuity discussed in chapter 2 (Sanders *et al.* 2002; Williams, 2000). In this way, participants accepted that physical capital was temporary and would diminish as they got older. This suggests that there was some embedding of recovery expectations within notions of ageing and again implicates time and the experience of it. This also resonates with Cornwell’s (1984) description of ‘health problems which are not illnesses’ which are characterised as conditions associated with the natural progress of ageing. This is likely to be more disruptive for those from deprived areas. This is because, as it has been argued in this thesis already, these participants seem to have an over-reliance on physical capital and also have less potential sources for symbolic and cultural capital to compensate for the loss of physical capital attributed to ageing. This attribution of conditions to ageing had the potential to reduce individual expectations. The following quote demonstrates the embodiment of ageing and how this was primarily related to biological decline which was something that the participant had come to accept as she had got older.

*And I always found early in the spring, you were a bit rusty and you’re not able to run much and...and...and I thought, ooh if I...you know, if I try a bit harder then in a few...in a few weeks time I will be fit, really fit and well. But I’ve come to the*
conclusion, this is not true anymore, because as you get older you don’t actually, um, regain your…your sprightliness, your…you know, you have to put up with…with…with what every day brings to you.

ID12: Marie, female, 76 years, cataracts, arthritis, high BP, polymyalgia, degenerative disc disorder, deprived

Health professionals and other people could attribute health problems to the process of ageing and this could be against participants’ own beliefs. Some participants appeared to find this derogatory and a way in which others could be dismissive of their condition. Instead, participants preferred medicalised explanations of their symptoms and this appeared related to the legitimacy attached to medicalised diagnoses.

As you get [older] he’ll say to you, ‘Oh, it’s your wear and tear.’ I said, ‘Hang on a minute…”

...Oh I hate that saying, they say that to older people don’t they, its wear and tear, I hate that saying.

Wear and tear, I said, ‘hang on a minute it’s not wear and tear,’ I said ‘it’s something else.’ He says, ‘Oh wear and tear means arthritis.’ I said, ‘So why don’t you just say arthritis?’

ID 10: Annette, female, 62 years, asthma, CHD, carpel tunnel syndrome, diabetes, high cholesterol and high BP, deprived.

6.4 Summary

This chapter built on preceding ones by exploring in more depth two dominant themes within the data; that of individual responsibility for recovery and expectations related to it. Participants varied along a spectrum in terms of the amount of responsibility they took for their condition and this seemed, at least to some extent, to be socially patterned. In line with phase 1 of the study, paternalism was a strong theme within the data. Participants also displayed a wide range of expectations for the future and the potential reasons for this have been explored. Whilst acknowledging that information relating to prognoses has improved over recent years, it still appeared that there was a lot of uncertainty. This meant that participants often relied on their own and others’ experiences. It is also likely that expectations have been affected by the techno scientifc and medical advances made over recent years attributed to biomedicalisation (Clarke et al. 2003) and also individualised notions of habitus which were useful concepts through which to examine the data as they allowed for the social and cultural environments in which the individual narratives are situated.
The next chapter will aim to build on these findings to derive typologies of recovery narratives relating to these two themes of responsibility and expectations. The model discussed in the next chapter aims to build on the preceding two chapters by further highlighting the themes discussed so far in an integrated manner.
CHAPTER 7: TYPOLOGIES OF RECOVERY

7.1 Introduction

This section aims to build on the previous chapter and develop a typology of recovery narratives whilst providing examples for each typology. Typologies were developed based on two dimensions which arose from the data analysis and were the focus of the preceding chapter; expectations and responsibility (figure 14). The diagram describing the typologies appears to suggest near linearity. However, the diagram aims solely to provide rough parameters in which to consider the participants and individuals can fall anywhere within the extremes (Frank, 1995). The diagram should also serve to advance and summarise the argument inherent within the thesis rather than trying to rigidly classify individuals or their stories. In line with other narrative analysts, the aim of these typologies was to further highlight and accentuate individual stories (Frank, 2010).

Expectations related to the ambition inherent in personal ‘recovery’ goals and also expectations related to health services as well as general expectations for the future. Responsibility was concerned with the level of individual responsibility participants took for their recovery and also reflected the level of paternalism within relationships with health services. Participants were categorised on both dimensions which resulted in four groups; high expectations - high responsibility, high expectations – low responsibility, low expectations – high responsibility and low expectations – low responsibility.

Figure 14 outlines these typologies and figure 15 provides details of key characteristics. As the diagram details a number of participants fell on the cusp of dimensions and the reasons for this will be explored within the relevant typology sections. The chapter then goes on to further define these individual typologies and provide examples from the data for each along with links to previous themes identified within the thesis.
Figure 14: Dimensions of recovery typologies: expectations and responsibility

- **Determined Maintenance Seekers** (low expectations - high responsibility)
  - ID4: Anne, ID6: Paula, ID14: Vera

- **ID5: Moira**
  - ID11: Colin
  - ID16: Marg
  - ID19: Helen
  - ID21: Michael
  - ID28: Ivy
  - ID29: Richard

- **Ambitious Go-Getters** (high expectations - high responsibility)
  - ID1: John, ID2: Reg, ID7: Andrew
  - ID8: Malcolm, ID13: Elizabeth
  - ID18: Barry, ID25: Thomas, ID 32: Jeff

- **Resigned Pessimists** (low expectations - low responsibility)
  - ID3: Phyliss, ID12: Marie, ID15: Ron
  - ID17: Arthur, ID23: Derek, ID30: Ken,
  - ID31: Sue, ID33: Becca, ID10: Annette

- **Disengaged Optimists** (high expectation - low responsibility)
  - ID20: Frank
### Figure 15: Key characteristics associated with recovery typologies

<table>
<thead>
<tr>
<th>Ambitious go-getters</th>
<th>Disengaged optimists</th>
<th>Determined maintenance seekers</th>
<th>Resigned pessimists</th>
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<tbody>
<tr>
<td>• Self-motivated goal setters</td>
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<tr>
<td>• Determined, active self-managers/high personal responsibility</td>
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<td>• High expectations</td>
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<tr>
<td>• Sees health professionals as a source of diagnoses/access</td>
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<td>• Expert of own body</td>
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<td>• Not self-motivated</td>
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<tr>
<td>• Lack of personal responsibility</td>
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<tr>
<td>• High, often unrealistic expectations for the future</td>
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<td>• Passive self-managers</td>
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<td>• Paternalistic relationships with health professionals</td>
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<tr>
<td>• Limited expectations for improvement (due to limited impact or experience of self and/or others)</td>
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<td>• Personal responsibility for self-management</td>
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<td>• Active self-manager but can be erratic</td>
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<tr>
<td>• Some have paternalistic relationships with health professionals</td>
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<td>• Not self-motivated and limited expectations</td>
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<td>• Lack of personal responsibility</td>
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<td>• Paternalistic relationship with health professionals</td>
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<td>• Often fatalistic</td>
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<tr>
<td>• Passive self-managers</td>
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#### 7.2 ‘About a fortnight after I’d had the event I was thinking about recovery’ - Ambitious go-getters (high expectations-high responsibility)

John (ID 1) will be presented as a case example of this type of individual. John was 80 years old and a retired pharmaceutical professor at a local university when he took part in the baseline interview. I interviewed him at his apartment in an affluent area in the centre of Wilmslow. As I arrived for the interview he was returning from the local gym. Prior to his recent stroke his health had been good. The stroke had impacted significantly on him and this related specifically to temporary paralysis on one side and reduced balanced, co-ordination, strength and stamina. It also appeared it had impacted on his confidence which was perhaps the most severe and lasting impact. These impacts demarcated severely from his pre-illness sense of identity as an independent, active individual who undertook a role he valued within society through his academic work which he was keen to perpetuate throughout the interview (a theme discussed in chapter 5).
The following quotes highlight the features of a ‘narrative’ as defined by Frank (2012a). For example, the story is temporal (couched in time), subjunctive (there is an awareness inherent in the narrative that he may or may not succeed in his hopes for the future) and the story is suspenseful (the temporal and subjunctive nature of the narrative render it suspenseful, there was a clear sense of uncertainty for the future as well as a sense of the vulnerability of the storyteller and there was something clearly at stake for the storyteller).

*When I retired from the university I formed a company in the Science Park and I had a small company there. There were eight of us to begin with and we were doing sort of, microbiological work for an industry. And so I was deeply involved in that. So I never got depressed.*

R: You kept busy.

A: I have plenty to do now. I mean, I still get many people call upon me and asking me to do things for nothing and quite regularly. It’s alright; I do it because it keeps me mentally active.

I suspect that I’ll get back to full action again and I just feel that I can make a contribution to something.

**ID1: John, male, 80 years, stroke, high blood pressure, affluent**

Prior to and since the stroke, he took an active role in staying healthy by exercising regularly and eating healthily. There was a clear sense of ambition and determination within his narrative. In this sense, ambitious go-getters were more likely to use elements of what Frank (1995) referred to as quest narratives in the foreground of their stories about recovery. This use of quest narrative seemed to reaffirm elements of his identity relating to being a high academic achiever in the past and not somebody who tolerated failure. In line with Frank’s (1995) work, heroes (storytellers) were portrayed as such through their perseverance in the face of suffering.

*I was in perfect health. I used to take 81mg of Aspirin a day and have done for twenty years, simply, you know, when that came out I just sort of, regarded that as being my protection if it was effective, but er, no, I was fine. I went to the gym before I had the stroke, in fact the very morning in fact I had the stroke I’d been to the gym. But I don’t do a great deal, but I just keep myself loose that’s all. But, yeah, I was fine.*

**ID1: John, male, 80 years, stroke, high blood pressure, affluent**

It appeared that as a result of his active lifestyle prior to the stroke he did not blame himself for the stroke and instead attributed the stroke to ‘bad luck’. He had high expectations for his recovery and also of the health professionals that treated him. For example, when he realised he may have had a stroke he went to his GP practice on a Saturday to find that it was not open. He was particularly aggrieved by this and felt that
given his under use of health services prior to this, that the very least they could was to be available to him when he needed them. In this sense, access to and use of health services were very much perceived as a right to him as a member of society who had contributed to the NHS through taxation. This appeared related to habitus in addition to the social patterning discussed in chapter 5.

*He's (GP) had thousands off me, that lot over there and I've never been.*

**ID1: John, male, 80 years, stroke, high blood pressure, affluent**

The use of his general practitioner was for access to diagnostic procedures and secondary care. He was additionally a member of BUPA so was referred straight away to the local private hospital. He also took the initiative to obtain physiotherapy in a timely manner in line with others who had high levels of personal responsibility (chapter 6) which he felt contributed to his recovery process and was something that he felt all people ‘with enough sense’ should do in the same situation. When he considered that not all people would be able to afford such interventions (private physiotherapy at a cost of £100 per session) he was keen to justify and normalise his privileged position. Determined go-getters appeared competent in shaping the medical field and building their own form of case management to suit their own individual narratives (e.g. quest narratives, (Frank, 1995)) as discussed in chapter 6.

*Yes, it's, you might argue that it's not socially right, but that's the way of the world isn't it? I did work damned hard. I worked for sixty-five years.*

**ID1: John, male, 80 years, stroke, high blood pressure, affluent**

Whilst acknowledging that his recovery would be a difficult process he appeared to have high expectations from the outset. These expectations related specifically to the recovery goals he set for himself and his likelihood of achieving them. His goals included regaining balance and strength and being able to play golf again and go on long-distance walking holidays and he took personal responsibility for achieving them. This is a good example of his customisation of health services to meet his needs reflecting the biomedicalisation of health (Clarke et al. 2003) and demonstrates the aforementioned personally defined manifestation of recovery goals in the data. Whilst only attending three of these physiotherapy sessions, he tailored the exercises and techniques he was taught for his own deficits and carried on with these in a regular manner at home and at a local gym.
I said to these guys here, I think I should have some physiotherapy, so they sent me to BUPA, which is a sort of, an out-station here, a BUPA out-station just across the road and they deal with; they don't do physiotherapy there, but they do sort of, orthopaedics and things of that nature. So they sent me down to the Alexandra and I went there for three sessions and I saw a young lady there who gave me certain exercises to do, which I could do at home here and I’ve binned those and now I'm doing my own. Trying to build up my strength.

**ID1: John, male, 80 years, stroke, high blood pressure, affluent**

He actively sought information in relation to his condition and its management and was adept at mobilising resources and utilising the support within his wider, resource intense social network. For example, his daughter was a nurse so he had spoken to her prior to his consultation with the GP to establish the tests he should have. In contrast with others, he was able to utilise this support without feeling as though he was burdening others as was the case for other participants (chapter 5).

Well my daughter's a nurse and she was here. She said, 'You need all these tests.' So I said, 'Well you tell me what tests I should have.' So she put them down and I went to the GP and he arranged for those. So I had cholesterol level and I had this and that and one thing and another. All of which were bang in the middle of what they should be, on the range. So I said, 'What the hell am I worried about?'

**ID1: John, male, 80 years, stroke, high blood pressure, affluent**

His relationship with health professionals was not paternalistic and whilst he was happy to defer to medical professionals in crisis situations, further decisions about his health and condition management were undertaken collaboratively. He was keen to distance himself from those he considered using health professionals in a palliative role and was vocal about using health services specifically for diagnostic procedures and for access to secondary care. He was happy to challenge health professionals where necessary. He felt that he was in the minority in this respect and that he related this to his upbringing and professional training (e.g. habitus).

*It's bound to be because they're not experts, they're not, they weren't brought up for this. So my view would be that the idea of people looking after themselves would be pie in the sky in the main...*

*... If you've done physiology you know, where the hell the organs are in the body and so on and so forth, you know, about blood volume and you know, about blood circulation and what function different organs have. You know, about excretions and so on and so forth, you know, hormones. Even though my knowledge is trivial now, inevitably, because things have moved on, it's sixty years since I graduated; you still have got some basic knowledge, which most people don't have.*

**ID1: John, male, 80 years, stroke, high blood pressure, affluent**
The follow-up interview demonstrated that his recovery goals had been achieved over the 12 month period and he credited this achievement to his taking responsibility for his own self-management and recovery goals. However this was not the case for all ambitious go-getters. Often external factors such as diagnoses with new conditions meant that the achieving of recovery goals was not possible and this caused great frustration for these types of individuals. It often appeared that narratives shifted as a result with the use of chaos narratives appearing more in the foreground of stories with an accompanied lack of desire for the future within narratives. This highlights the precarious nature of these linear type narratives (Ezzy, 2000) and indicates a possible source of intervention for these types of individuals.

Well that's what they keep banging on about, I try so I managed to under the ball figures last, last test so hallelujah having been well over double figures, well I'd say it's been hovering in the ten or eleven and it's now nine point two, but with the MND diagnosis, I just, I'm managing as well as I have done in the last 14 years - I don't hold out a great deal of hope that I'm going to get it any better, I know I really don't [think] it makes a huge amount of difference.

*ID7: Andrew, male, 53 years, diabetes, affluent.*

7.3 ‘Can they not clear my bronchial tubes out?’ - *Disengaged optimists (High expectation-low responsibility)*

The example for this type of recovery narrative relates to Frank (ID 20) aged 75. He reported high expectations for the future whilst taking limited responsibility for them. Frank was an ex-paratrooper and I interviewed him in an assisted living block of apartments during which his female friend was present. He lived in a fairly deprived area and his narrative started by him telling me about his prior health reflecting the previously described theme of illness narratives becoming enmeshed within biographical life stories discussed in chapter 5. His identity prior to illness was of a fit and healthy individual given his role within the military. His subsequent illness trajectory followed from this point and he told me how he had broken his back three times, had numerous chest infections, two heart attacks, stent operations and had more recently develop COPD. In this sense, his narrative followed a chaos and regressive format (Frank, 1995) and it appeared that the narrative contained a clear sense of resignation within it. The experience of COPD and use of chaos narratives has been found previously (Pinnock *et al.* 2011). The resignation inherent within his narrative appeared related to the regressive nature of his story and also because of the sheer
number of conditions he currently suffered with. It also seemed that he experienced a lot of anxiety related to his COPD which was caused by previous experience of breathing difficulties, which had culminated in anxiety attacks. He described his current health as ‘terrible’ and that, he felt that his life was ‘a waste of time’. He used humour as a way to deflect the seriousness of his condition throughout the interview which may reflect ‘covering’ to minimise stigma (Goffman, 1963). However, the impact of his COPD is demonstrated in the quote below in which he talks about his COPD and uses the metaphor of strangulation highlighting its significance to him.

_They reckon with me getting anxious I bring it on which I do. I’ve been told that before._

_Hmm mmm._

_So I’ve got to learn to control that but it’s a horrible thing… you think something is going round your neck and strangling you. You just stop breathing. Well, you don’t stop altogether but you think you do, well I do anyhow._

**ID20: Frank, male, 75 years, COPD, CHD, back problems, deprived**

He had smoked heavily (30-40 a day) for most of his life. Despite this, it was difficult to identify any contingent narratives in which he took responsibility for the fact that smoking may have led to any of his health conditions. At the beginning of the interview he talked about having stopped smoking and using inhalers to address the nicotine cravings. However, as the interview progressed it appeared he was still smoking but doing so covertly. He blamed others within the assisted living centre (including the friend present during the interview) who smoked around him for his inability to stop smoking entirely. He also made repeated attempts to normalise his smoking by acknowledging the negative consequences of smoking but concomitantly attributing smoking to the majority of society ‘we all know that but everybody smokes’. He also felt that giving up smoking would exacerbate the anxiety associated with his COPD and this perception reinforced the legitimacy of his continued smoking.

Despite admitting to me that his doctor had told him that one more cigarette could kill him, he admitted to smoking ‘the odd cigarette’ and not being able to see the problem with having ‘just the one’. The fact that he had escaped consequences from having these occasional cigarettes despite the doctor’s prediction served as further supporting evidence to him which allowed him to continue smoking. This further highlights the importance of the linkage between actions and consequences for this type of individual. The experience of others (akin to companion stories (Frank, 2012a)) within the centre who had COPD and continued to smoke without drastic consequences and the fact that
he felt his health was so bad that he may die anyway, further confirmed his views and perpetuated his behaviour. Here is a clear example of how the narrative as told by the doctor resulted in what Frank (1995) has coined narrative ambush. This ‘ambush’ had initial resonance but was not sustained once leaving the medical field and entering his life world (supporting the notion that recovery mostly occurs in the life worlds of individuals, chapter 5). This seemed to be because the narrative was not considered viable or accessible (‘fish out of water’) in the face of the other narratives available to him within this life world (e.g. all the other people smoking and not giving up, narrative habitus 19 (Frank, 2012a). This further highlights the role of social support and social networks in relation to behaviour change particularly for these types of individuals (Frank, 2012a). He appeared to have weighed up the advantages and disadvantages of giving up smoking and had made a rational decision. He felt he was ultimately going to die in the near future and that he would rather die ‘happy’ and carry on smoking as opposed to living out his remaining months unhappily and not smoking. This highlights the notion of making the most of perceived ‘time left’ as a central feature of recovery which has been highlighted in previous chapters.

_But I haven’t got any chance really I know that I’m going to die... so why can’t I smoke. The smoke will kill me. So, I’d like to die happy, smoking_

_ID20: Frank, male, 75 years, COPD, CHD, back problems, deprived_

The relationships he described with health professionals were highly paternalistic and similar to participants from deprived areas who took limited responsibility for their conditions (chapter 5 and 6). He felt there was a clear divide between himself and the medical professionals who treated him. This related to perceived expertise and knowledge on the part of the medical team (symbolic capital, chapter 5). He felt doctors were in a position of privilege and this was not something that he could, or should, challenge and that doing so would be socially inappropriate. He felt that doctors communicated in a medical language that was not accessible to ‘normal people like him’ and he was very grateful for any attempts on their behalf to simplify or explain things for him. As opposed to optimistic go-getters, these participants were less likely to be able to shape the medical field in line with their own narratives and this related to a discrepancy in perceived power.

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19 Narrative habitus relates to ‘the collection of stories in which a life is formed and that continue to shape lives’ (Frank, 2010, p49). Frank asserts that this ‘inner library’ of stories orientates the individual to attend to certain stories over others which resonate with storied within this inner compendium.
'Aye, you see how they miss things, to be fair we all do but they miss things but, well, we don’t know about it so we can’t say [anything] to them...

... Well I wouldn’t, I’d have to ask him why but I wouldn’t, I wouldn’t like to offend a doctor...

...Well they’re supposed to be in a position what they should know right away and they, people like us, well common people you can’t…a bloke who has been trained all them years, it’s rude.

ID20: Frank, male, 75 years, COPD, CHD, back problems, deprived

Frank talked about how treatment from health services had previously cured his other health problems (including narrowing of the arteries in his heart) by what he referred to as ‘cleaning out the pipes in his heart’ without the need to stop smoking or alter his lifestyle in any way. This had raised his expectations in relation to COPD and this incongruence between his high expectations and the medical reality caused him a lot of anxiety. In this sense, it could be argued then that recovery is a more holistically viewed process and not related to single conditions and in line with previous research patients demonstrate a process of transferring learning from one condition to another (Morris et al. 2011). This has implications for health policy and delivery and may support studies that argue that the sequential of individual conditions may be too simplistic (Bayliss, 2012; Morris et al. 2011).

This restitution type narrative in relation to COPD described in the preceding paragraph was not one that was accepted by medical professionals and was one that did not fit or have any resonance within the medical field. One interpretation of this is that this lack of perceived relationship between cure and the need to take personal responsibility for the condition had led to unrealistic expectations for the future of his other conditions, namely COPD and he used these as a means of retaining some form of hope (Barnard, 1995). He felt as though doctors should be able to do the same for his lungs especially given what he saw as improvements in health treatment and technology since his heart operation. This notion of hope for the future being visualised through external or divine intervention has been found previously but he was only one of two participants who made reference to this within the current study (Charmaz, 1991). Despite this, he often made reference to not wanting to be a burden on health services and that he was aware that they were already over stretched and in this way tried to portray himself to be socially and morally responsible patient. This was a common theme within the study and was discussed in more detail in chapter 5.
“Eh, well I should think this day and age, eh, they could, I asked them I said can you clear my bronchial tubes out? She said I don’t think so. But surely they do the heart.”

R: Hmm.

Don’t they? Well they’ve done my heart. I had a heart attack and one of the doctors put stents in.

R: Right.

Now why can’t they do the bronchial tubes the same?

**ID20: Frank, male, 75 years, COPD, CHD, back problems, deprived**

He was positive throughout the interview about his relationships with health professionals and was keen to praise them at every opportunity. He appeared to value honesty from the health professionals but the quote below shows how he often interpreted what they said in his own way once leaving the consultation and did not raise these interpretations again with his doctor.

“He’ll tell you anything, anything you ask him, I said to him one day I said am I dying he said well you know that he says, he said but I don’t think so yet.”

R: Right.

[laughing] In other words, yes you are, yeah.

**ID20: Frank, male, 75 years, COPD, CHD, back problems, deprived**

It may be that this positive perception of health services reflected an apparent collusion between himself and his GP. He told me that his GP knew that he still had the occasional cigarette and that he no longer challenged him on it. In a related point, the only negative perception about health services within his narrative related to past experiences of feeling that doctors were lecturing him, or trying to exert social control over him, by telling him categorically what he could and could not do. This related specifically to smoking and this perception of secondary prevention advice as ‘nagging’ or ‘lecturing’ was found amongst other participants who took limited responsibility for their conditions (chapter 6).

“Well I’m glad, you know, he keeps on to me, Doctor Frank, eh, ____ have you packed it in, I said yes packed it in, eh, how many have you smoked this morning [laughing]. He knows you see. So he’s good, he’s good like that.”

**ID20: Frank, male, 75 years, COPD, CHD, back problems, deprived**

A follow-up interview was not possible with this participant as unfortunately he died during the 12 month follow-up period.
7.4 ‘You can’t let an illness run you can you?’ - Determined maintenance seekers’ (Low expectations-high responsibility)

The majority of participants who fell within this category had limited impact from their health problems (highlighted in figure 14 on the cusp between high and low expectations). As a result, their expectations for recovery related predominantly to a maintenance of the current situation but they were also motivated to resist further deterioration. This diagnosis with limited impact seemed to put these patients in a ‘liminal’ space between health and illness which has been found previously in relation to cancer (Little et al. 1998) and was discussed earlier in the thesis (chapter 5). These participants tried to keep illness at the margins of their existence and detached from self-hood (Charmaz, 1991). However, there were other patients included in this category (figure 14) who had low expectations for the future due to the stories of others they had heard about or seen from other people with similar conditions or because of their own individual regressive health narrative. It is the case of Edward that will be provided as an example for this group of patients.

Edward (ID24) was a 59 year old man living with his wife in an affluent area of Greater Manchester. He told me that his health had been good for the first 50 years of his life until he was diagnosed with high blood pressure. It was during a 6 month review for high BP that he was also diagnosed with type II diabetes. He experienced no symptoms from his diabetes and he appeared to lead a healthy lifestyle which helped him manage it along with medication. As the following quote demonstrates, Edward appeared to take personal responsibility for his health and was motivated to proactively manage it himself in addition to taking the appropriate medication.

*I mean I never had any symptoms with anything; I felt perfectly alright, but I just thought I’ll go and check everything out, because if you’ve got something you want to find out, you can take something to help it can’t you? I’m not saying I’m an angel, but a lot of fellows just don’t like going to the doctors and they just put their head in the sand and the next minute you have a stroke or heart attack. It’s not for me, all that. Yeah, so then go regular for check-ups.*

**ID24: Edward, male, 59 years, high cholesterol, diabetes, affluent**

It appeared that biographical disruption was minimal for this participant because he considered himself a ‘borderline’ diabetic and that the medication he took was preventative. He described his pre-illness identity as one of a healthy individual exercising regularly and eating healthily. As a result the diagnosis had necessitated limited lifestyle changes and not impacted greatly on his sense of self.
But I was always borderline. I was never...I think when I first...seven point something. Or was it eight point...it’s when you go over a certain figure then you are diabetic. It wasn’t like ten or...it wasn’t like a huge difference, it was a marginal. But you’ve got it, you’ve got it haven’t you sort of thing, so...but, as I say, they did check quite regular before they put me onto the tablets.

**ID24: Edward, male, 59 years, high cholesterol, diabetes, affluent**

He talked about people he knew with diabetes who had experienced rapid declines post diagnosis and he was keen to distance himself from these types of diabetics. However, these experiences of others served to lower his expectations for the future. Social comparison was a strong theme within the wider data and has been discussed in more depth in previous chapters. Despite not having particularly high expectations for the future he felt that taking personal responsibility for managing and monitoring his condition was important. The quote below highlights the impact of other people’s experience on individual expectations and narratives and is reflective of Frank’s (2010) work which asserts that narratives are variations of familiarity and echo shared understandings of horizons. For these individuals, the provision of alternative narratives about recovery may be useful to expand their narrative horizons and increase the narrative resources available to them.

*I mean I’ve got somebody my mother knows down in Cornwall and he’s almost become an invalid, he’s scared to do anything, and, you know, you’ve got to run an illness, you can’t let an illness run you can you? If you sit down thinking all the things that could happen you wouldn’t go out would you? You know, it’s just life isn’t it. I mean you do hear of diabetes people losing toes and, you know, circulation problems...*

**ID24: Edward, male, 59 years, high cholesterol, diabetes, affluent**

Edward talked about taking responsibility to source information himself in relation to his condition. However, he made it clear that he felt that such information should be treated with caution and should not supersede one’s own notion (habitus) of what constitutes a healthy lifestyle and what does not.

*I mean just symptoms it tells you or...and then problems in the future or what you’ve got to look for, what parts of your body can be affected and things like that. Just enough knowledge. You know, not going into it in huge detail but just so you’ve got an idea and you’re aware that if something doesn’t feel right in your body maybe that is because of it, but, you know, I walk three miles a day with the dog and things so I keep fairly fit so it doesn’t impact much on my life.*
His hopes for the future related clearly to a maintenance position (probably due to the limited impact he experienced from his conditions) and warding off further deterioration. On a number of occasions within the narrative it appeared that he was trying to justify this position to me by normalising his own situation relative to others.

> It’s difficult isn’t it because its age related. I mean I don’t think there’s…I mean none of my mates...we’re all like similar ages and we’ve all got something wrong with us now. I mean it’s just maybe being healthy when you’re younger which I probably didn’t do as much as I should do. But some things are genetic aren’t they? I mean my family’s fairly healthy. don’t have a lot of…I mean nobody’s got diabetes in the family so…it’s just wear and tear on your body in a way as well.

**ID24: Edward, male, 59 years, high cholesterol, diabetes, affluent**

He had not discussed his notions of recovery with his doctor and felt that these were his responsibility. The doctor and nurse interceded at times when monitoring was due but most self management was undertaken by himself, his wife and his dog whose daily walk incorporated regular exercise into his regime. This supports previous research implicating the work of pets within the social networks of those with chronic conditions (Brooks et al. 2012).

There was a strong sense within Edward’s narrative that he was keen not to centralise diabetes within his identity or life and keep it on the periphery of experiences whilst he could. Edward along with other determined maintenance seekers used ‘life as normal’ type narratives to do this and these types of narratives were more commonly found within the foreground of these types of individuals (Frank, 1995). In Edward’s case, running his own business facilitated his ability to do this as this formed the focus of most of his everyday thinking. This highlights the positive impact of work on recovery discussed in chapter 5. He made reference on a number of occasions to hypochondria and felt that excessive worrying about the future could lead people to imagining symptoms or complications. He talked a lot about wider society and that he felt people, in general, were getting weaker and too immersed in their health problems.

> It does, it takes people over. They just like to wrap themselves up in cotton wool almost and they’re afraid to do anything. When it gets like that you’ve got a problem I think. But, again, it’s just how they are, it’s their makeup. Some people, they go on about stress. It’s just everyday life isn’t it that people now say it’s stressful, but it’s not. Just something’s not working as well as it should or something’s a bit harder but you just get over it don’t you. You don’t think oh god, you know, this…but I think society now seems a bit mentally weaker for some reason and people don’t seem to cope as well. But I suppose that’s just how life is.

**ID24: Edward, male, 59 years, high cholesterol, diabetes, affluent**
At the 12 month interview, his situation had changed very little and he felt that his maintenance goals had been achieved. He attributed this achievement to his own healthy lifestyle and keeping busy with work which allowed him to not focus too much on diabetes.

7.5 ‘Have you ever known a stroke victim walk’ - Resigned under achievers (Low expectations-low responsibility)

The example for this type of individual is Phyllis (ID3). She was an 81 year old woman living with her husband. Her husband was present for the preliminary stages of the interview before going out to do their shopping. She described him as her ‘carer’ and I also interviewed him at a later date.

Phyllis told me that her health had been relatively good for the first 73 years of her life and her pre-illness identity related to being the matriarch of the family. She was then diagnosed with high blood pressure and relatively quickly after that with micro globular anaemia. She made a decision to come off the medication for high blood pressure as she described becoming ‘zombie like’ whilst taking it. This disregarding of doctor’s recommendations and trading potential damage later on for current functioning has been documented previously (Charmaz, 1991). It was after stopping her medication that she suffered a stroke. Despite making the decision to come off the medication against doctor’s recommendations she did not attribute her stroke to her actions. During the interview it emerged that she was a Jehovah’s Witness and spiritually a very religious person. It appeared she felt that God had a plan for her and whatever happened to her was meant to happen. As a result of this fatalistic view, she took little responsibility for her own condition and self-management.

Oh, I'd love to be running about and you see I hope in the future that God will do that. You see we have a faith in the bible.

ID3: Phyllis, female, 81 years, high blood pressure, stroke, macro globular anaemia, diabetes, deprived

Perhaps the greatest impact in terms of her illness related to those associated with her stroke. Her mobility was greatly reduced and she found it difficult to do even the most basic of tasks. Her husband and daughter helped with day-to-day activities. This appeared to be in stark contrast to her pre-illness identity of a matriarch who cared for a number of family members up until their death.
Well, I can't do anything, I can't peel potatoes you know, because it would take me so long and er, I can't go upstairs, I've got the stair lift, so I go upstairs. I can't shower myself; he showers me. I got to the toilet, but then again, I can't clean myself properly, so he does it. Um, that I think is the worst thing that because, well it is isn't it you know. Um, I can't wash my own hair, he washes my hair, but then I can't put the curlers in you see, so I just have to try and put some in anywhere they go, you know, so next week my daughter's, on Friday my daughter's coming around to do it.

**ID3: Phyllis, female, 81 years, high blood pressure, stroke, macro globular anaemia, diabetes, deprived**

Her expectations for the future were low and this appeared to be related to the stories and experiences she knew from other people who had also experienced strokes. There was a clear sense of resignation within her narrative and she talked to me after the interview about not knowing whether she would ‘be here’ for the 12 month follow-up and seemed accepting of the fact that death was almost imminent. This reflects other research that has explored the ‘giving-in, given up’ complex in relation to illness (Engel 1968, cited in Kleinman, 1988).

The interview with her husband revealed that despite obtaining initial physiotherapy after her stroke she did not engage with it or carry on with the exercises she had learnt once the contact with physiotherapists had ceased. This contrasted starkly with the example for the ‘ambitious go-getters’. It appears again that these individuals appear constrained by the narratives available to them in relation to their recovery. In line with determined maintenance seekers, these individuals may benefit from the provision of alternative narratives to broaden expectation horizons and increase narrative resources (Frank, 2012a). However, as Frank notes these narratives would need to be supported by others within the social network in order for them to become viable narratives for an individual to draw on (see example of disengaged optimists discussed previously).

*Because have you ever known a stroke victim walk, you haven't, have you?*

**ID3: Phyllis, female, 81 years, high blood pressure, stroke, macro globular anaemia, diabetes, deprived**

She had difficult relationships with the health professionals responsible for her care and had not discussed recovery or management with them. This appeared related to her religious faith and also her low expectations in that she felt that there was little they could do for her and that they would laugh at her if she did express hope for the future. She frequently normalised her current physical state in relation to the normal ageing process and by comparing herself with others who had not lived as long as her or were in a worse state than her (discussed in chapter 5). Medical treatment was described as
something that was done to her and something that she was neither involved in or had responsibility for.

Well I think she (GP) tries and if it works she keeps to it, and if not, she tries something else.

**ID3: Phyllis, female, 81 years, high blood pressure, stroke, macro globular anaemia, diabetes, deprived**

It was not possible to conduct a follow-up interview with this participant as unfortunately she died during the 12 month follow-up period.

### 7.6 Summary

This chapter provided a typology of recovery narratives and illustrated these with examples for each typology. The typologies provided are ideal types and are by no means attempting to be all inclusive or prescriptive. Rather, the aim was to further highlight attention to the stories of illness as told by those included in the study. All narratives included followed the aforementioned trajectory of personal journeys of recovery that started from a personally constructed pre-illness self and from which individuals measured subsequent trajectories. The chapter further highlighted the significance of social and cultural factors in the experience of illness and recovery. The next chapter will move to compare the findings of this study directly with those from the mental health field.
CHAPTER 8: RECOVERY IN CHRONIC PHYSICAL HEALTH CONDITIONS: A COMPARISON WITH A MODEL DERIVED FROM THE MENTAL HEALTH FIELD

8.1 Introduction

This chapter builds on the findings from chapters 5, 6 and 7 by directly comparing the data with that from the mental health field discussed in chapter 2. The main body of the chapter explores conceptualisations of recovery within the data before moving to compare the data directly with the stages of recovery from one model discussed in chapter 2 (Andresen, 2003) and finally examines the level of stigma within the narratives. The chapter concludes by comparing the data with the work on illness careers undertaken by Fabrega and Manning (1972) to demonstrate what is unique and what constitutes continuity with mental health models and literature.

8.2 Conceptualisations of recovery

Participants rarely talked about recovery from their chronic condition in a restitutational manner or in line with the ‘recovery from’ mental health definition (Davidson and Roe, 2007) as described in chapter 2. This definition is based predominantly on a medical model and relates to an individual becoming asymptomatic following successful treatment for a specified condition. Rather, when participants talked about recovery, narratives reflected the ‘recovery in’ mental health definition as proposed by Davidson and Roe (2007) and the ‘recovery from invalidation’ definition proposed by Pilgrim (2010).

In line with the mental health literature, recovery for those with chronic physical conditions was not a simple, linear process. Instead participants reported a complex, personal journey and one which was often fraught with difficulties (Anthony, 1993; Leamy et al. 2011; Spaniol et al. 2002). Similarly in the current study, participants demonstrated high levels of resilience and recovery which appeared related to reconnecting or refinding valued roles within society (Deegan, 2005; Wisdom et al. 2008) particularly in relation to social activities and past times (Hush et al. 2009) and for those participants within the ambitious go-getters and determined maintenance seekers categories discussed in chapter 7.
Recovery in mental health refutes professional authority to define recovery and allows individuals to frame and define their own recovery. In line with this, participants within the current study reported working towards individualised and personally orientated recovery goals. These were goals that they had defined themselves and which were often not raised with health professionals. The use of personalised recovery goals and positive risk taking are central to recovery type programmes which have been used with some utility in the mental health field (Chadwick et al. 1996; Mead and Copeland, 2000; Mueser et al. 2006). It appears within the current study that for most participants (those within ambitious go-getters and determined maintenance seekers categories) this was occurring implicitly within participants’ self-management without the need for intervention. This has clear resonance to the field of mental health in relation to the notion of personal medicine which highlights the role of the individual within recovery and has been clearly separated from ‘pill medicine’. Personal medicine relates to personal and wellness strategies and activities which serve to improve mood, outlook, cognitions and behaviours. These strategies are often not raised with health professionals for a fear of disapproval on their part (Deegan, 2005). What follows and serves as a focus for the rest of this chapter is an analysis of the current data in relation to one particular model of recovery in mental health discussed in chapter 2 (Andresen et al. 2003).

8.3 Recovery as a process

As detailed in previous chapters, there has been considerable work undertaken within the mental health field to try and identify a process of recovery. With this in mind data relating to the experience of recovery will be reported under the main phases contained within Andresen’s previously reported five stage model of recovery which include moratorium, awareness, preparation, rebuilding, and growth (Andresen et al. 2003).

8.3.1 Moratorium

The stage of moratorium relates to a crisis period during which the individual often becomes submerged within the condition. Andresen et al. (2003) point to how a loss of self is associated with this stage (tables 5 and 6). This notion of crisis was apparent within the data and reflected the notion of biographical disruption found in the physical health literature (Bury, 1982). For the majority of participants this stage occurred at
diagnosis but it could also occur later in the experience of illness during periods of condition exacerbation.

I suppose I was shocked because it’s a real illness. It’s...I didn’t know that much about diabetes until I got it and I thought I did... And there’s just so much to it and it affects so many areas of life. It’s like your full...it’s unbelievable really. Where people are going on about obesity and some of the things that are said on telly, like you know, diabetes on a plate it’s like it’s more than that.

ID26: Lynne, female, 62 years, stomach ulcers, diabetes, high blood pressure, high cholesterol, thyroid problems, deprived.

Identity and a sense of self were central to narratives about recovery and prognosis. The scale of the disruption to notions of self following diagnosis or a health crisis was commonplace within the data. It also appeared that participants were keen to distance themselves from an identity of an ‘ill’ person and focus more on other, more ‘valued’ elements of their identity. As a result, narratives focused on positive aspects of identity and elements that could be useful within society including being an active self-manager and engaging in healthy lifestyle choices (e.g. being a responsible patient).

I'm an ex-smoker and I'm reasonably fit for my age I think. I play tennis twice a week, go sailing twice a week in the summer and run around on a hockey pitch blowing my whistle as an umpire during the hockey season in the winter, so I keep myself pretty active. I think I'm two pounds heavier than I was when I left school, so I haven't done too badly.

ID7: Andrew, male, 53 years, diabetes, affluent.

The impact from chronic conditions was also apparent within the narratives from friends and family members and it was often more pronounced within these narratives. In particular, spouses talked about more profound impacts on mental aspects including confidence and vulnerability than participants themselves had alluded to as in the quote below.

Andrew, it’s definitely knocked his confidence, he’s not the same person that he was before he was diabetic. I don’t know how you can be. You can’t escape from diabetes, ever. You can’t really have a relaxing day without it, because you have to inject yourself three or four times a day, so it’s always there...

...Well Andrew was always really, really confident. Very bright, always knew the answer. Even if he didn’t know the answer, he’d still say he knew the answer, and people believe him. But he’s lost that. You know, he’s lost that... he’s far more vulnerable now than he’s ever been before.

Spousal Interview, Hayley, female. Wife of ID7: Andrew, male, 53 years, diabetes, affluent.
In line with the data reported in the physical health field, this disruption was further heightened for those diagnosed at a younger age and interestingly for those who felt they had previously lived a healthy lifestyle which they felt would ward off long-term conditions (Sanders et al. 2002; Williams, 1996).

Yeah. I mean as a kid, if your friend has invited you for a stay over, you couldn't do it, right. You couldn't go...I couldn't go and stay with your mates or something overnight. You couldn't really go camping or walking, or doing anything too strenuous, right, just in case you caused yourself having an hypo, right. And with only being able to take two injections, then if you have a hypo and you deal with it, then you have the other effect, where you go hypoglycaemic and have too much sugar in your system, right, until you take that next lot of insulin. Right, so I mean it was pretty hard.

**ID25: Thomas, male, 41 years, diabetes, deprived**

Prior to coming and working for myself I think I’d half a day off in eight years, and that was food poisoning, that was work food, so! But, I mean, it was strange. And when they told me what had happened it was like, ‘Oh my God,’ you know. I think I was 42 at the time, something like that. There I was, I’d gone to the trouble of losing all this weight and everything else. Certainly, eating, yes, but I was smoking too much. I didn’t really drink. I haven’t really drank since my early twenties. So it was a bit of a knock back.

**ID30: Ken, male, 54 years, CHD, diabetes, deprived**

Interviews with significant others often revealed a more dramatic impact on family relationships as a result of chronic illness than were included in individual participants’ narratives. For example, spouses often talked about a dramatic shift in the marital relationships in that the role of the spouse had change from ‘wife’ to ‘carer’ and this adaption was often not an easy process. This reflected a disruption to the spouse’s role within the marriage and this was often one that they had not anticipated nor accepted easily. This was particularly exacerbated for those spouses who had not previously held this type of caring role within the marriage.

*I don’t want to be his nanny, I don’t want to be his carer. It’s changed our relationship, because to some part, I am a carer. So I’ve got two children and a dog and then I’m fine until he says, ‘I’ve left my insulin at home,’ and I sort of think, ‘Oh bugger,’ you know, alright, I’ll put my nurse’s hat on then, ‘We’d better go back and get it hadn’t we?’ you know, and I don’t really want to have to do that. I would love it if I didn’t ever have to do that again, but I do. So it does change... it’s changed our relationship.*

**Spousal Interview, Hayley, female. Wife of ID7: Andrew, male, 53 years, diabetes, affluent.**

### 8.3.2 Awareness

The awareness stage of the model discussed in chapter 2 is related to gaining insight into the condition and initiating the recovery process as well as becoming aware of a potentially more active self. This stage was less apparent within the current dataset and
participants often did not include this stage within their narratives about chronic condition. This was especially true for those participants within the resigned pessimistic category (chapter 7) who often had fatalistic views and limited expectations in relation to the future. This study has identified that the notion of mortality is one of the differences between the experiences of recovery from chronic physical and mental health conditions. This means that gaining awareness of a potentially more active self is less likely to be applicable to those with chronic physical conditions given their outlook. However, gaining insight into the condition and initiating the recovery process are likely to be more relevant. This study has demonstrated that this relates to the slowing of time, minimising the disruption to the status quo and making the most of perceived time left. Again the ambitious go-getters and determined maintenance seekers are more likely to be able to gain insight and initiate recovery without the need for intervention when compared to the disengaged optimists and resigned pessimists discussed in chapter 7.

The majority of participants seemed aware of the long-term consequences of their condition but did not describe a time whereby this awareness arose. It seemed this stage occurred implicitly and, as a result, did not factor into participants’ narratives about their conditions once it had occurred. The most relevant literature from the physical health field in relation to this stage of the model is that related to death awareness following diagnosis with terminal disease. During the period of biomedicalisation, it has been asserted that information provision has improved and now the majority of terminally ill patients know about their prognosis and are considered in a state of ‘open awareness’ (Glaser and Strauss, 1966, cited in Timmermans, 1994). This state of open awareness has been further broken down into three additional states; suspended open awareness (characterised by denial and disbelief), uncertain open awareness (which is facilitated by uncertainty and involves ignoring some negative elements of prognosis and focusing instead on hope for the future) and active open awareness (all parties are fully understanding and accepting of the prognosis (Timmermans, 1994). It seems them that participants within this study fell more within the realms of ‘uncertain open awareness’ as they focused to a limited extent within their narratives on the long-term prognoses of conditions and preferred instead to give prominence to their hopes for making the most of their perceived time left. This was facilitated by the often uncertain expectations relating to prognosis which were discussed in chapter 6 and being within the ambitious go-getters and determined maintenance seekers categories. Those within
the other two categories (disengaged optimists and resigned pessimists) often had unrealistic expectations (overly fatalistic or unrealistically high expectations) for the future coupled with a lack of individual responsibility.

However, it was possible to identify some participants who had yet to reach this stage. For example, there were a number of participants who did not seem aware of the potential long-term complications associated with conditions such as diabetes or they did not directly relate them to their own condition. This was particularly true of those who had limited symptoms or current impacts from their condition which resulted in a decreased visibility of the condition (identified on the cusp between determined maintenance seekers and ambitious go-getters, figure 14). The effect of the visibility of conditions on stigma and disclosure is well documented but these findings indicate that it may also impact on other stages of the illness trajectory such as those relating to prognosis and recovery (Joachim and Acorn, 2000).

No not at all. I monitor my blood sugar; I have a machine, which they gave me at the doctors er, but I don't do that as often as I should do.

R: Right.

Um, if I feel like eating cake I eat cake. If I feel like eating chocolate I eat chocolate.

R: Mmm.

And to hell with it, you know.

ID30: Ken, male, 54 years, CHD, diabetes, deprived

In this sense, awareness was impacted on by an individual’s perception of wellness. In their narratives about health some participants tried to socially distance themselves from other people with similar or different conditions whom they perceived to be ‘iller’. In this respect, a falsely held perception of one’s own illness and health could detract from awareness and moving to the later stages of recovery. This has implications for policy and was also identified in phase 1 of the study. It has been argued within the literature that awareness might not lead to recovery but can instead result in a greater adoption of the sick role (Young and Ensing, 1999). However, this was only apparent within one or two narratives and within the majority of the data, awareness appeared strongly related to positive self-management.

Well I mean the one that’s with me, he had a heart attack a couple of years ago so, they cope with him, and he’s bad with diabetes as well, and the other one, the other mate of mine he’s just a complete loss I think, he’s got everything. He’s laid up, he just got diabetes a couple of weeks ago and he’s laid up with that! He’s had a couple of heart...
attacks and he’s got arthritis so there’s not much...if you come down there you can write about anything, just jump over the fence and run!! Sorry I was only teasing you.

**ID23: Derek, male, 67 years, epileptic, diabetes, CHD, arthritis, deprived**

### 8.3.3 Preparation

This phase represents a contemplative phase whereby participants undergo a period of introspection during which decisions are made for the future. This stage was identified in this study through the identification of critical decision or turning points within narratives. These included critical life events, making decisions about future self-management, employment status and smoking/drinking habits.

*You've just got to believe that it's that what's caused it. And it's that that's making your health deteriorate daily. You've just got to believe that, and once you do that, once you've decided that this is something that you definitely shouldn't be doing, you know, it's like crossing the road when a bus is coming both ways, it's something you just don’t do. I mean, as I say, several times I tried to stop and I couldn't. But once I found out that it definitely had affected me personally then... And it's weird because I never wanted to smoke after. I had no cravings honest to god. It was just unbelievable. It was like a switch had gone off in my head and everything stopped with it.*

**ID28: Ivy, female, 66 years, chronic heart disease, deprived**

These turning points could also be instigated by external factors such as a change in environment through moving house for example.

*So the turning point in my life has been moving over here, like starting here. And that has changed my life completely. If I had have stayed over there I would probably still have been smoking, and I probably wouldn’t have seen 50, not without major health issues like a heart attack or whatever, because heart attacks run in the family, so they do.*

**ID29: Richard, male, 45 years, diabetes, high blood pressure, depression, irritable bowel syndrome, deprived**

In relation to physical health conditions, this stage has some overlap to the planning for end of life care. The recent drive within the policy discourse associated with biomedicalisation promotes responsibility for health above and beyond when health is compromised. Instead, attention is directed to risk minimisation and encouraging patients to take an active role in both their treatment planning and planning for end of life care. However, it has been demonstrated that encouraging participants to prepare and plan for end of life care can make patients feel uncomfortable (Sanders *et al.* 2008). Furthermore, participants said that an overt focus on end of life planning caused thoughts previously kept to the periphery of consciousness (e.g. the actual thought of dying) to be brought to the forefront which was often difficult for participants (Sanders
et al. 2008). This relates to the aforementioned notion of participants being in a state of uncertain open awareness (Timmermans, 1994) in which there is a delicate relationship between a state of uncertainty about prognosis and the creation of hope. It seems then that forcing participants to overtly face the certainty of their conditions can be disruptive to their perceptions of hope for the future.

### 8.3.4 Rebuilding

The rebuilding discourses evident in the data appear to mirror adaptation within the wider literature. As detailed in previous sections, the recovery movement has a focus on adaptation and reintegration (Liberman et al. 2002) or what has been referred to as ‘getting on with life’ (Noordsy et al. 2002). This includes work, social and community integration. Adaptation and living with a chronic condition was a strong theme within the current study. It was perhaps unsurprising that the majority of those recruited to the study displayed adaptation as research has shown that crisis periods render the individual unable to consider the future (Charmaz, 1991) and as a result these participants may not have felt comfortable taking part in the study.

> It seems to be as you get older bits fall off you know, so you just have to accept it and get on with it don’t you.

**ID18: Barry, male, 69 years, high blood pressure, high cholesterol, long-standing back problem (clodication), deprived.**

Some participants took the philosophical position that despite their condition, they were lucky to have had the life they have had to date and not to be as ill as others. This was particularly true for older participants.

> But you’re accepting, you know, what…what comes along and you’re glad for every day there is. You know, every day is a gift isn’t it.

**ID12: Marie, female, 76 years, cataracts, arthritis, high BP, polymyalgia, degenerative disc disorder, deprived.**

Often being diagnosed with a condition such as diabetes or CHD caused disruption not just to a person’s sense of self, but in terms of their integration with friends, family, work and social activities. This often occurred as a result of lifestyle changes necessitated by the diagnosis and links back to the notion of burden discussed in chapter 5 which can impact negatively on hopes for the future. As the quote below demonstrates, adapting to a chronic condition often meant that social networks were decreased.
I had to change my lifestyle really. So this is going to sound awful but I don’t drink very much these days, I’ll have a glass of wine with a meal and the people...I’m working behind bars and drinking was important to us. I mean, we weren’t like, you know, the...these days where it’s all booze and then going out just to get hammered but I’ve found that people step back or my social circle’s changed because I wasn’t getting drunk and I was feeling to find them a little bit boring when I heard the same joke for the fiftieth time because I was sober and then also it was always, “Oh you’ve not been drinking so you can drive us home”. So from a social point of view, maybe it’s just me but we weren’t the same anymore.

**ID26: Lynne, female, 62 years, stomach ulcers, diabetes, high blood pressure, high cholesterol, thyroid problems, deprived.**

There was evidence within the data that most participants displayed adaptation and the routinisation of self-management strategies and techniques. This related similarly to this stage of Andresen’s model and prior literature asserting that recovery was associated with regaining a sense of self and having hope for the future (Young and Ensing, 1999). Specifically, participants talked about becoming more informed about medical conditions, the routinisation of self-management regimes and rebuilding social lives and re-engaging or carrying on with valued hobbies and pastimes and this was particularly true of those within the ambitious go-getters and determined maintenance seekers categories discussed in chapter 7. This included explaining to friends or family who they undertook these activities with about their condition.

*I’m conscious [now] of when my blood sugars running low and I take corrected measures when I feel that coming on. I do take a glucagon injection kit with me when I go sailing or skiing because obviously I’m out of touch with dry land and you know, try and get yourself off a hill or off a boat in a bloody helicopter when you’re unconscious isn’t desperately clever, so I do brief my skiing and sailing companions with what they need to do if I start to make no sense, but touch-wood we haven’t had to use that yet.**

**ID7: Andrew, male, 53 years, diabetes, affluent.**

However, there were some participants who did not seem to be adapted in terms of their chronic illness. These participants were those currently immersed in chaotic periods of their illness and for whom treatment was not currently working. This appeared to be a highly frustrating experience and was often apparent for those within the resigned pessimist category. An example of this is provided below by a participant from this category.

*Especially when it comes to an illness that affects everybody in your life. You get a cold yeah, then it’s a sniffle, you know yourself you’ve got to go to work, you’ve got to do this, and you fight your way through it and you think to yourself ‘Yeah I’m going to have an early night’ but that’s how I used to be, I was never one to when I’m not well go and lock myself in the room. No, get on it, yeah I’m feeling a bit crap but I’ll be all right in a couple of days, I’ll take my Beechams or whatever and I’ll be alright. But I think when it affects the whole house, and it does because the kids can see when I’m not feeling 100% you know, and it does have an effect on your relationship, you know,*
when you’re meant to be going out, or doing this and thinking ‘I really just can’t be bothered.’

**ID33 Becca, female, 38 years, diabetes, heart murmur, deprived**

In line with literature from the mental health field, recovery did not appear linear and participants described moving forwards and backwards between stages dependent of the current experience of their condition. For example, they moved further towards growth during asymptomatic periods and back towards earlier stages during crises.

### 8.3.5 Growth

In line with previous research (Bonney and Stickley, 2008), the model asserts that in some cases diagnosis with a mental health condition can make a patient feel as if they are a better person for having the condition akin to the auto mythology narratives identified by Frank (1995). This has been found previously in narratives about tuberculosis whereby sufferers were often credited as having an enhanced personality or identity but has not been identified to the same extent for other conditions (Sontag, 1990). Charmaz (1983, p.176) spoke of a minority of patients who had improved following severe episodes of illness and for whom ‘illness had become a tool of self-discovery and a fundamental source of later self-development’ and this may reflect a form of narrative reconstruction (Williams, 1984). Other studies have argued that the positive effects of physical illness are more common than is often believed (Sodergren and Hyland, 2000). This stage seems to incorporate some new age values in that being successfully ill can transcend illness and age; however, this does not seem universally applicable to all chronic health conditions (Sontag, 1990) and other research has commented on the patients’ perceptions of recovery as unremarkable and the normalisation of adversity (Killoran et al. 2002).

There were a number of participants within the current study who had similar perceptions of their post illness identity particularly in relation to lifestyle choices; however, they were in the minority. This minority talked about ‘becoming a new person’ since diagnosis and feeling a lot more positive about their life and lifestyle choices. They also expressed concern about where they might have been should they not had experienced transcendence and become a ‘new person’.

*So being diagnosed isn’t the end of the world. In some ways it was a wake-up call.*

**ID25: Thomas, male, 41 years, diabetes, deprived**
8.4 Stigma

Stigma is a prevalent theme with the data from the mental health field and has been found to be a barrier to recovery and social adaptation (Perlick et al. 2001). This section will explore both felt and enacted stigma (Scrambler, 2004).

Felt stigma is found in an individual’s own views of feeling inferior to others or feeling devalued and incorporates shame (Scrambler, 2004). Felt stigma experienced by participants was commonplace within the data although this did appear to be of a lesser extent than that described in the mental health literature. However, it could still impact in a negative way on an individual’s sense of self which echoes previous research (Charmaz, 1983; Jackson, 2005) and is likely to impact on recovery. The type of stigma experienced by participants included potential stigma. For example, not wanting to walk with a stick for fear of what people might think, stigma relating to retiring from work due to ill health, and the negative connotations attached to having to inject insulin.

And what the doctor says to me, 'cos he says to use your walking stick at the doctors, but I keep thinking to myself why should I? I am only sixty-two, I am not ready, I am not ready for that sort of thing. And really the doctor, the doctor says to me, 'You are being silly,' he said 'think of yourself not what other people think.'

ID 10: Annette, female, 62 years, asthma, CHD, carpal tunnel syndrome, diabetes, high cholesterol and high BP, deprived

Participants often reported feeling stigmatised following diagnosis and one example of a type of felt stigma was a participant who discussed not being invited out in the evening by friends post diabetes diagnosis because she no longer drank alcohol. In this way chronic illness could contribute to the ‘pulling in’ or shrinking of social networks (Charmaz, 1991) which has also been found in the mental health field (Forrester-Jones, 2012).

Well yeah, I mean, in some ways I wasn’t invited out anymore [chuckles] or, you know, because they knew I wasn’t drinking and that I’d be boring and that’s what I became, I became boring because I wouldn’t go out and get hammered.

ID26: Lynne, female, 62 years, stomach ulcers, diabetes, high blood pressure, high cholesterol, thyroid problems, deprived

This stigma appeared particularly difficult for those participants who were diagnosed at relatively young ages. For example, the quote below shows how this 53 year old participant felt stigmatised following a heart attack and that this was exacerbated due to her age. She also had young daughters and following her heart attack she was unable to participate in some activities with them that she should have been able to given her age.
It makes me feel old, and I never did before, you know I never did, nor acting my age do you know what I mean.

How old are you?

I’m 53 next. And I think really that’s because I was the youngest one there, they used to call me girl, girl in that room. You know because it’s an old person’s thing isn’t it really like, until I were in Wythenshaw that were different because people from everywhere go there, and there was like people younger than me. Like there were one about 35, another and a woman came in who were like 42 and I think that made me feel a bit better, not for long like but...

...If anything, I don’t know, just like, I suppose it’s the stigma attached to like having a heart attack you know.

R: Right.

But I mean it has made me depressed, and like when I came out of hospital I couldn’t go to work for a couple of months, which I’ve never, you know, I’ve never had time off work. You know, so that just got on my nerves a bit, you know, being stuck at home. And then in June, we’d already booked to go to Florida with my two daughters and their families, and I suppose when you were there doing different things, you know, ’cos I were diving on all the rides, but because you know it’d only been a couple of months I couldn’t go on the rides. You know, and that, you know, I was fed up because I love going on all the big rides, you know, so that made me a bit fed up just standing there like watching everybody. I felt like I were really missing something, so then you get it in your head like ohhh, you know, that’s it like.

ID31: Sue, female, 53 years, CHD, unstable angina, underactive thyroid, deprived

Stigma was apparent within the data in relation to smoking. Smoking was universally portrayed as a socially unacceptable thing to do (even by those participants who were still smoking) and as something that could cause, and in some cases had caused, chronic health conditions. The same was true was true for being overweight and the development of diabetes albeit to a lesser extent.

I mean we could be talking, go out for a meal and talking away and then he’ll say; I’m just nipping out for a smoke, he’ll take his drink and go out for a smoke for like five, ten minutes.

R: Yeah.

So he comes back and he’s missed all this conversation that we’re having or whatever, yeah. So...and he must feel like a leper really.

ID22: Nick, male, 60 years, CHD, sciatica, high BP and high cholesterol, affluent

But there are books around and there’s an argument that overweight people get diabetes but which comes first. You know, it’s like, because I’ve gone onto Metformin and I’ve just lost three stone. I mean, I am trying; obviously I’m trying to eat the right things. I’m not eating biscuits [chuckles] and chocolates and crisps and all that but I can see that argument, I can see how it is. But it’s interesting other people’s reaction because, like, ‘Well you are overweight aren’t you’, ‘Okay’, but its only type two diabetes it’s not type one. An interesting thing is some type ones seem to resent type
twos. Like, “Well it’s a completely different disease”, and it’s like, “I didn’t say it wasn’t.” “You don’t have to use any insulin whereas I do and my body rejects it”, well…and that’s, you know, so it’s…it’s interesting, very interesting.

**ID26: Lynne, female, 62 years, stomach ulcers, diabetes, high blood pressure, high cholesterol, thyroid problems, deprived.**

In a small number of transcripts, there was also direct reference to the stigma attached to mental illness. It appeared that this stigma was still quite pervasive for those it pertained to.

*And it’s only since I’ve finished work and everything that I’ve thought maybe that was a sign as well that I wasn’t seeing. And probably I’m not going to think of myself, I don’t know. I am not proud of this point of view, but I didn’t want to associate me with some kind of mental problem, in its widest sense. It’s probably the old working class macho type manly men don’t cry, men don’t have feelings, maybe there was a lot of that involved with it, I don’t know. I hope not but I think there must have been to be honest. It’s alright for my wife to feel like that but not me. And so maybe I’ve been able to take a more realistic view since I’ve finished work.*

**ID 32: Jeff, male, 60 years, kidney stones, high blood pressure, CHD, angina, deprived**

There was only one participant who reported experiencing enacted stigma which is found in the direct action and behaviours of others (Scrambler, 2004). She was a young diabetic woman who had poorly controlled diabetes. She was experiencing difficulties as a result of this lack of control and she described herself as ‘very depressed’. The incident happened when she attended an accident and emergency department after diabetes complications and she talked about being spoken to in a manner she did not like by one of the doctors on duty. She felt so upset by the experience that she said she was less likely to attend the hospital again should she have further complications. She did subsequently receive an apology from the hospital but this had not been sufficient to encourage her to attend that hospital again.

*Don’t get me wrong, the A&E were great, I can’t knock them in any way, shape or form, they did my bloods, they gave me an ECG, they said obviously because there’s heart problems that run in the family, they don’t want to take any, you know, take every precaution should I say. They found out I hadn’t had a stroke or anything like that but the doctors on the ward, or this one particular doctor, was actually arrogant. I’ve never cried so much in my life; I took myself off my heart monitor and demanded I want to go home. Basically ‘Well, you’re diabetic because you’re fat, I thought how ignorant are you to, you know, to the illness itself; you know, ‘Have you thought about losing some weight?’ and I thought I did actually stop him and said ‘Just stop a minute’ I said, you know, I didn’t swear and I didn’t rant and rave, I said ‘You don’t know the first thing about me’. I said ‘You’re stood there, you’ve taken one look and summed up what you think to be the problem’ and I said, ‘And you’re so far from the truth’ and I walked out basically.*

**ID33 Becca, female, 38 years, diabetes, heart murmur, deprived**
Some enacted stigma was also reported within the narratives from significant others. This stigma related to the participant but had only been vocalised in front of the spouse. This most commonly related to social situations and a lack of understanding of the condition.

_We’ve always encouraged him to inject himself openly, because... I remember the first time I went to a couple of dinner parties, he’d gone into the loo and I thought, ‘That’s not right. It’s not a horrid thing you’re doing, you should do it openly.’ And then one of our friends said to me at a party once, ‘Oh it’s good I’m not diabetic.’ And I said, ‘Why’s that?’ And he said, ‘Because I don’t like needles.’ And I said, ‘I don’t know what makes you think Andrew does.’ Erm but that’s the sort of attitude you get. People don’t really understand it._

*Spousal Interview, Hayley, female. Wife of ID7: Andrew, male, 53 years, diabetes, affluent.*

Potential, felt and enacted stigma were apparent within the current dataset. However, it did not appear as disruptive and pervasive as that detailed in the mental health literature which demonstrates that dealing with the stigma and social consequences of mental illness is often more difficult than dealing with effects of the condition itself (Bonney and Stickley, 2008). Furthermore, the stigma identified in this thesis was often not related to the condition per se and instead focused on the behaviour that led to the development of the condition (e.g. obesity).

### 8.5 Recovery and the legitimacy of long-term chronic physical conditions

Whilst the focus of this chapter has been exploring conceptualisation of recovery and comparing these directly to one model of mental health recovery (Andresen, 2003, see chapter 2 for more detail), it will also now explore Fabrega and Manning’s (1972) work on illness careers. In this chapter, the authors differentiate between the illness careers of those with chronic physical health conditions and chronic mental health conditions. The illness careers of those with chronic physical conditions such as diabetes and CHD (or type II illness careers) are characterised as:

- Patients not held responsible for their condition;
- An acceptance that the condition will not go away;
- Long duration with increasing pain and disability ultimately ending in death;
- Patients legitimately excluded from some social roles and responsibilities;
Potential to experience social consequences of being labelled with the condition.

In this way they are separated from type I (temporary infections) conditions due the duration of the condition, degree of impact from the condition, and potential for stigmatisation of the group with the condition.

Chronic physical conditions are also differentiated from mental health conditions (type IV) for what appears to be reasons of legitimation and the nature of the deviance associated with the condition (Fabrega and Manning, 1972). For example, the authors provide an example of a cough or skin rash that would readily be perceived by both the general public and trained medical professionals as being a legitimate health condition. Furthermore biomedical deviance associated with conditions such as diabetes (type II conditions) is ascertained clearly through medical tests. However, detachment from reality in the case of mental health conditions for example, is harder to identify objectively.

Type II (chronic conditions with long range consequences and exemplified by diabetes) and type IV conditions have similarities in that the invisibility of the condition is similar for both types of careers. For example, it would not be possible for an untrained individual to see that a person has either depression or diabetes (without seeing test results). The main difference as identified by Fabrega and Manning (1972) is that for type II conditions, it is possible to separate the self from the illness whereas mental health conditions are considered as an illness of self. Furthermore, he argues that mental health conditions have greater social consequences than physical health conditions. However, the data presented in this study challenges this distinction between the two types of conditions based on these reasons. In participants’ narratives about their chronic condition, it seemed that they too sometimes found it difficult to separate their condition from a sense of self and narratives often delved into the past to make sense of the present. This was especially true for those with diabetes and CHD who often blamed themselves in the contingent narratives they produced in relation to their perceived cause of their condition which supports previous research (Blaxter, 1997).

And I was always quite active at school. I played football in three teams when I was fifteen, sixteen. And when I left school, I got into work and stuff like that and I didn’t really understand the consequences of like putting on a lot of weight and all, whatever. I got a hernia. I’ve had a couple of hernias. I put a lot of weight on dead quick because I couldn’t do any manual work and stuff, so I banged a lot of weight. And I never really lost it. And that was the true effect of me probably getting diabetes. It wasn’t explained to me properly until I got diabetes, why I got diabetes. So it would have been...maybe I
could have done something about it a little bit better, if I’d have known the consequences earlier on. But I didn’t know that so I’ve just led a normal life and ate what I wanted, drank what I wanted.

**ID21: Michael, male, 42 years, diabetes, deprived**

Participants often reported that there was a perception amongst friends and family and some health professionals that chronic conditions were caused by an individual’s lifestyle.

*Now I know it’s genetic rather than it was my fault whatever, now I know it’s there in the family that takes off some of the pressure because like, what am I doing wrong. Because some of my mum’s family were going, “Oh what have you done to get that.” Oh it must be me. So that’s when I stopped drinking my whisky and yeah it’s different knowing both sides of the family.*

**ID26: Lynne, female, 62 years, stomach ulcers, diabetes, high blood pressure, high cholesterol, thyroid problems, deprived**

This embracing of individual responsibility appeared to reduce the perceived legitimacy of the condition in their own eyes and the eyes of others. This was further enhanced if participants were still currently employed and trying to hold down full-time jobs. If long-term conditions were not well understood in the workplace, symptoms were not given consideration which caused stress to the individual. This was increasingly difficult for symptoms such as tiredness or lethargy which could be attributed to more socially unacceptable causes such as excessive socialising or being ‘lazy’. Furthermore, if participants carried on smoking or eating badly post diagnosis, this deviance was perceived to be social (or related to self) rather than biological both by themselves and others around them. For those who had made the recommended lifestyle choices post diagnosis, they were keen to distance themselves from this kind of social deviance.

*I remember a lad, you know, a few years ago, he was in a wheelchair, he had one of his legs cut off, right. That was part of his diabetes. But he wasn’t helping himself, right, he was in the pub on a daily basis, drinking cider, which is high sugar content, and brandy and coke. Right, so he was overloading his system with sugar, right, he wasn’t taking his medication, right, and he died, right, an early death.*

**ID25: Thomas, male, 41 years, diabetes, deprived**

This conferred deviance or moral inferiority (Scott, 1972) served to reinforce an individual’s own positive self-identity. This may be related to the shift in perceptions of smoking and obesity towards socially inappropriate or socially deviant acts. This is reflected in the recent smoking ban and media coverage of people not being offered operations by the NHS if they are obese. It is possible that this distancing from those individuals deemed to be socially deviant not only reinforces individual identity but also
moves the individual closer to the non-chronically ill within society. The illness careers were defined by Fabrega and Manning in 1972 and it may be that since then scientific developments and societal changes have affected the legitimisation of separating the self entirely from long-term physical conditions. Furthermore, advances in brain scanning techniques and other objective medical techniques may have enhanced support for causes related to biological deviance to be attributed to mental health conditions thus further separating the condition from an individual selfhood. One interpretation of this is that it may result in more overlap between these two types of conditions.

Yeah, but he's got three, he loves drinking, he loves smoking and he loves eating. He'll eat anything, yeah, he will, he's really one of those...

...and I said: why don't you give up drinking? I'd give up drinking before I give up smoking, he loves it and his brother's the same, yeah. I said: you think you're...people at work, they've got some young people at work like eighteen year olds and they smoke, and I think...and I say to them; surely you know, you should know better than us about the effects of smoking.

**ID22: Nick, male, 60 years, CHD, sciatica, high BP and high cholesterol, affluent**

The data collected in this study also challenge Fabrega and Manning’s (1972) assumptions that mental health conditions can be separated from other types of conditions due to their impact on social relations with others and their close relationship with social transactions. Participants and their spouses (where applicable) included in this study talked about strong impacts from chronic physical conditions on their relationships and on a range of wider social relationships.

The differences in the illness careers of those with chronic physical conditions included in this study related instead to the differing threats on the horizons of individual careers (mortality for those with chronic physical conditions and coercive treatment for those with mental health conditions, see page 66 footnote 14). There were also differences in the future orientation of narratives. For example, studies reported in chapter 2 describe future oriented narratives and highlight the centrality of hope for the future. However, the participants in this study focused instead on the slowing of time, minimising current disruption and making the most of time left.

This section highlighted the lack of legitimisation attributed to chronic conditions for some participants included in the study. In this sense participants did not feel resolved of the responsibility for their condition as described in Fabrega and Manning’s (1972) definitions of illness careers. Furthermore, despite their assertion that type II careers were characterised by a long duration with increasing pain and disability ultimately
ending in death, it appeared that some patients with these types of conditions had long asymptomatic periods (perhaps due to improved treatment since the development of these notions of illness careers) during which they had little impact from the condition. This resulted in some study participants appearing to be in a liminal place between health and illness. This suggests a greater overlap between the experience of chronic physical conditions and chronic mental health conditions whilst identifying additional nuanced differences between the two.

8.6 **Summary**

This chapter has discussed the findings of the study in direct relation to data from the mental health field as well as providing links to the previous chapters where appropriate. It appeared that there was some overlap within the findings from the two areas, particularly in relation to recovery being experienced as an individualised and personal journey, but also some nuanced differences between them. This chapter used Fabrega and Manning’s (1972) work on illness careers. This model was beneficial to the process of analysis as it provided an overarching framework which encompassed a range of relevant issues including stigma and treatment. The findings of the current study challenge Fabrega and Manning’s distinction between mental and physical health conditions based on the impact on social relations or the ability to separate a sense of self from illness. Instead differences identified in this study relate to the notion of mortality, experience of time, and future orientation of narratives. The next chapter will discuss the findings from the study as a whole and in the context of the wider literature discussed in earlier chapters of the thesis.
CHAPTER 9: DISCUSSION

9.1 Introduction

In this final chapter, the findings from the study are summarised and then discussed in light of the original research objectives, previous literature, and the conceptual framework/research design. The chapter then moves to discuss the implications of the study in relation to both policy and practice as well as for future research before ending the chapter by considering the strengths and weaknesses of the study.

9.2 Summary of findings in relation to the research objectives

9.2.1 Patients’ perceptions and experiences of prognosis and recovery and their impact on self-management and living with a chronic physical condition

Phase 1 of the study identified that participants often spent a lot of time talking about the impact of conditions and talked to a limited extent about the future. However, this analysis did allow for the identification of some areas for further exploration in phase 2 of the study including themes related to the ‘slowing of experience of time’ and the ‘minimisation of current disruption’.

Phase 2 allowed in-depth exploration of perceptions of recovery and prognosis. It appeared that recovery for those with chronic physical health conditions related to the setting of realistic goals that seemed personally achievable. Goals were manifest in an individual basis and were not medically focused. For the most part, goals reflected incremental or maintenance type recovery ambitions and were idiosyncratic and wide ranging. It appeared that goals were derived from the identity that participants had prior to illness and reflected moral aspects of experience. Goals were closely linked to the desirability of undertaking activities that made up participants’ social lives and in this way, recovery was associated with regaining valued activities. The reporting of personalised goals demonstrated that recovery seemed implicitly important, formed part of being a responsible patient and is likely to be related to the era of biomedicalisation discussed in chapters 1 and 2 (Clarke et al. 2003).
For the most part, participants had accepted the prognosis that their condition was not curable. Restitution type narratives were only identifiable in curable conditions such as colds and not in relation to chronic conditions. Notions of recovery reflected a personal journey for participants and a sense of purpose and reflexive monitoring. Accounts of personal journeys varied in degree of difficulty and the level of impact. These journeys started from a personally constructed pre-illness self from which individuals measured subsequent trajectories. Recovery was not perceived to be an easy journey and instead was often a laborious and slow process interspersed with very difficult periods.

Data from both phases revealed that recovery goals were often not discussed with health professionals and so remained integral to a ‘personal journey’ outside of the formal medical domain. Phase 2 allowed a more in-depth exploration of the reasons for this. It appeared that in most cases goals had not been raised with health professionals because individuals felt that recovery was their own responsibility. Whilst others would have welcomed support from health professionals, they often felt that medical consultations were not the correct arenas in which to raise these concerns due to limited resources. A minority had attempted to raise recovery concerns but had found health professionals to be dismissive of them and this inhibited their subsequent discussion.

The analysis also developed a model of recovery based on two dimensions; responsibility and expectations. This model allowed four ideal typologies of recovery narratives to be identified: determined maintenance seekers, ambitious go-getters, resigned pessimists and disengaged optimists. These typologies may go some way to explaining why some patients do and some do not engage with self-management and enhance the understanding of the experience of chronic illness. These themes and types presented may initially seem like previously critiqued attempts at trying to unify the illness experiences (Franks, 1995). However, the model follows the work of Frank (1995) by trying to use typologies to highlight elements of the illness experience and increasing the likelihood that the stories from the chronically ill are attended to.

9.2.2 How perceptions and experiences of prognosis and recovery change over time

Perceptions and experiences of prognosis and recovery appeared relatively stable for those re-interviewed after 12 months. However, they could be disrupted by major life events. In addition, individual goals could be flexible in response to internal or external change (both outside and within an individual’s control), in which case goals were
renormalized to accommodate new circumstances. Factors influencing perceptions of recovery, prognosis, and the associated goals for the future included: diagnosis with a new condition, deteriorating illness, family problems, mental health interventions, or readjustment to shifting notions of expectations and responsibility.

9.2.3 The applicability of concepts of ‘recovery in’ and ‘recovery from invalidation’ found in the mental health literature to the field of long-term physical health conditions

Whilst the study identified that there were some overlaps between the experience of recovery from mental and physical health conditions, it appeared that recovery models from the mental health field are not entirely relevant to those with chronic physical conditions. This is because of differences relating to variation in stigma, the notion of mortality, the experience of time, and the extent to which narratives are future orientated.

Narratives were similar to the notion of recovery from the mental health field because participants rarely talked about recovery in a restitutational manner. Rather, data resonated with the concept of ‘recovery in’ mental health (Davidson and Roe, 2007; Pilgrim, 2010). Similarly, recovery was not expressed as a simple linear process but instead reflected a complex personal journey centred on reconnecting or re-finding valued roles in society (Deegan, 2005; Hush et al. 2009; Wisdom et al. 2008).

The central theme which appears to separate the experience of recovery from physical and mental health conditions is that of mortality. Whilst in mental health mortality may be relevant as part of dramatic incidents (suicide) or shortening of life through iatrogenesis and poor physical health, such concerns are not represented in discussions about recovery in the mental health field. In contrast, mortality is a constant background concern and integral to the experience of long-term physical conditions. Currently, illness trajectories for the latter group of patients are more likely to be associated with deterioration and death; whereas the former are likely to be concerned about the potential threat of coercive treatment which is part of the service and policy landscape (Rogers, 1993). This appears to have altered the experience of recovery for those with physical health conditions. For example, narratives about mental health recovery appeared more future orientated through their focus on the centrality of hope and the awareness of a more active self. This contrasts with the narratives of participants in this study who appeared much more focused on the present, minimising disruption and
maintaining or restoring the status quo (Barnard, 1995). In this sense, the experience of
time for those with chronic physical conditions was different as they wished to slow
down the experience of time and make the most of the time they perceived to have left,
rather than make significant plans for the future. These results are presented in a
diagrammatic representation in figure 16 below. These differences might relate to
discussions had within chapters 1 and 2 in relation to the assertion that the majority of
research has been undertaken in mental health recovery within the field of psychosis
whereby social control is more formalised (e.g. detention under the Mental Health Act,
1983). The findings from the emerging literature on depression and recovery as well as
the multimorbidity studies discussed in earlier chapters (Gask et al. 2011; Ridge and
Ziebland, 2006; Cherenomas, 1997; Fullager and O’Brien 2012 ; Goldman and
McClean 1998) would fit well within this overlap area on the diagram with their focus
on the role of self in relation to recovery and highlight that these notions of recovery are
closer to the management of long-term physical health conditions than traditional
models of recovery emanating from the field of psychosis.

*Figure 16: Summary of the similarities and differences in relation to data from the
mental health field*
Comparing themes from the data against Andresen’s five stage model of recovery (see chapter 8), there were also some important, nuanced differences (Andresen et al. 2003). There are clear overlaps between the *moratorium* stage of the model and the notion of illness as a biographical disruption (Bury, 1982). Furthermore, the *rebuilding* phase seemed to mirror adaptation within the wider literature and it was possible to identify these stages of recovery from mental health in the narratives about physical health conditions. However, other stages such as the *awareness* and *growth* stage of the model were more difficult to identify and apply to chronic physical health conditions. During the analysis of these stages it seemed that the data were being forced into the categories rather than mapping naturally onto them. It is perhaps unsurprising given the nature of conditions such as diabetes and heart disease, that only a minority of people within the dataset felt that having conditions had made them a better person. Again, this is likely to be related to the notion of mortality described previously, as well as previous discussions about neuro- and biodiversity. Consequently, the findings indicate that physical health conditions do not pass through the stages of *awareness* and *growth* to the same extent as those with mental health conditions; the findings indicate the need for two additional stages: *acquiescence* and *reconnecting with valued activities*.

Stigma is a central theme within mental health literature and was one of the drivers of the recovery movement. Whilst stigma was included in patients’ narratives about chronic physical conditions, this did not appear to be experienced in the same way for the participants included in this study. This is likely to stem from the notion that mental health conditions are considered as illnesses of self to a greater extent than physical illnesses (Pilgrim and Tomasini, 2012). However, there was an element of stigma attached to some conditions such as diabetes, whereby participants felt that there was a perception of moral responsibility within society that the conditions were the outcome of personal behaviour and caused by being overweight or not eating healthily. This is likely to be another way in which biomedicalisation is expressed as experiences of living with long-term conditions. This stigma was echoed for those participants who smoked and had heart disease or COPD. There was a sense in the data that obesity was becoming socially unacceptable in the same way that smoking had become. Given recent press coverage about patients being denied operations because of their weight and the associated coverage insinuating that smokers should pay for medical treatment, it may be that this type of stigma will increase for these conditions particularly in the current period of austerity.
Whilst using the notion of recovery derived from the mental health field has been a useful lens to look at data from the physical health field, some important differences have been identified. Furthermore, the study has extended the lens of ‘recovery’ identifying important aspects of recovery and prognosis which have hitherto been under examined. The study was also able to demonstrate how the era of biomedicalisation is expressed as features of the experience of patients with long-term conditions.

9.2.4 Social factors (e.g. age, gender and socio-economic status) that impact on perceptions and expectations of prognosis and recovery

The main social factor that appeared to impact on perceptions of recovery and prognosis was socio-economic status. However, there were also differences in relation to age. It appeared that some conditions could be attributed to the natural ageing process (e.g. arthritis) and, as a result, participants felt they should have been anticipated (Hinojosa et al. 2008; Sanders et al. 2002). In addition, disruption as a result of illness was often heightened for younger participants and for those who felt they had previously lived a healthy lifestyle which they felt would ward off long-term conditions (Sanders et al. 2002). However, no differences were identified in relation to gender.

The differences in relation to socio-economic status are summarised in a figure in appendix 12. It appeared that the relationship between social patterning, habitus and recovery could potentially increase an individual’s vulnerability in terms of chronic illness at various stages on the illness trajectory. Firstly, there was a perception that the limited capital of those from the lower socio-economic groups could predispose an individual to chronic illness through unhealthy or uninformed lifestyle choices. This lack of capital appeared to inhibit or diminish relationships with health professionals. Furthermore, the feeling of being a burden on others was more pronounced amongst those within lower socio-economic groups. In addition, more deprived individuals could not pay to speed up access to health services by paying for private treatment. Finally, it is likely that habitus will impact significantly on expectations for the future and, in this sense, on recovery.

Within the data, it appeared that participants’ narratives reflected the aforementioned notion of biomedicalisation and the shift of health focus onto prevention and promotion. This resulted in a sense of a constant pressure for patients to be working towards health or individual lifestyle changes. This is reflected in the quote from Clarke et al (2003) “No rest for the weary”. This study has demonstrated that social differences also relate
to relationships with health professionals, narrative habitus, notions of burden and expectations for the future.

9.2.5 The similarities and differences in notions of recovery and prognosis for different conditions

Whilst it did not appear that there were major differences in notions of recovery and prognosis between the different physical conditions included in the study, it was possible to identify some social comparisons being made by participants in relation to other physical conditions and others with the same condition. Participants with one condition compared themselves with others who had more than one condition and those with physical conditions compared themselves with those with dementia or other neurodegenerative conditions. This internal hierarchy constructed by participants was a recurring theme in the data and potentially seemed to reduce the likelihood of an individual focusing on ‘recovery’ or on an ideal ‘recovery’ state.

Participants often used deviance to redefine and shape notions of their own illness and identity. For example, they would often cite other people who were not self-managing well, those who they considered to have caused their own condition, or those who overused health services. They would then push these characters to the fringes of society within their narratives and attempt to distance themselves from them in an attempt to normalise their own situation. This social comparison has been discussed in relation to studies which have found similar findings (Bury and Holme, 1991; Pound et al. 1998; Rogers et al. 2009b; Sanders et al. 2002).

9.2.6 The factors that are perceived to promote or inhibit ‘recovery’ from chronic physical health conditions

Data from both phases of the study identified some factors that were perceived to promote or inhibit recovery. Factors which were considered to impede recovery included:

- Competing priorities/agendas which distracted patients from establishing and maintaining illness routines and regimens. These included looking after others, work and familial responsibilities

- Lack of visibility of illness or falsely held perception of wellness

- Normalisation through social comparison and justification
• Low expectations
• Low personal responsibility
• Paternalism in clinician-patient relationship which appeared particularly marked for those from more deprived areas
• Notions and beliefs about what constitutes being a ‘good patient’ and its relationship with passivity
• Notions of being a burden to others including family member, friends and health services
• Financial difficulties
• Additional illness or deterioration of existing ones

The narrative emplotments undertaken post interview and the analysis of the interviews identified the limited role of health professionals in relation to recovery when compared with other research that has shown that nurses and allied health professionals are skilled in opening up and expanding narratives (Mattingly, 1998).

In terms of the factors considered to promote recovery based approaches, the model indicates that those with greater levels of personal responsibility for illness and higher (but realistic) expectations for the future were more likely to adopt a recovery type approach to self-management. Furthermore, the narrative emplotments identified that support from family members, friends, colleagues and pets, when supportive, promoted recovery from chronic physical conditions.

9.2.7 Summary

This section has endeavoured to summarise the findings from the study in relation to the original research aims and objectives. The chapter will now move to considering the relevance of the conceptual framework before discussing the implications of the study and the strengths and weaknesses of it.

9.3 Relevance of conceptual framework/research design

In chapter 3 I documented the methods employed, detailed the rationale and application to the research questions, and reflected on the process of undertaking the research.
Whilst drawing on a number of different qualitative methodological approaches, this study was aligned to a constructionism epistemology (but also explored subjectivist origins of meaning). This appeared to serve the study well in that recovery did not appear to be an objective reality and instead participants provided accounts of individualised perceptions of recovery which were shaped by background and experience. It is likely that using quantitative methods to assess notions of recovery would not have been able to capture this notion of individuality and all of its complexity. As previously discussed, qualitative methods especially narrative interviews allowed individual stories to be explored in depth and in context to gain a thorough understanding of individual experience.

I was strongly influenced by the paper discussed in chapters 1 and 2 relating to biomedicalisation (Clarke et al. 2003), and was interested in the impact of these wider narratives about society and health. Using a recovery lens through which to look at the data further highlighted the social and cultural experience of illness and the ways in which patients were using their wider experiences to base recovery goals and hopes for the future on. Using these frameworks was important as narratives do not occur in a vacuum but rather against a backdrop of social environments and wider health services changes. In this way, narratives were engrossed and entrenched in societal narratives which surrounded them (Frank, 1995; Kleinman, 1988; Woods, 2011).

The social patterning of recovery was a concern in this study because this had not been addressed in the existing literature. The results supported the importance of viewing narratives within the social and personal contexts in which they are based (Charmaz, 1991). Recovery necessarily requires a focus on a movement through time and the use of longitudinal methods enabled the complexity of this experience to be captured. The narrative method used allowed participants and their individual stories to guide interviews. This hopefully allowed them to raise issues relating to recovery and prognosis that were important to them and not ones that were important to other people (e.g. researchers). It also highlighted the need to understand individual explanatory frameworks (specifically related to expectations and recovery) as these often served as justifications of practical actions and may explain why or why patients do, or do not engage with self-management type activities.
9.4 **What the study adds to existing literature**

The study adds to the existing literature in a number of ways. The findings were discussed in relation to existing literature throughout the results chapters but will be summarised here:

- The findings add to what is known about the experience of physical health conditions by adding an understanding of recovery and prognosis. The study highlights the need to understand views about recovery and prognosis as a way of understanding why self-management is, or is not, undertaken.

- The study also demonstrates the social patterning of perceptions of recovery and prognosis which were hitherto underexplored within either the physical or mental health field.

- The findings examined how the experience of ‘biomedicalisation’ defined previously is experienced by patients with long-term conditions which adds to existing research.

- The results supplement knowledge about lay perspectives of illness. This is because it contributes to the understanding of expectations and perceptions of the future from those who already have conditions. Previously studies examining lay perspectives of illness have tended to focus on the extent to which conditions are preventable from people who are not yet ill.

- The study shows overlap, and calls for potentially better integration between research from the mental and physical health fields. The similarity related to the shared underpinning of chronicity and the experience of recovery as a personalised journey. However, there were nuanced differences between the two which related to notions of mortality, hope, the experience of time and future orientation of narratives. Previous studies exploring overlap between the two fields have focused on those participants who have both physical and mental health conditions (Gask et al. 2011; Lau, 2005).

- The study adds to knowledge of recovery and prognosis by identifying influential relationships within personal social networks implicated in supporting recovery.
• The findings build on Fabrega and Manning’s (1972) work on illness careers and whilst it did not challenge the distinction in careers between the two fields, the study did contest the assumptions behind this distinction. This study would assert that differences in illness careers between the two types of patients relates instead to the notions of mortality and coercive treatment, the experience of time and future orientation of narratives about illness.

• The study has applied a process model of recovery from the mental health field to those chronic physical conditions. Whilst there is some applicability in terms of understanding the individualised experience of illness as a personal journey, there were some elements of the notion of recovery from mental illness that were not applicable to those with chronic physical conditions and these related specifically to areas of awareness of a more active self and personal growth in the future.

9.5 Implications for practice and policy

This section will critically consider the implications of this thesis for health practice and policy. These implications relate to health promotion activities and campaigns, self-management support, and care plans.

Relevant health policy documentation was discussed in chapter 1. The most commonly used way of supporting patients with long-term health conditions is through the third tier of the NHS and Social Care Long-Term Conditions Model. This involves promoting self care through five elements; healthy lifestyle choices, support networks, skills and confidence training, and tools such as self-monitoring devices (Department of Health, 2005a). Recent mental health policy similarly calls for the improvement of quality of life and access to education, training and employment (Department of Health, 2011) as well as incorporating core values of choice and control. In addition, recent policy documentation in both fields includes the introduction of personal care plans which implicate notions of recovery and consideration on the part of the patient about prognosis. However, as this thesis has identified, relatively little is known about perceptions of recovery and prognosis from the point of view of those with physical health conditions.
The findings of this thesis question the utility of abstracted targets within health which can create expectations of patients with long-term conditions, which strongly imply that they should conform to a recovery type modus operandi in a particular formulaic way. If these are internalised but unrealistic, these may lead to guilt and shame at not being able to reach targets or to disengagement altogether. This study implies the need for advocating a new generation of self-management support which is more sensitive to patient agendas and responsive to the influence of others within wider social networks.

This study casts doubt on the above policy focus relating to choice and control and instead supports attention being focused on previous work which prioritises good patient care over choice and profit \(^{20}\) (Mol, 2008; 2009). Mol questions the logic of choice (individual patient choice which implicates planning and control) when patients are diagnosed with a condition which they had not planned for, or chosen for, themselves. The current thesis demonstrated that participants can obtain some moral worth through the undertaking of valorised behaviours. However as it has been demonstrated previously, control in relation to chronic conditions such as diabetes and CHD is likely to remain an illusion (Mol, 2009) given the often erratic nature of these conditions and the unpredictability of the future. Furthermore, the need to be constantly active in relation to self-management could potentially become oppressive for the patients involved given the already heavy burden of chronic illness.

In participants’ narratives, perceptions of recovery and prognosis appeared to be centred on the slowing of the experience of time and easing their current situation by minimising disruption to the status quo. This is reflected in the incremental recovery goals reported by participants. Perhaps unsurprisingly, a sense of impending mortality looms large for those with chronic physical conditions and it is inevitable that such people require some degree of psychological distance from this. It appears that the fear of condition specific complications, deterioration, and the risk of additional conditions manifest at the periphery of individuals’ consciousness. It may be then that blanket health promotion activities and campaigns used for both those with and without chronic conditions are not particularly effective or relevant. This may be because they reflect a ‘one size fits all’ approach and so fail to respond to the diversity of illness (Sanders et al. 2008). Instead, this thesis would propose that health promotion aimed at those with

\(^{20}\) Whilst recent policy documentation has not been concerned with profit (as in the work of Mol (2008; 2009) in the USA), given the current financial zeitgeist in the UK it is perhaps unsurprising that large volumes of recent reports focus on cost reduction and deficit reduction.
chronic physical conditions should focus on reinforcing and improving the quality of the time left and addressing any loss of previous notions of self. This is likely in any case to be a context which is a prerequisite for considering behavioural change but these issues identified within the thesis would need to be addressed first.

Traditional health promotion messages and activities have tended to focus on the need for people to strive to prolong a long and healthy life. Whilst some people with long-term conditions do live long lives that they would describe as ‘healthy’, despite their condition, for others these are not realistic aims. The narrative approach provided here has demonstrated that the stories inherent within health promotion campaigns have a different impact on different people. For example, this study has demonstrated that for some participants, particularly those from more deprived areas, these messages can be perceived as ‘nagging’ or construed in a potentially oppressive way (‘no rest for the weary’, Clarke et al. 2003). These participants do not appear to engage in the necessary lifestyle changes due to what they describe and foresee as minimal returns. Instead narratives about recovery and prognosis focus on trying to re-engage with valued or meaningful activities and past times or valued roles within families in what appears to be an attempt to make the most out of ‘time left’. There may be an argument then for a greater focus in health promotion activities and health policy on quality of life and engagement with meaningful activity and fostering positive social relationships which are now becoming more apparent within mental health policy (Department of Health, 2011). However, such policy would need to also address patients concerns about focusing too much on illness within their lives which was highlighted in the current study. These findings highlight the importance of recent initiatives such as Games4life (Games4life, 2012) and the Patient Led Needs Assessment tool (PLANS, 2012) which both aim to reconnect patients with local activities and groups based on individual needs and desires and relate more to ordinary living – the life worlds of patients that are seemingly more marginal to explicit health and illness goals. These elements would also need to be considered in quality of life assessments. In addition, recent mental health policy has argued for more life course approaches to protect well being and resilience which appears to be more holistic than the apparent outcome focus of self-management support within policy about physical health.

As discussed in chapter 1, it was envisaged in the NHS and Social Care Long-Term Conditions Model that all patients with long-terms conditions would have a care plan by
2010. However, if this has been realised in practice then it was not something that was recognised by the patients included in this study. This challenges their central features of collaborative decision making, co-construction and regular reviewing. This study would support the use of care plans but would highlight the importance of understanding and incorporating individual expectations of, and responsibility for, recovery and prognosis and the influence of others as a point of reference. Furthermore, any treatment plans would need to address the complexity of the experience around recovery identified within this study and also address the paternalistic relationships identified within consultations particularly amongst those from more deprived areas, which were identified within this study and others (Protheroe et al. in press). This paternalism implicates the limits of shared decision making which is often assumed to prevail in chronic illness management. These issues are likely to become further exacerbated as responsibility for commissioning and budgets are transferred to GP commissioning groups.

The focus on information provision within recent policy documentation highlights the pertinence of some of the findings of the current study. The patient narratives revealed the limited recognition of the importance of information in terms of recovery and prognosis. Specifically, this was concerned with some participants feeling that it was difficult to get reliable or adequately tailored information. They felt that even if it was possible to receive such information, that it may put undue pressure on people who may not ‘recover’ in the same way. It should be noted that some participants said they would have liked to have had information written by patients in similar situations.

Additionally, following the findings of this study, access to too much information can add pressure to individuals with chronic health conditions leading to what participants referred to as becoming ‘over knowledged’ which can lead to concern and worry and add to the burden of chronic illness (Clarke et al. 2003). Participants also queried the legitimacy of some types of information and this related predominantly to internet based information. This at the very least highlights the need to tailor information provision to the individual and that information provision is not necessarily a good thing in its own right (Blickem et al. 2011).

For health services to reflect the patient centeredness advocated in recent policy documents, this study indicates the need for attention to perceptions about recovery and prognosis in order to understand health related ‘choices’. For example, patients in the
resigned pessimist’s category (described in chapter 7) might opt for poorer quality treatment nearby rather than a better performing service further afield because of limited expectations and personal responsibility. Such barriers to choice need to be addressed to successfully attend to service limitations. Furthermore, the use of personalised health budgets (Department of Health, 2010) may be constrained by patients with long-term health conditions who already feel as if they are a burden on health services. This study along with others has demonstrated that patients appear to ration their use of health services, and this appears particularly marked for those in deprived areas (Rogers et al. 1999b).

This study supports previous work demonstrating the importance of holistic treatment over the treatment of individual conditions because, as with other studies, it has shown how learning about illness is transferred between different conditions (Morris et al. 2011). This directly contravenes the sequential model of how health professionals currently treat long-term conditions. This study has also demonstrated that this is likely to be further nuanced because those with chronic conditions need different health strategies than those without chronic conditions but not condition specific ones.

Reducing the stigma that service users experience is at the heart of recent mental health policy (Department of Health, 2011) but is markedly less apparent within that for physical health conditions. The stigma experienced by those in this study did not appear as severe as that from the mental health field. However, felt stigma was discussed on a number of occasions with enacted stigma reported by one participant. It may be that with the limited resources within health services currently, felt stigma increases amongst those with chronic physical conditions and this may become an important consideration for the future.

This section has highlighted the implications of the study which are policy and practice relevant given the number of people suffering with chronic conditions. They may also potentially explain why self-management programmes are poorly engaged with and why care for these patients is still not meeting quality targets (National Audit Office, 2012; National Institute for Health and Clinical Excellence, 2008). This is likely to become increasingly relevant given that the number of patients with chronic conditions is expected to increase even further over the coming years and the financial constraints associated with the period of austerity that the UK is currently experiencing.


9.6  **Implications for future research**

The findings from this study implicate a number of areas for future work. Given the apparent importance of responsibility for, and expectations of, prognosis and recovery, tools could be developed to encourage practitioners to better understand expectations and levels of responsibility for health. These may then impact on engagement with self-management and aspiration for the future. Practitioners would need to be encouraged to find out what would improve quality of life for those individuals with chronic conditions and how this can realistically be achieved. Specifically this might relate to the use of life histories akin to ‘mini ethnographies’ to elicit explanatory models and explore social and cultural worlds (Kleinman, 1988) but additionally to incorporate an exploration of expectations and responsibility. This would extend the traditional approach to medical history taking within clinical encounters. It appeared that some participants were more motivated to giving these life histories to health professionals (though these were not always responded to by health professionals) but this was not as apparent in the narratives of those with lower socio-economic status.

Whilst the typologies reported in chapter 7 are ideal types, they might prove useful in designing tailored interventions for the different typologies reported within this study. Previous research has argued that matching patients on the types of narratives they produce and providing ‘counter narratives’ has potential utility for patients with spinal cord injuries (Smith and Sparks, 2008). Furthermore, enhancing the narrative resources available to some patients could potentially be used to adapt expectations. The study also identified some tensions between lay and professionals’ perceptions of risk and recovery found previously (Kleinman, 1988) which could be further explored from the point of view of health professionals.

The study recruited participants on the basis of their having a chronic condition which meant it did not allow for an in-depth exploration of recovery from specific conditions. Given the exploratory nature of the study, chronicity was an adequate inclusion criterion; however, future work may develop more detailed exploration of individual conditions and thus have the potential to identify differences between conditions that this study did not have the capacity to find which has been indicated previously (Murray et al. 2002; Pinnock et al. 2011).

Talking to significant others further illuminated the experience of illness for the individual participants so there may be a case for including them in the discussions
about treatment and to encourage the adoption of new ‘narratives’ within the wider social circle. However, this would need to be tested and any attempts to implement this would need to consider the issue of burden because in this study only nine participants identified significant others to include in the study which may reflect the notion that they are already burdening friends and family and do not want to further exacerbate this.

There is a concern about the rise of chronic conditions and multi-morbidity (Marder et al., 2004; Singleton et al., 2001). Recent research has demonstrated that those with severe mental health problems have reduced life expectancy when compared to the general population, with two-thirds of the mortality gap explained by physical health problems (Wahlbeck et al. 2011). Consequently, this is becoming a policy priority within primary care given the recent development of additional QOF indicators (NICE, 2009). However, there is currently no research on combined notions of recovery. The key areas of recovery that appear to overlap between physical and mental health conditions as identified within this thesis are: recovery as a complex, nonlinear personal journey, the input from and influence of significant others, notions of burden and the impact of conditions on self and identity. These elements could be further explored in future research and tested subsequently with other populations. Of particular interest is likely to be the social networks of patients and their impact on care planning and self-management and further more detailed research could be undertaken in this regard.

These links between the research data and existing literature on comorbidity (and particularly in relation to the emerging literature around recovery and depression) indicates the need to explore in more detail as a major area for future research the explication of these links. In particular, the impact on self for both those with chronic physical health conditions, those with depression and those with both conditions should be examined which it was not possible to do within the remit of the current study.

9.7 **Strengths and Limitations**

Specific issues relating to the reliability and validity of the methodology used within the study can be found in chapter 3. The study gains its strengths from the in-depth nature of the interviews and its longitudinal design which allowed participants’ perceptions and expectations to be explored over time. This allowed the impact of critical life events on perceptions of recovery and prognosis to be explored and should limit the effect of temporality on the results. In addition, the 12 month follow up interview allowed the
data collected in the baseline interview to be checked for accuracy (through the presentation of summative narrative emplotments to participants). This use of follow up interviews also, I felt, facilitated a stronger connection between myself and the interviewees which may not have been achieved through the use of one off interviews and may have led to greater use of private rather than public accounts of experience (Chapter 2, Cornwell, 1984; Radley and Billig, 1996). This also allowed recovery journeys and trajectories to be explored and unfolding truths over time to be examined. This connection with the participant was also aided by the incorporation of interviews with significant others (where applicable) as this increased the contact I had with the individual participant. Whilst the study design would likely have benefitted from an even longer follow up period this was not feasible given the time constraints on the project. It is worth noting, however, that using a recovery lens to look at the data is likely to render some things within the experience of illness visible and others invisible which needs to be kept in mind when considering the results. It has also been asserted that interviews naturally lead to salutogenic approaches because people want to portray themselves in a positive light (Silverman, 1993). In addition, some of the issues raised in this study, especially those relating to health professionals, are likely to benefit from observational work and interviews with health professionals to gain a more balanced view.

Another key strength of the study design which was not anticipated at the outset was the use of summative narrative emplotments which were originally included to provide a source of member validation. They were useful in this respect and provided a quick and easy way of reminding participants about what was discussed during the baseline interview and checking data extraction was correct. However, what was not anticipated was their utility in undertaking the data analysis. Given the large number of transcripts that the study produced these emplotments became vital summative documents for the researcher which aided the organisation, understanding and contextualisation of emerging themes and concepts. For example, I could spread the documents out on the floor and see in an instant which participants had multiple versus single health events or those who had downward or stable illness trajectories and look at emerging codes respectively. Benefits of the narrative emplotments to the individual participants are discussed later in the section.
One of the principal components of narrative inquiry is that narratives are produced in a collaborative way with the researcher as discussed in chapter 3 (page 97). The literature demonstrates that what is critical to this process is the development of time and space with participants to enable an environment to be created that is conducive to both parties feeling comfortable and able to talk freely and equitably (Fetterman, 1998). I felt that for the majority of participants this was achieved through leaving the choice for the time and date of the interview to the discretion of the interviewee and being flexible if the need to change this arose. I felt that participants talked freely to me and was not aware of how I influenced the narrative to any great extent (apart from the focus on recovery). However, there were two interviews where the interview conditions were perhaps not ideal. One participant requested that I interview him at his place of work which was a small shop. The interview was undertaken in the stock room and there were a number of interruptions from delivery men and staff working within the shop. I offered on a number of occasions to come back at a more convenient time but he did not feel he had time to do this. Another participant’s daughter was present during the interview which was disruptive as she frequently disturbed the flow of his narrative. The narratives produced within each of these interviews would probably have benefitted from more appropriate circumstances. I also took detailed field notes from each interview to help contextualise the narratives and used these during the analysis process to aid the understanding and interpretation of results.

As discussed in chapter 3 narrative methods have been used in emancipatory ways (page 79) and are considered empowering for those taking part (Pavlenko, 2002). This relates to participants being able to talk about issues that have previously been untellable, to provide order and cohesion to past events through the art of story telling or that through telling illness stories in an active patients are better able to accept illness and take the opportunities that illness has afforded to them Frank (1991). This had some resonance to the participants in the current study. For example, the participants appeared to value seeing the narrative emplotment diagrams during the 12 month follow up interview and some asked to be sent a copy to keep. It may be that the interviews along with these emplotments did go some way to provide order and cohesion to past events experienced by participants in line with the work of Frank (1991). Other participants, albeit a small number, told me that they had divulged information during the interviews that they had not told to anybody else and these participants described this as a cathartic experience and valued the confidentiality that the interviews provided.
As discussed in chapter 3 (page 88) the length of the interviews varied between 30 minutes and 1 hour and 45 minutes. All questions on both interview schedules (appendix 4 and appendix 5) were asked to all participants included in the study. Whilst the majority fell towards the higher end of the time spectrum one or two were considerably shorter than the rest. These cases included the two previously mentioned interviews (page 223) whereby distractions meant that it was difficult to engage participants in longer narratives. On the whole, shorter interviews tended to be conducted with those participants who were functioning well in their day to day lives and had less impact from their conditions.

I was motivated towards the use of patient narratives due to the limited voice patients often have in academic reports and publications. Conducting the patient narratives, whilst sometimes a difficult experience for both interviewer and interviewee, appeared to have a therapeutic benefit for some participants. Producing narratives made individuals reflect on their lives and experiences of having a chronic condition. I was told by participants that the interviews had given them a valid opportunity to talk about themselves in a safe environment, to a sympathetic listener, which they had not had the chance to do before. This was often because they felt they had already burdened family, friends and health professionals enough and did not want to increase this further by complaining to them. This has important implications considering Frank’s work on the potential reparative value to the self imbued in storytelling. Given that their talking to me was something that they had been asked to do and that value was attached to it, the issue of burden did not seem to arise as frequently. However, some participants (especially those of lower socio-economic status) had initial concerns that their stories did not have value and as a result they tried to truncate their stories because they did not want to waste my time. This took some encouragement on my part to make them feel that their story had value and to make them feel comfortable enough to tell it. I was also aware of a motivation on behalf of patients of wanting to help others with similar conditions, and this was often cited as a reason for wanting to take part in the study and some appeared to take moral value from this. This was especially true in the case of one participant who was diagnosed with motor neurone disease during the 12 month follow-up period. Despite, having been given a limited amount of time to live since diagnosis, he still wanted to take part in the follow-up interview. This was quite an emotional interview for the participant (and myself) but he was adamant that he wanted to take part in the follow-up to contribute to the improvement of knowledge about diabetes and
other chronic conditions. This also demonstrates the level of investment from participants.

The study endeavoured to include the narratives of other people in participants’ lives that were important to them. The reasoning for this was previous research which has demonstrated the dynamic relationship between an individual with a condition and their social environment (Swift, 2012; Rogers et al. 2011). Despite the fact that only a limited amount of people agreed to take part (n=9), these narratives were of value to the study as they demonstrated how illness narratives are often shared with spouses and that subsequent understanding of the illness experience and perceptions of recovery and prognosis are also shared. It also supported previous research which has indicated that involving significant others is important so that all parties have similar levels of understanding and access to information and support (Swift, 2012) which has implications for health services use. For example, within this study significant others often reported feeling excluded from their partner/spouses medical consultations and having to interpret information ‘second hand’. The only real difference between the narratives of participants and their significant other appeared to relate to severity and impact with spouses sometimes reporting that illness had had a more pronounced impact on the individual participant and their marriage than that which they disclosed themselves. As a result, if I were to do the study again I would include interviews with significant others in the design despite the limited uptake.

9.8 Conclusion

This study was designed to explore the perceptions of recovery and prognosis from the point of view of those with long-term physical health conditions such as arthritis and diabetes. This was due to a perceived lack of empirical literature on the topic, especially when compared to the field of mental health. The study supports literature from the mental health field in that participants felt that recovery was a personal journey and one that was often very arduous. However, there were some nuanced differences between findings from this study and the findings from the mental health field and subsequently the illness careers of the two sets of patients. These differences related predominately to the experience of time and centrality and extent of hope for the future. Those with chronic physical conditions talked about slowing down the experience of time to allow them to make the most of the time they perceived to have left and to limit the disruption from conditions. This contrasts with the field of mental health whereby recovery often
centres on the acknowledgement of a more active self, hope for the future and working towards these aspirations. There were also differences in relation to stigma with it appearing that those with mental health problems experienced individual stigma which was more marked than those with chronic physical conditions. This is not to say that the model is not useful when applied to physical health conditions. Using a recovery approach has highlighted elements of the experience of illness which have hitherto been under-examined. However, attention should be given to these differences if applying the model to physical health conditions.

The study demonstrated the need to explore perceptions about recovery and prognosis in order to better understand why patients do, or do not, engage with self-management for their condition. Another finding of the study is the need to understand patient narratives within the wider social and societal context in which they are based. These notions of recovery in relation to an individual, organisational and societal level are summarised in figure 17.
The results from the study challenge the recent policy drive towards choice and autonomy and would argue for a focus instead on patient care in line with other researchers (Mol, 2008; 2009) in an attempt to decrease the already heavy burden of chronic illness. Given the results of this study it is difficult to envisage how patients can be engaged in self-management activities or be provided with patient centred care if the health professionals treating them do not understand their expectations for, or perceptions of, recovery and prognosis. In this sense, self-management may seem inappropriate for those with low expectations for the future given the potential limited returns from making significant lifestyle changes.
The products of the study are a revised stage process theory of recovery and a model of recovery perceptions which includes two dimensions; responsibility and expectations along with a typology of recovery narratives based on these dimensions. Whilst these were ideal types of narratives and not intended to be prescriptive, it is envisaged that with further testing and exploration they may provide a way to better engage with, and meet the needs of, patients with chronic physical conditions.
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Appendices

Appendix 1: Literature search terms (including key words, databases searched and results)

Appendix 2: Timeline of research

Appendix 3: Information sheets for two larger projects that the current project sat within for phase 2 of the study

Appendix 4: Interview schedule for phase 2 (including participation schedule for interviews included in phase 1 of the study)

Appendix 5: Interview schedules for WSD project included in phase 1 of the study

Appendix 6: Consent forms for phase 2 of the study

Appendix 7: Follow-up interview schedule for phase 2

Appendix 8: Examples of initial coding categories arising during data analysis

Appendix 9: Example of field notes taking post interview

Appendix 10: Concept diagram for the code of adaption

Appendix 11: Example of baseline narrative emplotment

Appendix 12: Summary of differences between different social classes
Appendix 1: Search terms and databases

Sources included in OVID search:

- Your Journals@Ovid
- EBM Reviews - Cochrane Database of Systematic Reviews 2005 to August 2012
- Books@Ovid August 23, 2012
- EBM Reviews - ACP Journal Club 1991 to August 2012
- EBM Reviews - Database of Abstracts of Reviews of Effects 3rd Quarter 2012
- EBM Reviews - Cochrane Central Register of Controlled Trials August 2012
- EBM Reviews - Cochrane Methodology Register 3rd Quarter 2012
- EBM Reviews - Health Technology Assessment 3rd Quarter 2012
- EBM Reviews - NHS Economic Evaluation Database 3rd Quarter 2012
- AMED (Allied and Complementary Medicine) 1985 to August 2012
- ATLA Religion Database + ATLAS 1949 to May 2012
- CAB Abstracts 1973 to 2012 Week 33
- Econlit 1961 to July 2012
- GEOBASE 1994 to July 2012
- Global Health 1910 to July 2012
- Health and Psychosocial Instruments 1985 to July 2012
- HMIC Health Management Information Consortium 1979 to July 2012
- International Pharmaceutical Abstracts 1970 to August 2012
- Maternity and Infant Care 1971 to August 2012
- Ovid MEDLINE(R) 1946 to August Week 3 2012
- Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations August 28, 2012
For search results that contained large numbers of hits, the first 1000 were scanned and considered for inclusion. Exclusion criteria included those that focussed purely on clinical or biomedical recovery or those that focussed solely of recovery from substance abuse, addition of eating disorders (Leamy et al. 2011).
(1) Recovery and mental health search terms and articles generated

“recovery$” or “recover*” in web of knowledge.

Depress.mp

OR Exp mental disorders

OR psych.mp

OR anxiety.mp

OR exp social problems

OR exp emotions

OR mental health.mp

OR exp mental health services

(informed by Wilczynski & Haynes, 2006)

OVID and ISI Web of Science used first (date parameters 29th August 2012)

Ovid: 93007 *

Amended to specify search terms had to appear in the title: 1036

Web of knowledge: 270

Cochrane (all Cochrane products): 1470

CINAHL (recovery in title and mental health in all text): 1054

British Nursing Index (recovery in title and mental health in all text): 178
(2) Experience of illness search terms and articles generated

(a) Chronic illness

   OR Chronic condition

   OR Chronically ill

   OR Long-term illness

   OR Diab$ or Diab* in web of knowledge.

   OR Heart disease

   OR Cancer

   OR Hypertension

   OR High blood pressure

   OR Arthritis

   OR Musculoskeletal

   OR Asthma

   OR COPD

   OR Chronic obstructive pulmonary disorder

AND

Illness experience

OR Labelling

OR Disability

OR Adjustment

OR Stigma

OR Medicalisation

OR Biomedicalisation

OR Biography
OR Disruption

OR Narrative

OR Self-management

OR Self-care

OVID and ISI Web of Science used first (date parameters 29th August 2012)

Ovid: 268,609

LIMITED TO TITLE ONLY FIELD: 11,624

Web of knowledge: 441,207

LIMITED TO TITLE ONLY FIELD: 23,495

LIMITED TO ARTICLES IN ENGLISH: 14,764

(Observed a lot of biomedical papers so restricted to arts and humanities and social science articles): 3,074

Cochrane (all Cochrane products): 4453

LIMITED TO TITLE, ABSTRACT AND KEY WORDS: 243

CINAHL (recovery in title and mental health in all text): 18,213

LIMITED TO TITLE: 1712

British Nursing Index: 1674

LIMITED TO TITLE : 364
(3) *Recovery and chronic physical health conditions*

“recovery$” or “recover*” in web of knowledge.

AND

Chronic illness

- OR Chronic condition
- OR Chronically ill
- OR Long-term illness
- OR Diab$ or Diab* in web of knowledge.
- OR Heart disease
- OR Cancer
- OR Hypertension
- OR High blood pressure
- OR Arthritis
- OR Musculoskeletal
- OR Asthma
- OR COPD
- OR Chronic obstructive pulmonary disorder

OVID and ISI Web of Science used first (date parameters 29th August 2012)

Ovid: 114,481

Limited to key words in the title: 2,412

Web of knowledge: 163, 376

LIMITED TO TITLE ONLY FIELD: 2,018
(Observed a lot of biomedical papers so restricted to arts and humanities and social science articles): 237

Cochrane (all Cochrane products): 1337

Restricted to title, abstract and key words: 22

CINAHL: 340

British Nursing Index: 112
## Appendix 2: Research Timeline

<table>
<thead>
<tr>
<th>SCHEDULE</th>
<th>PLANNING</th>
<th>LITERATURE REVIEW</th>
<th>RECRUITMENT</th>
<th>DATA COLLECTION</th>
<th>REPORT WRITING</th>
<th>KEY OUTPUTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year 1</td>
<td></td>
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<tr>
<td>1/4</td>
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<td>• Brief Literature Review</td>
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<td>• Finalising aims and methodology</td>
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<td></td>
<td>• Commence recruitment</td>
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<td></td>
<td></td>
<td>• Commence data collection</td>
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<td>2/4</td>
<td>XXXX</td>
<td>XXXX</td>
<td>XXXX</td>
<td>XXXX</td>
<td></td>
<td>• 6 month progress meeting</td>
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<tr>
<td>3/4</td>
<td>XXXX</td>
<td>XXXX</td>
<td>XXXX</td>
<td>XXXX</td>
<td></td>
<td>• 9 month continuation planning meeting</td>
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<td>4/4</td>
<td>XXXX</td>
<td>XXXX</td>
<td>XXXX</td>
<td>XXXX</td>
<td>XXXX</td>
<td>• End of year report and VIVA</td>
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<td>Year 2</td>
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<td>1/4</td>
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<td>XXXX</td>
<td>XXXX</td>
<td>• 13 month planning meeting</td>
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<td>• End of year report and progress meeting</td>
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<td>Year 3</td>
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<td>1/4</td>
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<td>XXXX</td>
<td>• 30 month thesis meeting</td>
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<td>2/4</td>
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<td>Year 4</td>
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<td>XXXX</td>
<td>• Thesis submission and VIVA</td>
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<td>1/4</td>
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</table>
Appendix 3: Information sheets for two larger projects that the current project sat within (phase 2).

Understanding Networks of Care and Information Needs of People with Diabetes, Heart Disease and Kidney Disease

Patient Information Sheet

Dear Sir/ Madam,

You are being invited to take part in a research study. Please take time to read the following information to decide whether or not you wish to take part.

What is the aim of the research study?

The study is designed to see how the NHS can help support people with diabetes, heart disease and kidney disease to better manage their health. To do this, we need to ask you how you are managing and about what help you are getting from other people.

What would I be asked to do if I took part?

You will be asked to take part in two interviews; the second interview will be 12 months after the first interview. We will phone you to arrange to visit you at home or meet at a place that you choose, in order to talk about:

- What it is like to live with your condition and how you manage it.
- The information you need to help you manage your condition.
- The support you need to manage your condition, e.g. family, friends and the NHS.
We will record the interviews with a voice recorder. Only members of the research team will have access to this information. When we write about the results of the research, all personal details will be removed so that no-one will know who you are. No real names will be used.

When you contact us we will send you a questionnaire to fill out before the interview. However, if you prefer, a researcher can fill in the questionnaire with you when you meet.

We are also asking for your consent to ask your GP practice to give us information about test results related to your condition. This may include blood glucose levels, cholesterol levels and blood pressure readings. This data will be anonymised and stored securely in a way that cannot be linked to you.

Please note that if you decide to take part, you are free to withdraw at any time/stage without giving a reason. This will not affect the current care you receive.

**Will I be paid for participating in the research?**

Yes, you will be paid £15 for taking part in the first interview. You will be paid a further £5 for taking part in the second interview.

**What do I do now?**

If you decide you would like to take part in the study please use the reply slip to send us your contact details in the stamped addressed envelope provided. When you have done this a member of the research team will contact you by telephone.

If you have any further questions you would like to ask the research team, please contact us on free phone **0800 0270661**.

Many thanks for your help

The U-NET Research Team  
CLAHRC Patient Theme  
5th Floor Williamson Building  
The University of Manchester  
Oxford Road  
Manchester  
M13 9PL
We want to talk to you about how involved you feel you are in your own health care (or in keeping healthy)

Your views are important
Patient Information sheet

Taking part in health – an interview study of participation in health care.

You are being invited to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what it will involve. Please take time to read this information carefully and discuss it with friends, relatives and your GP if you wish. Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of this study?

Patients are being encouraged to be more involved in their health care. This is especially important in people who have long standing medical conditions. We want to know how involved you feel you already are in your health care and where things are good and where things could be made better.

Why have I been chosen?

Three doctors’ practices in Greater Manchester have been chosen. We are inviting people who regularly visit their GP or nurse to talk to us.

Do I have to take part and what if I change my mind?

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign and return the enclosed consent form. After deciding to take part you are still free to withdraw at any time and without giving a reason. This will not affect the care you receive from your doctor in any way.

What will happen during the study?

A researcher will contact you by telephone or post to arrange to meet and discuss your views and feelings about your experiences of being involved in your own health care. The researcher will come to your home to talk to you. You will be asked if the interview can be tape-recorded, but it is ok to say no. The interview will last about 45 minutes.

What are the possible disadvantages to taking part?

The only disadvantage is the time taken to talk to the researcher. You will not be expected to travel to meet the researcher, but if you do incur any expenses, they will be
reimbursed. If you decide not to take part at all then the care that you receive from your practice will not be affected in anyway.

**What are the possible benefits of taking part?**

Your views may help to change the way doctors involve patients like you in their own care in the future.

**What will happen to the information I give?**

All information that is collected about you during the course of the research will be kept strictly confidential. All information about you will have your name and address removed so that you cannot be recognised from it. This information will be kept securely at the University of Manchester for 5 years, and then will be destroyed.

**What will happen to the results of the research study?**

The results will be written up for publication in a research journal. They will also be presented at research meetings. You may have a copy of the results if you wish.

**Who is organising and funding the research?**

The study is being organised by the National Primary Care Research and Development Centre in the University of Manchester. The study is funded by the Research Councils UK. This study has been reviewed by senior researchers at the University and by a local Ethics Committee.

**What do I do now?**

If you want to take part in this study, please sign the enclosed consent form and return it in the reply-paid envelope.

If you have any questions about the study you can contact either Helen Cording or Dr Joanne Protheroe, on 0161 2757653. My address is NPCRDC, Williamson Building, University of Manchester, Oxford Road, Manchester, M13 9PL
Appendix 4: Interview schedule for phase 2.

Table of prompts: Taking part in health care.

Start with narrative about health; “can you tell me what has lead you to where you are now in terms of your health”. Then explore prognosis, where they see themselves in five years.

Extra prompts:

Pre-diagnosis – day to day life

Diagnosis – main impacts, probe relationship with doctor

Can you describe your health now – day to day life, main differences before diagnosis

Prognosis -

- Can you describe your ideal state of health for me?
- Where would they ideally like to be in 1 year/5 years? (physically, emotionally, social networks)
- How realistic do you think that is?
- Can self-management techniques contribute to that?
- What are the barriers/facilitators to this ideal state?

<table>
<thead>
<tr>
<th>Introductions</th>
<th>Was it your usual Dr/N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Which chronic disease register</td>
<td>do you mind telling me what it was about?</td>
</tr>
<tr>
<td>Sign consent for tape recorder</td>
<td>is that why you usually go?</td>
</tr>
<tr>
<td>Last time went to see Dr or nurse</td>
<td>why else – or for what else do you go to your health centre?</td>
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<tr>
<td></td>
<td>did that visit go well – why? If not, why not?</td>
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<tr>
<td></td>
<td>can you remember one that went less well? – why?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Coping with things on daily basis</th>
<th>What are the most important things you have to cope with in your life on a daily basis?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Probe: children/family including elderly parents, work, managing the shopping etc…</td>
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<tr>
<td></td>
<td>How often do you worry about your health….your family’s health?</td>
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<td></td>
<td>What’s important to you about your health?</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Discussing aspects of daily life with Dr/nurse</th>
<th>When you are with the doctor or nurse, do you ever discuss things about your daily life?</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Probe: what sorts of foods to eat, smoking, the job that you do…money or family worries</td>
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<tr>
<td>Different subjects with Dr and nurse?</td>
<td>Do you think these things should be talked about at the doctors?</td>
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<td>---------------------------------------------------------------</td>
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<tr>
<td></td>
<td>- Probe by whom – Dr /nurse?,</td>
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<td></td>
<td>- Are these issues important?</td>
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<td></td>
<td>- Is it the doctors /Ns business?</td>
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<td></td>
<td>What sorts of things generally can people take to the doctors?</td>
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<td></td>
<td>Is there anything that you personally would not want to talk about with the doctor? Why</td>
</tr>
<tr>
<td></td>
<td>Can you talk about different things with the nurse</td>
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<td></td>
<td>- Probe specific examples?</td>
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<td></td>
<td>Do you ever prepare what you might say/what you want to cover before going to see the doctor?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Feeling listened to and understood</th>
<th>What makes you feel as though the Dr/nurse is listening to you or understands you?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>- Probe: Does anything make you feel they don’t/ aren’t</td>
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<td></td>
<td>- Does your doctor understand your point of view? What makes you say that?</td>
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<td></td>
<td>Do you understand everything the doctor?</td>
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<td></td>
<td>- Probe: differences with nurse?</td>
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<tr>
<td></td>
<td>Do you believe everything the doctor says?</td>
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<td></td>
<td>- Probe: differences with nurse</td>
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<td></td>
<td>Do Ever agree in surgery but disagree later when think about is and not necessarily follow advice?</td>
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<td></td>
<td>- Probe: ever feel need to ‘bite tongue’ within the consultation?</td>
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<td></td>
<td>Do you ever offer your own ideas or solutions to problems?</td>
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<td></td>
<td>- Probe: Do you think that you could/should? Why? (what stops you?)</td>
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</tbody>
</table>

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<thead>
<tr>
<th>Continuity of care</th>
<th>Do you usually see the same doctor / nurse?</th>
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<tbody>
<tr>
<td></td>
<td>- Probe: does this matter? Why?</td>
</tr>
<tr>
<td></td>
<td>- Are there occasions you choose to see a Dr/n you don’t normally see? Why?</td>
</tr>
</tbody>
</table>

<p>| Talking to health professionals | Do you feel that you behave differently when in with the doctor than if you were explaining to a friend how you feel and what you feel is wrong with you? Why? |</p>
<table>
<thead>
<tr>
<th>Decision making</th>
<th>Information sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you expect your opinions about your illness/your problems to be taken into</td>
<td>Who do you receive information from?</td>
</tr>
<tr>
<td>account?</td>
<td>• Probe: should they? About all things?</td>
</tr>
<tr>
<td>• Probe: should they? About all things?</td>
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<tr>
<td>Do you feel able to question your doctor?</td>
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<tr>
<td>Feel able to disagree with him/her?</td>
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</tr>
<tr>
<td>Decision making</td>
<td></td>
</tr>
<tr>
<td>Can you think of a specific recent decision that was made in relation to your</td>
<td>Who do you receive information from?</td>
</tr>
<tr>
<td>health care (e.g. being referred to a consultant, trying a new treatment). Who</td>
<td>• Probe: newspapers, internet, blogs, etc</td>
</tr>
<tr>
<td>made the decisions about treatment / management?</td>
<td>• If not – why not?</td>
</tr>
<tr>
<td>• Probe: how involved did you feel?</td>
<td>• Probe general reading of newspapers books etc.</td>
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<tr>
<td>• Probe: did you feel able to have your say?</td>
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<td>• How confident did you feel to get your view across and make things happen in</td>
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<td>relation to chronic illness management (e.g. of with what with whom?)?</td>
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<td>Do you discuss your health with anyone else?</td>
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<tr>
<td>• Probe: family, friends</td>
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<tr>
<td>Information sources</td>
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<tr>
<td>(also gentle enquiries regarding reading books/papers for pleasure and/or</td>
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<tr>
<td>information)</td>
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<tr>
<td>Information from health professionals</td>
<td></td>
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<tr>
<td>Do you get info from the GP surgery?</td>
<td></td>
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<tr>
<td>• Probe: what sort – from where/who?</td>
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<tr>
<td>Can you think of an example of information you have received from the Dr – then</td>
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<tr>
<td>nurse</td>
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<tr>
<td>• What information did you get – what sort – illness/management/treatment</td>
<td></td>
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<tr>
<td>• Probe: did you understand it?</td>
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<tr>
<td>Is there any difference in the types of information you receive from the</td>
<td></td>
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<tr>
<td>practice nurse / GP / other?</td>
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<tr>
<td>Format of information</td>
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<tr>
<td>What sort of information do you prefer?</td>
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<tr>
<td>• Probe: leaflets, websites, face to face etc</td>
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<tr>
<td>• Do you prefer asking questions; prefer to receive written info/ magazine/</td>
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<td>audio/visual</td>
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<tr>
<td>Can you think of an Information leaflet you have received recently?</td>
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<tr>
<td>- what was it about</td>
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<td>- were you given it – or did you pick it up?</td>
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<tr>
<td>- if given – how – some discussion?</td>
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<tr>
<td>- if picked up – where from?</td>
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<tr>
<td>- what was it like?</td>
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<tr>
<td>- Do you ever feel that the language used is tricky? Who?</td>
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<td>What about information given with tablets from the chemist?</td>
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<tr>
<td>Can it be difficult to understand?</td>
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<tr>
<td>Do you ever need help reading information or filling in forms from doctors,</td>
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<tr>
<td>nurses or hospitals?</td>
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</tbody>
</table>
| Amount of information | Would you like to receive more information?  
**Probe:** what about? Illness you have now, preventing illness, looking after yourself, treatment, benefits....?  
Why not? Too busy/ more important things/  
Is it up to people to find out this information – or should it be provided / given to every one? |
| Current problems/ concerns with health | Thinking now about your [ chronic (diabetes/resps symps etc) ]...what troubles you the most – have you ever had opportunity to tell Dr/nurse about this?  
Does he/she know how important this is to you? Should they?  
Have you been trying, with your doctor, to get this better?  
Is this by using treatments or things that you do for yourself? |
| Management plan | Do you feel that there is a plan of action for looking after your (diabetes / respiratory illness / coronary disease)?  
Do you know what it is?  
Do you understand when Dr/nurse explains things about your treatment?  
For e.g. [condition specific] diabetes – about your blood sugar; CVD – blood pressure or resp disease – inhalers – or any relevant treatment patient mentions.  
How successful do you feel your treatment plan is?  
How would you like to see it improve? |
| Self-management | Are you managing your condition well yourself?  
Are there some parts of your condition that you can look after yourself?  
**Probe:** What are they? What do you do?  
Do you think other people always do this? Any examples.  
What do you think is right for people who have (diabetes/ bad chests / heart problems...) to go to the doctors about – and what do you think people could do themselves?  
Do you feel that you know when to contact the Dr or nurse about your condition?  
If yes – when and in what circumstances  
If no – would you find that sort of information helpful?  
How successful do you perceive your self-management to be?  
Why?  
How could it improve?  
To what extent do you think that your contact with hospital and GP recently for your long term condition has been focused on involving you in your care? |
<p>|  | Do you feel that current health care is fair – do you get your ‘fair share’ of health opportunities? |</p>
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<th>Do you think that people with more money are more healthy?</th>
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<td>Are you involved with others with similar conditions in a group</td>
<td>Are you involved in policy or politics about long term</td>
</tr>
<tr>
<td>of voluntary organisation?</td>
<td>conditions locally or nationally etc?</td>
</tr>
<tr>
<td>Are you involved in policy or politics about long term conditions</td>
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<td>locally or nationally etc?</td>
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**Explore potential for follow-up interviews and interviews with other stakeholders e.g. friends and family.**
Appendix 5: Interview schedules for the additional WSD transcripts included in phase 1 of the study.

Whole System Demonstrator Evaluation Study: service user and carer perspectives.

History of health problems and existing management

- How would you describe your current health?
- Can you tell me about any health problems you have?
- What is the worst problem you have?
- How long have you had this condition(s) for?
- To what extent does your condition interfere with your day-to-day life and what types of changes have you needed to make to adjust to living with a long-term condition?
- What do you do to look after yourself and manage your health problems? – Has this always been the case? Have you had different ways of managing and changed this over time? If so in what ways? Have there been any significant turning points when you have felt your condition has become much worse or much improved?
- What resources do you use other than the health service for managing? What is most important to you in terms of support or help with your long term condition?

Informal support

- Do receive help from relatives or friends to manage on a day-to-day basis due to your health problems?
- Who helps you?
- What do they do to help?
- How often?
- Are you involved in any activities/ clubs or organisations outside your home that you find helpful or supportive?
- Do you get any help from friends or neighbours?

Previous and current use of health and social services and interactions with professionals

- Can you tell us about your previous experiences of using health services?
- Can you tell us about previous admissions to hospital over the last couple of years and the circumstances that led to these? Which professionals have been involved most in providing care for your existing health problems?
- How long ago did you start consulting and being treated by them?
- How often have you been seeing them up to now?
- Has this been sufficient? – too little or too much?
- Have you been satisfied with advice and/or treatment you have received?
- Have you had previous experience of consulting social services professionals in relation to your health and social care needs?
• Has this been helpful? – in what way?
• Do you think health and social services professionals have worked together in meeting your needs? – in what ways?
• What kinds of things are most important to you when you consult health and social care professionals about your care?
• Do you feel that your views about your health and social needs are taken on board in decisions made about your treatment and care?

Previous and current use of technologies and devices to assist in managing condition

• Have you ever used the internet to find information or support in relation to your health problems? – has this been helpful? If not, why not? What are most valuable sources of information and support to you?
• Have you used any devices to help in managing your health problems prior to the start of this study? – e.g. blood pressure monitor, glucose monitor, care alarm, or even low tech devices such as mobility aids? – how have you found using such devices?

Views about telecare (TC) and telehealth (TH)

• Did you know about these technologies before the study?
• What would describe as the purpose of these technologies?
• Do you think you can benefit from this kind of technology?
• If respondent has turned down offer of TC or TH ask why they did not want to receive this sort of technology as part of their care?
• For those waiting to receive TH or TC kit, ask how they think it might affect the management of their health problems? Or, if they have just received it, ask about their first impressions of the kit, ease of use etc.

Follow-up interviews for those who have received telehealth or telecare kit

Using the device

• How have you found using the device for these first few months?
• Did you have any difficulties using the device in the beginning?
• Have your views about the device changed since the previous interview? – what has changed your mind?
• Do you think it works for the purpose intended? - have you made any changes to the device? – have you used it for any other purposes, or has anyone else used it?

Impact on relationships and provision of informal and formal care

• Do you think TC or TH kit has changed any relationships with your friends or relatives who help you at home? – in what ways?
Do you think it has changed the relationship you have with health and social care professionals? – in what ways?
Do you think it has changed the relationship between health and social care professionals involved in your care? – in what ways?
Do you think it has changed the management of your condition and delivery of care by professionals? – in what ways?
How have professionals responded to any abnormal results/ readings or emergencies detected by the TC/TH kit?
Has it changed the amount of contact you have with health services?

Integration of kit within everyday life

- How well do you think the kit fits into your everyday life? – has it changed anything that you usually do?
- How much time do you spend using it?
- Where do you keep it?
- Are you aware of it, even when you are not using it?

Impact on managing condition

- Before using the device, how much in control of your condition do you think you were? – has this changed?
- Have you made any changes to the way you manage your condition? – how? – what?
- Do you monitor your condition/ health problems more now than before the study?
- Has the TC/TH changed the way in which you think about your condition?
- How do you feel if you have an abnormal result/ reading?
- Have you experienced any emergencies detected by the kit? - how did that make you feel?
- Has it changed the level of confidence you have to manage your condition?

Views about long-term and future access

- Is TC or TH something you see yourself needing for the rest of your life?
- Having had experience of using the kit, who else do you think would benefit from using TC/TH?
Appendix 6: Consent forms for phase 2 of the study.

Understanding Networks of Care and Information Needs of People with Diabetes, Heart Disease and Kidney Disease

Please initial box

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<tr>
<td>1.</td>
<td>I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.</td>
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<tr>
<td>2.</td>
<td>I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.</td>
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<td>3.</td>
<td>I agree to take part in the above study.</td>
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<td>4.</td>
<td>I agree that the interview will be voice recorded.</td>
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<td>5.</td>
<td>I understand that when this research is completed the audio file will be retained and securely archived for a period of 10 years. This archive can only be accessed by request from the research team and all files will be destroyed at the end of that period</td>
</tr>
<tr>
<td>6.</td>
<td>I understand that some quotes from interviews may be used in publications but my name and personal details will not be used in these publications and all information will be anonymised.</td>
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<tr>
<td>7.</td>
<td>I agree for my GP practice to give the research team information about test results related to my condition.</td>
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<tr>
<th>Name of Participant</th>
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TAKING PART IN HEALTH CARE

CONSENT FORM

1. I have read and understood the information sheet for the above study and have had the chance to ask questions.

☐

2. I understand that taking part is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

☐

3. I understand that everything I say, all information I give will remain strictly confidential.

☐

4. I give permission for my address and phone number to be passed on to the researcher.

☐

5. I agree to take part in the above study.

☐

___________________   ___________________   ____________
Name of patient       Signature       Date

Please provide a contact number so a suitable time and date for the interview can be arranged:

Phone number: ______________________

___________________   ___________________   ____________
Name of researcher    Signature       Date
Appendix 7: Follow-up interview schedule for phase 2.

Follow-up interview schedule

Show and briefly explain the narrative emplotment, record any comments, amendments and major events over the last 12 months.

Explore any individual issues that arose from the baseline interview.

Briefly summarise their 12 month goals set at the baseline interview.

- Have they achieved what they wanted to?
  - If so, what/who helped.
  - If so, what/who hindered.
  - If not, what has stopped them.

What gives them the most difficulty now and how has this changed over the last 12 months.

What would their ideal health state be in 12 months time.

- Do you they have any longer term goals?

What are their main worries about their health.

What does the word recovery mean to them?

- How does this relate to their chronic health condition?

Explain briefly the notion of recovery from the mental health literature and explore its use in chronic disease management.

- Whose responsibility would this be?
- Who could help/hinder with this.
- Do they have any opinions on recent NHS/Government/Policy changes?
  - How does/could this impact on healthcare?
  - How does/could this impact on their health?
  - How does this impact on their priorities over the next 12 months.
Appendix 8: Example of initial coding categories arising during data analysis.

Acceptance
Adaption - early
Adaption – later
Ageing
All encompassing health problems
Awareness
Barriers to recovery
Blame/contingent narratives
Burden
Changing/critical points
Co-morbidity
Confidence
Continuity
Continuity and recovery
Deferring to doctor in certain situations crisis
Degenerative narratives
Diagnosis as a positive thing (e.g. impact in life)
Direct reference to recovery
Distrust of Health Professionals
Doing things for others
Engagement/participation
Environment/place
Erratic medical symptoms can decrease self management
Expectation
Expectations and other people’s experiences
Expectations of health service
Feeling anxious questioning the doctor
Fighting against all encompassing illness
Financial concerns
Frustration
General recovery
Generational differences
Guilt
Habit
Health professionals dismissive of recovery goals
Health professionals imposing expectations
Helping others
Hopes for future
Humour
Identity
Impact
Impact of past experience
Impact of children
Independence
Individual responsibility for recovery
Individualisation
Information
Initial biographical disruption
Interaction not geared around recovery focused on treatable condition
Interaction with health professional
Isolation
Justification
Lack of holistic treatment
Lack of ownership
Lack of personal responsibility
Lay descriptions of health
Lifestyle
Looking for confirmation
Medicalisation
Medication
Mental health
Metaphor
Narrative
Negative aspect of not listening to medical advice
Negative illness trajectory
Normalisation
Not being believed
Not sharing recovery goals
Only focusing on negative elements of health
Other priorities
Participation
Paternalism
Patient as an expert of their own body
Perception of being ill not being yourself
Perception of health service
Perception of other peoples experiences
Perception of illness
Perception of wellness
Personal responsibility
Political views
Poor health can degenerative narratives can impinge on wider aspects of life
Power of experiential learning
Pressure
Prognosis
Prognosis and fear
Prognosis and health professionals
Recovery
Recovery and blame
Recovery and co morbidity
Recovery and expectations
Recovery and fate
Recovery and home life world
Recovery and impact of treatment
Recovery and information
Recovery and medicalisation
Recovery and other people
Recovery and personal responsibility
Recovery and private health care
Recovery and realism
Recovery goals - individual
Relationship with health professional
Resignation
Restitution narrative
Routinisation
Self management and advice and lecturing
Self management and collusion with medical professionals
Self management and recovery
Self management and tick box exercises
Smoking
Social comparison
Social distancing from others
Social distancing from smokers
Social support
Societal changes
Stigma
Stoicism
Struggle
Rationality – summing and weighing up pros and cons of decisions
Symptoms likening to being drunk
Technology
Lay understanding
Use of health services
Visibility and self management
Visibility of condition
Wastage in the system
Weighing up pros and cons and making decisions
Work
Worry
Appendix 9: Example of field notes taken post interview.

Example of field notes from ID4

Baseline interview: 15.3.2010

ID4 was a 78 year old female diabetic who had retired from work. She was widowed and had lost her husband after nursing him through a long illness. Her house was five minutes or so out of the centre of Wilmslow and off a main road. Her house was situated on a country lane and it was initially difficult to find. She had no immediate neighbours as the house was detached and there was a substantial distance to the neighbouring properties. I tried a number of times to knock on the front door after navigating through a complex gating system but there was no response. I walked around the back and found an alternative door which she answered. She said she never used the front door and couldn’t hear if anybody knocked there. She seemed unconcerned if that meant she missed any callers. I was greeted by herself and a large dog. We sat in an airy conservatory and had a cup of tea prior to starting the interview. After initially being reluctant, she seemed keen to talk and I got the initial impression she was quite lonely. It appeared she seemed concerned that what she said would not be of value to me. Once she got talking, the told a number of stories and it appeared these were related to her identity (e.g. nursing stories).

She lived alone in a large house with a lot of land. She had a number of animals; dogs, horses, and ponies and seemed to get a lot of support from them. She called her dog her ‘life support’ and it was present throughout the interview. It was clear from the rapport between them how close they were.

In terms of her current health, she had had an arduous 12 months with a lumpectomy for breast cancer, radical mastectomy, two leg ulcers, a minor stroke and labyrinthitis. She had also found a lump on her dog and was going through the process of getting this examined by the vet. More widely she was having some financial issues with recent large gas and electric bills. Prior to this she had also previously had colon cancer. It seemed that her illness trajectory had been quite degenerative and that this had had a strong impact on her, particularly on how she felt about herself and this was exacerbated by the lack of support around her.
Her husband died some years ago from cancer and she said she had no friends or family. Apart from the animals, I felt that she was quite isolated. During the interview she appeared very down and was concerned about the future of her heath with the impending follow-up appointments for breast cancer and colon cancer.

As an ex-nurse she had a great understanding of the NHS and has seen it change over the years. When the tape recorder stopped she told me that she felt that there was no discipline in the nurse training anymore which resulted in a perceived lack of professionalism in the nursing sector at present. Despite not thinking that what she said was interesting or useful to me she said she would be happy if I contacted her again in six months. As she reported having no friends or family I decided against asking about interviewing anyone else in her social network.

When she talked about feeling depressed and down, I did ask whether she was going to seek help for this and she said that she had made an appointment to see her GP about it that morning. She expressed some stoicness in that she wanted to make it clear that this wasn’t something that she would normally do and that it was only that she felt at her wits end that she was going to see the doctor. She appeared to see herself as very independent and able to cope on her own. Thus viewing herself as someone who needed to rely on others for help and support was not something that she viewed positively.

*Follow-up interview: 12 months later.*

ID4 appeared much happier than when I saw her 12 months ago. Little had changed about the house, surrounding areas, or living arrangements.

She still had strong feelings about the NHS and the problems within it which she was keen to talk about. She had recently had two falls in the snow which had necessitated two trips to casualty and she felt there were some serious flaws within the system of the Accident and Emergency Department she visited. Obviously her prior role as a nurse formed a large part of current identity which indicates the pervasiveness of it. This was less clear at the baseline interview when the prevailing feelings I came away with were loneliness, isolation and depression. She appeared much more engaged and active within her discussions about the interactions she had with health professions compared with this time twelve months ago when she seemed much more passive. She had questioned the nurses within casualty about the treatment or lack of treatment she had received and had also actively sought physiotherapy for another condition. It became
apparent early on in the interview that the doctor’s appointment she had made the day I interviewed her last time had gone well. The GP had put her on anti-depressants which she felt have worked well. She also said that she wasn’t as anxious asking the GP for help because she knew her through her work at a local hospice. She felt in this respect that the GP would trust that her need to see her was valid and that she wasn’t just a time waster. This validity seemed to support the view that she was an independent person who would only seek support from others if entirely necessary. She had also resolved the outstanding issues with the gas, electric and phone bills.

In terms of the recovery goals she set at the baseline interview (which related specifically to tiredness and the general ‘down’ feeling) she felt that she had achieved these and this appeared to have a positive impact on her well being. She said she felt back to ‘normal’ whilst acknowledging that this ‘normal’ wasn’t a pre-illness ‘normal. It appeared this related more to coping with her everyday tasks despite the illnesses she suffered with. She had also joined a local bridge club which addressed some of the aforementioned issues I raised at baseline in relation to isolation.

When asked about her hopes for the future, these related to maintenance of the current level of functioning. She felt that the responsibility for achieving these rested solely with her and that she wouldn’t like the opportunity to talk to anybody about these. It appeared this was closely related to her identity as an independent person and not wanting to ask others for help.
Appendix 10: Concept map for the code of adaption.

- Expectations of health service
- Prognosis and uncertainty
- Identity
- Impact of past experience
- Social comparison
- Negative illness trajectory
- Acceptance
- Relationship with medical professional and health services
- Perception of health service
- Perception of wellness/illness
- Relationship to self management
- Habit
- Experience of others
- Health professionals imposing own expectations and attributions
- Ageing (normal experience versus disruption)
- Social patterning
Appendix 11: Example of baseline narrative emplotment (ID11).

**Context**
 Moved back from Spain

**Symptoms**
 Shortness of breath and chest
 Heart Attack
 Unstable angina
 Bypass Operation
 Shortness of breath and chest
 Unstable angina
 Angiogram

**Diagnosis**
 Heart Attack
 Unstable angina
 Angiogram
 Stroke
 Wife diagnosed with cancer
 Broken Hip

**Operations**
 Moved nearer family
 Nine years stable functioning

**Self-perceiving functioning**

Key to diagram
Appendix 12: Summary table of differences between social classes

- Perception amongst those with higher SES that they have greater capital than those from lower SES. This impacts on dialogue with health professionals and understanding of medical information and test results.
- This increased capital also leads to better lifestyle choices amongst those from higher SES areas. The increased capital is also seen to make it easier to gain further capital.
- Those from lower SES areas do not accept these assertions and focus instead on individual responsibility rather than structural factors.
- However, both groups agree that economic capital can make a difference in relation to health (e.g. in enabling those with more capital to buy private treatment when required to speed up or enhance treatment and enabling them to buy higher quality food and more healthy food).
- Those with lower SES tend to have more fatalistic views in relation to the development in health conditions and even the aforementioned increased economic capital cannot ward off health problems entirely.
- Those from higher SES areas tend to view access to and equal dialogue with health professionals as a right not a privilege and generally find this easier to do.
- Those from lower SES areas are more concerned with wasting the limited resources of health services which can deter them from accessing treatment.
- Different groups take moral value from different behaviours (that constitute a ‘good patient’). Higher SES take value from being active participants in the health process whereas those with lower SES utilise more negative strategies by minimising the use of health services to protect resources.
- The sense of a being a burden on others (including health services) is more pronounced amongst those with lower SES.
- An individual's ‘sense of self’ appears more related to physical capital amongst those with lower SES. This could increase the negative impact of ageing for these participants.
- Those from higher SES appear to have a greater repertoire of different types of capital (symbolic, cultural and physical) and narrative resources available to them than those from lower SES.
- The ambition inherent within recovery hopes and expectation was generally greater amongst those from higher SES groups.
- The impact of continuity on both groups was different. Those from higher SES groups valued continuity and found it easy to shape consultations with HPS and preferred to see health professionals who ‘knew them well’. However, whilst those from lower SES groups also appeared to value continuity but found it more difficult to challenge the status quo within longstanding relationships.
- Lower SES participants displayed more paternalism and power differentials in their relationships with health professionals.
- Higher SES participants recognised the limitations of individual health professionals and actively sought out second opinions or additional health information more often than those from lower SES groups.
- Generally responsibility and expectations were higher amongst those with higher SES.