Older People and their Carers' Perspectives of Causes and Risk Factors to Hospital Readmissions.

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PhD.

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Declaration.

No part of the work referred to in the thesis has been submitted in respect of an application for another degree or qualification of this or any other University or other institute of learning. The study was designed and data was collected and analysed by the author under the supervision of Dr Andrew Sixsmith, Late Dr Andrea Litva, Dr Paula Byrne of the Department of Primary care and Dr Ciara Kieran, of the Department of Public Health, University of Liverpool. The study gained ethical approval from National Health Service Research Ethics Committee and from Halton and St Helen's Primary Care Trust Research Ethics Committee.

Notes on Copyright.

Abstract

Title; Older People and their Carers' Perspectives of Causes and Risk Factors to Hospital Readmissions. By Mrs Roseline Henry- Nweye.

Background; Emergency readmission to hospital is one of the greatest pressures on the National Health Service and research shows that 40% are avoidable (Department of Health 2000; Nikolaus et al 1992, ONS 2002;). Hospital readmissions have generally been researched form a quantitative approach and perceived as unavoidable or avoidable. For example, evidence suggests that unavoidable readmissions are caused by relapse of chronic disease, the changes in family life and the effect of limitation of primary care services, (Bound et al 2002; Dobrzanska & Newell, 2006) while the avoidable readmissions are due to non-involvement in carers, unresolved health problems on discharge, lack of support in the homes, and poor communication across sectors of health care (Buell 2008, Gravelle et al 2007,). However, there is a lack of research on older people and their carers perceived reasons for readmissions.

Aim; The overall purpose of this study was to explore individual older person and their carers' perceptions of hospital readmissions, with the goal of providing evidence for the development of safe and effective intervention strategies to decrease costly hospital readmissions for older patients in the United Kingdom.

Methodology; Qualitative method, with a descriptive phenomenological approach was used as the research design. The setting for the study was in the community where in-depth interviews with older people and their main carers were conducted and used as to access and explore their experiences regarding health and social care services at home after initial hospital discharge.

Analysis; The purposive sample consisted of 30 in-depth interviews with nineteen older people who had been discharged from hospital and eleven of their carers. The older people are 65years and over, all lived within Liverpool, Halton and St Helen's Primary Care Trusts in the North West of England in the United Kingdom. Interviews were audio-recorded and transcribed, and were analysed thematically.

Results; Participants reported a preference for care to be delivered to them in their homes. The problems identified are lack of empowerment and involvement in care suggesting a need for additional individualised support at home. Additionally, inadequacy of care provision, overburden and lack of supports to informal carers' is also highlighted. The resultant effect is that older people were making hurried, life-changing decisions to move into sheltered accommodation, residential or nursing homes.

Discussion; In order to control hospital readmissions, the author recommends that those in charge of policy-making for continuing care of older people in the community should direct health practitioners to provide individualised support to older people after discharge from hospital. Some recommended services could include health risk assessment, routine health screening which includes nutrition screening and counselling, health promotion programs, home injury control services, depression and mental health screening and medication management and counselling. The study revealed that care at home is possible with support from family members/friends, with the implication that those without families should be considered for care elsewhere.

Key words: old people, elder people, older people, seniors, geriatric, Hospital readmission, unplanned readmission, readmissions, systematic literature review, home care, hospital discharge to community, community rehabilitation, hospital to home.

Chapter One: Historical transition and policy context.

1.1 Introduction

Emergency admission to hospital is one of the greatest pressures on the National Health Service (NHS). People over sixty-five occupy almost two thirds of acute hospital beds, and majority of them have chronic diseases (Department of Health 2000). Chronic disease represents a significant challenge for the NHS as it means that those hospitals that have a complex case mix of chronic conditions will treat patients who require more hospital resources, and both the hospital and the patients will experience greater treatment difficulty. However, good chronic disease management offers opportunities for improvement in patients' care and the quality of the service they receive could also reduce cost and the demand for beds (Department of Health 2004). In Britain, six out of ten adults are reported as having long-term conditions that cannot currently be cured. People with long-term illnesses often suffer from more than one condition making their care even more complex (Department of Health 2004) and a good number of individuals who fall within this category experience frequent hospital readmissions (Department of Health 2004)

For the purpose of this thesis, index hospitalisation or index admission is the first admission of an older person at any point in the three months before readmission irrespective of whether the cause of the readmission was related to the cause of index admission. Readmission is thus a situation where an older person has to be readmitted into hospital following an index admission within the last 3months. The choice of three months is because most of the older people have co-morbid conditions such as malignancies, chronic liver or kidney diseases etc that do, sometimes, return them to hospital. Through the exploration of the factors leading to readmission, older people and their carers are able to identify whether their readmissions were planned by the hospital as a course of their disease management or if it was unplanned. For the purposes of this thesis, an 'older person' is defined by the state pension age of 65years. However the UK is phasing out the Default Retirement Age and the Coalition government has confirmed that from 1 October 2011 there will no longer be a default retirement age (DRA) of 65. Draft Regulations were laid before Parliament in February, 2011 but after much criticism over how they should be interpreted; a revised draft of those Regulations has been reproduced. An employer would have to rely on the grounds of capability or conduct or some other substantial reason to dismiss an employee fairly if he felt that the employee's age rendered him unfit to continue his job (Reed Smith 2011). All the participants in this study were aged 65years and above. Older people are often admitted for acute hospital care, for example; in the United States, the over 65s account for 36% of hospital admissions and almost 50% of hospital expenditure (Landfeld 2003). However some carers to the older people are also aged older person if they are more than 65years.

1.2 Statement of problem

Readmission to hospital and in particular, the experience of multiple hospital admissions by individuals is an important contributor to the overall use of hospital beds. Research shows that one hundred and forty-nine older people experienced unplanned readmission within one month of discharge from hospital (Harrop and Joppling 2009). This shows a twenty-seven percent increase in the number of older people being readmitted within one month between 1998/1999 and 2006/2007 in the UK. Although, it is not clear how much was readmitted as a result of increased frailty or from poor standard of care. However, it is a clear indication that readmission within 28days of hospital discharge is still a problem in the UK. Previously, research based on an analysis of Parliamentary questions showed that the number of people who are discharged and readmitted into hospital within 28days had risen from 26,523 in the period between October/December 1999 to 31,427 in October/December 2001, It is estimated that people aged 65 years and over make up about one-third of all UK hospital admissions, and two-thirds of hospital bed days (Department of Health 2000; ONS 2002). Older people in a survey accounted for half of the recent growth in emergency admissions to hospitals (CHAI 2006). However the rate of emergency readmission after 28 days of acute hospital discharge in the United Kingdom in 2002-2003 varied between 5% and 11% (Health Care Commission; 2004). By 2004, the numbers rose to 2,327 (ISD Scotland 2003; Scottish Health Statistics, 2006). Most of the increase was accounted for by fewer than 5,000 patients aged over 80, with three or more emergency admissions in a year (NHS National Service Scotland 2006).

The long history of the north-south divide in the regions of England in health and economics is well documented. The persistent north-south divide in health in England has posed a public health challenge, as well as a political and economic challenge to successive governments. The main implication is that they point towards a severe, long term, and worsening structural health problem in the geography of England (Baker and Billinge 2004, Department of Health 2008). A study in the Greater Manchester area showed that deprivation indeed exerted significant effect on the risk of emergency readmissions (Lyratzopoulos et al, 2005)

Table 1. Showing males and females life expectancy in different regions of England.

English government office regions	Life expectancy (years) at birth, 2006-8 (95% CI)		SMR, 2006-8 (95% CI)	
	Males	Females	Males	Females
North East	76.5 (76.3- 76.6)	80.6 (80.5 - 80.7)	113.3 (114.4- 112.2)	112.6 (111.5- 113.7)
North West	76.3 (76.2 to 76.4)	80.6 (80.5 - 80.7)	113.1 (112.4- 113.8)	111.9 (111.2- 112.6)
Yorkshire and Humber	77.1 (77.0 - 77.2)	81.3 (81.2 - 81.4)	106.2 (105.4- 107.0)	105.8 (105.1- 106.5)
East Midlands	77.8 (77.7 - 77.9)	81.8 (81.7 -81.9)	101.4 (100.6- 102.2)	102.1 (101.3- 102.9)
West Midlands	77.2 (77.1 -77.3)	81.6 (81.5 - 81.7)	105.8 (105.1 to 106.6)	102.8 (102.1 to 103.5)
East	78.9 (78.9 to 79.0)	82.8 (82.7 - 82.8)	93.3 (92.6 to 94.0)	95.5 (94.8 to 96.2)
London	78.2 (78.1 to 78.3)	82.7 (82.6 - 82.8)	96.4 (95.7 to 97.1)	93.5 (92.8 to 94.2)
South East	79.2 (79.1 - 79.3)	83.0 (82.9 - 83.0)	91.1 (90.6 to 91.7)	93.6 (93.1 to 94.1)
South West	79.0 (78.9 - 79.1)	83.1 (83.0 - 83.2)	92.1 (91.4 to 92.8)	92.4 (91.8 to 93.0)
All England	77.9 (77.9 -78.0)	82.0 (82.0 - 82.1)	100.0 (99.8 to 100.2)	100.0 (99.8 to

Source; Life expectancy at birth and all age standardised mortality ratios (SMRs) by English government office region, 2006-8, according to Office for National Statistics

Table 1 gives statistics on mortality and life expectancy at birth for the nine government office regions in England. Each southern region has significantly better mortality and life expectancy at birth than the average for England, and each northern region has values that are significantly worse than the average for England. The values for the southern regions are similar, especially among females. Even males in London, with less favourable statistics than for men in other southern regions, and are still much better off than their northern counterparts. The five northern regions show some longitudinal variation and roughly divide into two groups—namely, East Midlands and West Midlands, and Yorkshire and Humber, and the North West and North East: the former group have similar values, which are much worse than those of the southern government office regions but not as extreme as those of the North West and North East.

Table 2 Parameter Estimates of Regional Effects, Effect Estimate P-values Regional Codes for COPD.

Regions	Parameter Estimates	p.values	Regional codes
North East	0.3788	.<.0001	1
North West	0.3431	<.0001	2
Yorkshire and The Humber	0.4960	<.0001	3
East Midlands	0.1466	<.0001 4	4
West Midlands	0.0548	0.0003	5
East of England	0.0191	0.2384	6
London	0.0300	0.1181	7
South East Coast .	01612	<.0001	8
South Central	-0.0046	0.8022	9

Source; Adeyemi, et al (2009). The analyses of individual patient pathways: investigating regional variation in COPD readmissions. Health and Social Care Modelling Group, Department of Information Systems and Computing. University of Westminster, London W1W 6UW, United Kingdom

Regional variation for those treated for chronic obstructive pulmonary disease (COPD) has been studied amongst many public health issues. Data on COPD patients were extracted from the national (England) hospital episodes statistics (HES) dataset. Individual patient pathways from initial admission through to more than four readmissions are captured. Here, patients are classified into the low risk of readmission group (LRRG) and the high risk of readmission group (HRRG). Significant regional differences were found in each readmission and classification groups (HRRG or LRRG). For example, COPD patients from the North West of England were found to be 16% more likely to experience multiple readmissions than Yorkshire and The Humber region. The results are based on using South West of England as a baseline, and show that South Central of England is significantly (statistical) better off in terms of COPD multiple readmissions than all the other regions, as shown in the Table of log odds. However, the difference between these two regions is statistically insignificant. East of England and London are not statistically different from the South West.

So, generally there is considerable variation in hospital readmission between regions in the United Kingdom and it was claimed that one of the area affected in the country was North West of England, with an increase of 79% from 3,323 to 5,419 in 2 years (Burstow 2002), which also warrants this research. It was also observed that bed use by patients with multiple hospital admissions accounts for a significant proportion of the total cost (Burstow 2002, Goodacre et al 2003; Health Care Commission, 2004;).

Since this research was identified from clinical practice, the author observed in the course of her practice, in the North West of England (2006-2010), that residents who had to leave their homes for readmissions, and who had to come into residential homes for intermediate care (rehabilitation unit), typically, did not receive other appropriate form of care and so tended to deteriorate, particularly where they lacked personal care or support. In addition, most of the patients in home care after intermediate care had to return to accident and emergency shortly after hospital discharge and, in turn, into intermediate care leading to a further round of intermediate care before they could be judge fit to return home. These observations suggested to the author that hospital readmission remains a problem.

It is claimed that a significant number of readmissions are avoidable and potentially preventable with its occurrence distressing to older people (Halfon et al 2006). For example, William and Fritton (1988), in their study claimed that fifty-nine percent of readmissions were thought to be avoidable, while Nikolaus et al (1992) estimated that more than 40% of early readmissions were avoidable. Research shows that readmission studies results in improvement in hospital and home care and it could result in reduction in readmissions and in medical and social care cost (Ashton and Clark 1990; Pittsburgh Business Group on Health 1989; Wray 1996).

The rationale behind this thesis was to examine the reasons for the 'revolving door culture' in the NHS that has put such huge pressure on Accident and Emergency departments. A key aim was to consider how information and findings from the thesis may ultimately help in future service provision for older people. Specifically, to help older people remain in their homes by finding out from patients and their relatives or carers, all of whom live in the Merseyside Region of the North West of England, why they felt they had been readmitted to hospital and what could have been done to prevent it. The benefit of patients' and carers involvement in their care is widely recognised (Carr 2004). Engaging patients and their carers may benefit services to be delivered in a more cost efficient and cost effective way. This study was meant to provide an opportunity for transforming health care, by identifying factors that are within reach for older people, specifically within their homes, so that they can participate fully in their care and maintain their dignity till death. Adopting the recommendations proposed from this thesis would enable a move away from complex services and entitlements which professionals are in charge of, towards a system where older people can tell health professionals what they want, and where health professionals help to devise solutions, often by simply drawing on resources that are readily available in communities and neighbourhoods. It is essential to understand from the lay perspective of older people, the causes of their readmissions. It is only with this new understanding that the process of enabling older people to increase control over, and improve their health can take place. This study I focused on older peoples' view and perspectives, on their needs and experiences of care and support as they grow older. It identified the extent to which they felt their needs might be met, and by whom. Also it explored their views on current health care provision and their aspirations for the future, and included older people and carers from across a range of communities in the European city of culture, 2008; Liverpool, and Halton and St Helens, all in the North West of England to inform holistic, patient-centred practice in secondary and tertiary care.

1.3 Organisation of the Thesis

Chapter one introduces the study by highlighting the historical transition of ageing and its health and social implications. It describes the policy contexts of social care in the United Kingdom and then, proceeds to the study of readmission and why it is a problem.

Chapter two provides an overview of the literature as well as providing an introduction to the main theoretical issues examined in this thesis. The review was conducted with the purpose of framing research question and developing a methodology for this research and this chapter discusses the search strategies used and the criteria employed for including studies for the review

Chapter three explains the aims and objectives of the study and provides an introduction to the philosophical background that informed the phenomenological approach adopted for the purposes of this study. Furthermore chapter three details the methods used in the study and highlight the sampling method and strategies used in the recruitment of patients and their carers, It also deals with the interview instruments used and their design as well as method used to analyse the data.

Chapter four opens discussion on the result of the study. As it is true of the thesis as a whole, it concentrates on the perception of older people and their carers. As much as possible, it draws on the participants own descriptions. It does include as much of some participants dialogue as possible to describe their experiences of readmission, the causative factors which led to it and their experiences of older age and living with chronic conditions. The chapter deals with one particular team which emerged in the data analysis "Patients' information, engagement and choice of care" which is discussed and illustrated with quotes from the patients and their carers.

Chapter five continuous the discussion on the results of the data analysis, by introducing the further theme of; "service provision from health and social care". The analysis presented makes use of the verbatim quotes from concerning the perception of the quality of care they received and the problems they encountered upon readmission.

Chapter six demonstrates how older people manage a diverse range of problems which affect their health and lead to readmissions to hospital. Issues relating to the theme of "Nutrition, Co morbidity and Social Isolation" are brought to full discussion.

In Chapter seven, the emphasis shifts to a discussion of how older people talked about their family and other close contacts. Those interviewed were clear that support from family and friends was what made living and being care for at home a possibility. Even those living alone expressed the view that living at home was not viable without support. The centrality of these forms of support to home and care arrangements suggests that those older people without the necessary social ties should be considered for care in other settings.

Finally Chapter eight discusses the recommendations for policy and practice in the care of older people after discharge from hospital. While recognising the limitations of this particular study, the evidence gathered highlights the need for more and better research in this area.

1.4 Historical transition in old age and their social and economic implications.

Along with other European Union (EU) countries, the United Kingdom has an ageing population. A country can be defined as 'ageing' when the proportion of its population aged 65 and over reached 12.5%. Figures shows that 16% of the British population are aged 65 and over putting it squarely within this category (Laslet 1989). What is more, the trend is set to continue. The larger 'post war' baby boom generation is about to reach retirement age. As a consequence, current projections suggest that by 2031 the population of the under 45s would have fallen, while those aged 60-74 are expected to rise by about 50% and those over 75years by 70% (Bootle 2005) The retired population will stand at 16 million, that is 5 million more than at present. This demographic transition is explained by modern living conditions and effective health care solutions combined with advances in medicine which have ensured that most individuals in the western world, like Europe, United States of America, and Australia, live a longer life and die, for the most part, at an old age (Wait, 2005). In the Western World the demographic trend towards increasing older population is also linked to what has been referred to as 'epidemiological transition' (Howse, 2006), a shift from conditions under which pestilence and famine generate high and fluctuating mortality to conditions within which pandemics are brought under control. Mortality levels decline progressively and the age of onset, at which degenerative and man-made disease most frequently occur continues to decline. Coupled with improved survival rates and a general decline in fertility rates, the outcome has been a population structure with lower proportions of younger people to older people than seen at any time in the past (Stewart et al 1999; Thatcher 1999).

The result of longer life expectancy and aging older population has created challenges for the National Health Service as it inevitably places even greater demands on the existing health care system (Bickerstaffe 2002). When the NHS was founded, geriatric services only provided basic care for older people, in contrast to current use, many health care systems were initially fashioned to meet the needs of a relatively young adult population and have undergone major revisions in order to extend its services to accommodate the needs of the UK's growing older population (Garfield et al 2008).

Research shows that degenerative disease occur more frequently and with greater severity, the incidence of limiting long term illnesses rises steadily through the life course (Social Trends 2007).

In thinking about this intertwining of health problems with social trends, it is important to move beyond certain preconceptions. Older people are generally perceived as a homogenous group, as frail and dependent. Social trend provides government framework and, sets out its proposals for the next stages of constitutional renewal in which democracy is reinvigorated. For example, a national framework for greater citizen engagement was published by the Ministry of Justice in 2008 which sets out a proposed framework for greater citizen engagement, using innovative methods such as citizens' summits and juries to inform national policy-making. By so doing, the House of Commons can be petitioned concerning an issue bothering the citizens for whom the government can gather views from Parliament and the public on the content of the discussions they have had. Government policies are aimed at everyone, in the public sector and beyond, with an interest in the Department's policy responsibilities, including those who need to understand the spatial implications of policy (A national framework for greater citizen engagement, 2008). The need to address the problems of older people in the United Kingdom using social trends stems from the fact that it provides the principles of public economics, and how these apply in a spatial context. In so doing, it passes power to communities and older people by giving them real control and influence over their care. It also provides a conceptual framework for analyzing the rationale for involving Communities and Local governments in decision making The UK Government's policy interventions, are based on the three main rationales for government intervention known as the "three Es"; efficiency, equity, and the environment (Department for Communities and Local Government, 2007). Most policy documents in the United Kingdom reflect this view without considering aging from the perspective of the aged. This characterisation can be broken up in various ways. For instance, 'the social framework' (Social Trend 2007) provided a description of the elderly in terms of the phases of the life course in which different individuals find themselves. It distinguishes; those entering old age who have completed their careers, and who are trying to promote well-being and suppress morbidity; those in transitional phases concerned to identify any emerging long term dependency they might be experiencing; those who are becoming increasingly frail and who have greater health and social care needs as a result; and, those at the end of life with the particular configuration of social, health and emotional care needs that define terminal conditions. Given the complexity and variety of needs amongst these groups, the costs associated with their health care are high. A recent survey by the Office for National Statistics (ONS) in the United Kingdom shows that 2/5$^{\text{ths}}$ of total health expenditure was connected to the delivery of services to the elderly, with people aged 65 and over accounting for about half of the total expenditure in the field of personal social services in the same year (Social Trend 2006).

1.5 Policy Context of social care for older people in the United Kingdom.

The World Health Organisation (WHO) framework identifies the three fundamental goals of a healthcare system as; improving health; ensuring responsiveness to population expectations; and assuring fairness of financial contribution and overall equity in health distribution (Murray and Frank 2000). In order to meet these fundamental goals, health systems must provide services to key population groups including older people, for example around living healthy lives in the community, while remaining sensitive to their health needs and providing measures that can improve their health. To do so in a way that is compatible with the WHO framework, this involves making sure that ways of financing their health and social care needs are in place. Finding ways of meeting these performance indicators has been the subject of international debate and countries with older populations have undertaken considerable work to identify and address the issues associated with the provision of adequate, affordable care. Some developed countries such as the United Kingdom, United States of America and Australia have developed national plans for meeting the health care needs of their older people. Major healthcare reforms were common throughout the Organisation for Economic Cooperation and Development (OECD) in the 1980s and 1990s, The European Union's policy framework has also been important, highlighting, as it does, the need for member states to empower their citizens so that they can make healthy choices at an individual level while being involved right from the start in policy making at the collective level (European Social Network 2004)

To trace the development of social care in the United Kingdom, it may be necessary to start in the 1930s and 1940s, during the pre-war period, when older people were the biggest group of residents in the large Public Assistance Institutions, very little attempt was made to offer different regimes, types and levels of support to reflect their different needs. Following this, Free Universal Health Care was introduced by the National Health Service Act in 1946, with long-term health care for chronically sick older people being provided by the NHS. The Act placed a duty on the unified District Health Authorities and Family Health Authorities to seek advice from health care professionals in order to fulfil their duties (Wade 1971). Since 1948, the NHS has aimed to provide a full range of health services such as hospitals, rehabilitation services and general practitioners, to all, on the basis of need, and free at the point of delivery services. Following recommendations made by Rucker (1946), locally elected authorities, fund institutional, day care and domiciliary services from a mixture of central and local taxation, as well as from the contributions of means-tested co-payments from service users, so that older people in need of social welfare needs can be separately provided for in a new type of Local Authority Residential Home, away from the old public assistance institutions (Rucker Report, 1946).

However, the standard of health care offered to older people in the UK has caused increasing concern over the last decade (King's Fund 2001, Lothian and Philip 2001). Specific problems have been raised about the quality of assessment for older people (Clinical Standard Advisory Group 1998), the fragmentation of care, the increase in the use of nursing and residential home care provision and the quality of care in care homes (Audit Commission 1997).The high proportion of health budgets consumed by older people has led to discrimination against them within the health care and within British society, with older people increasingly framed as a financial drain on scarce resources (Audit Commission 1997, Clinical Standard Advisory Group 1998). Unsurprisingly, given these concerns, the future health care of older people has become a priority item on the political agenda (Royal Commission, 1998; Scottish Executive 2001a, 2001b). The Department of Health (1990) formulated the NHS and Community Act which emphasised promotion of choice and independence for individuals and the cost effectiveness of service provision on the basis of needs assessment. The government initiatives outlined in the National Service Framework (NSF) for older people and the NHS plan placed the focus on rehabilitation and care of older people (Department of Health 2001a, 2001b). The National Service Framework provided an important national impetus to promote age equality that centred on concepts of inclusion, independence and citizenship in issues relating to quality, accessibility and outcome of care. This refocusing presents an opportunity for creative thinking and a challenge to practitioners involved in delivering services to patients in their homes. In the United Kingdom, standards of care and support for older people, though delivered by local government, are defined at the central governmental level and services are financed by general taxation. The system in place is part of a broader social security system that is embedded in a largely shared economic, social and cultural heritage (Goodacre et. al. 2004). At present, there is an unregulated market in which central government sets the terms within which providers and commissioners operate and independent regulators monitor quality and standards (Klein 2007). Health and social care services are highly fragmented and there is no single institutional site with overall responsibility for the delivery of care to older people so that they have to grapple with a highly complex institutional environment. Continuing care provided by NHS is free at point of delivery while that provided by social services is mean tested (Twigs 2000).

There has been ongoing debates about how to distinguish health care and social care needs, with a strong view from social services departments that the NHS often 'dump' cases for them to handle. Older people often occupy hospital beds because of increased frailty or co morbidity. The N HS, the main provider of health care in the UK since its establishment in 1948, has also had some forms of reforms over the last two decades, beginning in the early 1990s with the introduction of a functional split between the provision and commissioning of care as well as the attempt to introduce an 'internal market' for providers (CSCI 2006). In 1993, services and resources, which were tightly controlled by central government, were allocated to individual older people following assessments of their needs and financial means, with the intention that a new market of providers would compete to provide those services with maximum flexibility and cost efficiency (Glennerster, 1996; Hoyes et al., 1994). However, this led to a further hardening of attitudes about organizational and professional responsibilities, and less flexibility at the margins between NHS and local authority services, leading to continuing disputes over the boundaries between health and social care. A study done by Mur-Veeman et al. (2008) describes health and local authority divide as a "Berlin Wall" since the two entities are different among governing bodies, organizations, providers, funding as well as professional. This conflict is presently ongoing and care of older people appears to rely heavily on families.

The National Beds Inquiry in 2000 estimated that about 20% of the 'bed-days' for people aged 65+ were provided for patients who no longer needed the resources of an acute hospital, but were not ready to be discharged to their own homes (Department of Health, 2000). And in 2003 the National Audit Office reported that nearly 9% of older people occupying hospital beds had been declared fit to leave hospital but had not done so; and about a quarter of these were waiting for care home placements (NAO 2003b). The idea that older people inappropriately occupy acute hospital beds when their needs would be better served by other forms of care in the UK did acquire a new degree of urgency through the introduction of the community care reforms at the end of the 1980s. This has however led to systemic difficulties in the coordination of health and social care services for older people in this country, fuelled by increasing demand and decreasing supply of acute hospital beds over this period, which was happening at the same time as the NHS was getting rid of most of its non-acute beds for people. Furthermore, delay-discharge fines were also introduced under the Community Care Act (2003) in which a fine of one hundred pounds a day is imposed on local government councils unable to take a patient 'well enough' to be released from hospital but too sick to return home. The shift of patient care from the acute to the primary setting, as outlined in the government white paper, *Designed to Care* (Department of Health 1998; 1999), has resulted in increased numbers of older people preferring to remain in their homes until they die or just before they die. Such government initiative however, relies heavily on the input of the family or informal carers (Evers1995). Furthermore, in 2005 the government introduced the National Health Service and Social Care Model

(Green Paper). This model outlines how people with long term conditions will be identified and receive care according to their needs; through an expansion of initiatives like 'Expert Patients' to promote self management; the appointment of Community Matrons and Specialist Nurses to support people with complex needs; and by explaining how teams of staff will be encouraged to work together with people with long term conditions and their families/carers (Chatterjee 2005; Department of Health 'Supporting people with long term conditions' 2005; 2001; Hutt 2004). The White Paper, 'Our Health, Our Care, Our Say (2006) helped further channel this 'new' direction for community services. It built upon public sector reforms, and was designed to help people to live more independently and to exercise greater personal choice. The White Paper sets out how the Government is to take forward the 'Independence, Well-Being and Choice' (2005) for older people. Independence, Well-being and Choice sets out seven outcomes for social care: improved health; improved quality of life; making a positive contribution; exercise of choice and control; freedom from discrimination or harassment; economic well-being; personal dignity. It demonstrated that older people too often find joint working between different services to be poor, particularly at the boundary of health and social care. The White Paper aims to improve health and patient outcomes for people with long term conditions who are likely to need ongoing support from health and social care service providers. It seeks to provide a framework for support and care which is built around individual needs and choices that are not fragmented, with greater focus on disease prevention, early treatment and prevention of readmissions into hospital (Our Health, Our Care, Our Say, 2006).

> "improve health outcomes for people with long-term conditions by offering a personalised care plan for vulnerable people most at risk; and to reduce emergency bed days by 5% by 2008, through improved care in primary care and community settings for people with long-term conditions" and to "increase the proportion of older people being supported to live in their own home by 1% annually in 2007 and 2008." (Our Health, Our Care, Our Say, 2006; Objective 291).

The Wanless Review was set up in 2002 to devise a method to increase spending and improve the quality of care. They envisaged a more devolved NHS, with a diversity of public, private and voluntary providers all paid by results, and a much expanded and effective role for patient choice (Wanless Review 2002). Yet, a Department of Health review of research evidence about why people entered care homes concluded that the main message was that most older people, given the choice and the necessary support, would prefer to live in their own homes for as long as possible (Warburton, 1994). What older people say they want for themselves is to stay in their own homes for as long as possible. Like many European governments, the UK government is committed and has shifted the balance of provision for older people with relatively high levels of dependency, away from institutional care to home-based care that is supposed to be safe and appropriate. This shift towards the provision of long-term care services which enable older people to continue to live 'in the community' has also brought with it an increased awareness of the importance of what 'informal' care usually provided by family members at home. However, the Observatory on Social Exclusion (1992) has pointed out that the institution of the family has weakened substantially in the last thirty years, so care functions have had to be taken over by the state. Older people often live apart from their children, are often widows or widowers and so live alone towards the end of life. The availability of informal carers has, in other words, changed. Since old age is frequently associated with increased disability, this has raised concerns about how to meet the health and social needs of the ageing population (Lloyd 2000; Seale, 2000). Family is simply not there to plug the gap in the way it once was. The situation at the moment is that older people with the kinds of care need that would previously have triggered a move to institutional care are increasingly being cared for at home, often by a family member, or formal services, and sometimes by a combination of the two.

To increase the safety and adequacy of care for older people, the Commission for Social Care Inspection (CSCI) in its 2006 annual report recommended that carers should be placed at the centre of the adult social services strategy, to ensure that carers are not overstretched and that they should remain able and willing to provide their support (Clements 2007). Recent legislation such as Carers and Disabled Children's Act (2000) has also given carers more rights in law to have their views taken into account by a social services department when it is considering how best to make provision for an older person; and the right to a 'carer's assessment', which will determine whether or not they are entitled to help with caring. Also the United Nations' International Plan of Action on Ageing' (2000) recommends that family solidarity should be encouraged. It emphasizes that efforts should be made to support, protect and strengthen families in agreement with each society's system of cultural values and in response to the needs of its ageing members. To do this, governments must promote social policies that encourage the maintenance of family solidarity among generations, with all members of the family participating (UN/Division for Social Policy and Development 2000). The question is; are modern families and informal carers well placed to support relatives and older people who are chronically ill? More importantly, perhaps, is enough being done to support them in that role? Also it assesses if care of older people at home has been safe and adequate for the individual older person. Why is readmission of older people still a problem in the UK?

1.6 Summary

This chapter introduced the study and set out what each chapter would look at. It highlighted historical transitions in patterns of ageing and their health and social implications. It demonstrated the policy contexts within which social care is delivered in the United Kingdom before proceeding to an examination of hospital readmission and why it is a problem.

The next chapter looks at the main causes and risk factors involved in hospital readmissions.

Chapter Two: Medical and social scientific studies on readmissions of older people.

2.1 Introduction

This chapter provides an overview of some of the principal analytical and substantive themes identified in the diverse literatures that touch on the problem of the care of the elderly, as well as an interrogation of the theoretical approaches that underpin medical and social studies which touch on the empirical focus of this thesis as a whole: readmissions of older people to hospital. Identifying, locating and understanding this literature contributed to the development of the research questions and informed the methodology which drove the research for this thesis.

The initial purpose of the review was to identify work relevant to the research using a number of search strategies in order to map the field of research that centres on this subject. Producing that map was not a straightforward task. Hospital readmissions amongst older people, quite apart from their personal impact, have a variety of social, cultural, political and economic repercussions. It should come as no surprise, therefore, that the bodies of research which touch upon this area are themselves extremely varied and span a variety of disciplines.

As discussed at length in the first chapter, hospital readmissions among older people have become a matter of concern due to their implications for both the cost and the quality of hospital care, and the heavy burdens they tend to place on patients, families and carers who have to deal with their consequences (Anderson and Steinberg, 1984; Daly, 2005). The cost of readmission to a nation's health service is high as it is estimated that it may be responsible for 60% of hospital expenditure (Weinberger et al 1996). The cost of hospital readmission to the older patients and their families in terms of distress, morbidity and mortality is also immeasurable. In older patients, the literature revealed that repeated hospital readmission promotes dependency, and leads to a self perpetuating circle often described as 'revolving door syndrome' (Brown and Gray 1998). The resultant effect on older people is feeling lost and confused and also it demoralises them. The growing emphasis that is being placed on the economic implications of readmissions, particularly within economics, political science and epidemiology, has resulted in large numbers of studies designed to isolate, measure and monitor the 'objective' impact of changes in the organisation of national health care systems on readmission rates (Anderson and Steinberg 1984; Schroeder et al 1979; Zook and Moore 1980;). As a result, interventions that reduce the frequency and duration of hospital readmissions, increase the efficiency of the services delivered and so reduce costs within the NHS have become an extremely important preoccupation within this area of research in the UK (Benbassat and Taragin, 2000).

In thinking about readmissions it is important to make a distinction between unplanned readmissions (often on emergency), and follow up readmissions planned by doctors in advance as part of a course of treatment for specific conditions. Within research in this area, this distinction is marked by dividing readmissions into two categories: the 'avoidable' and the 'unavoidable' (Buell 2008; Dai et al 2002; Graham and Livesley 1983; Gravelle et al 2007; McInnes et al 1983, Sridhar et 2008). In other words, within the literature some hospital readmissions are thought to be unnecessary in circumstances where the right preventative measures ought to be in place. It is important to note, however, that some readmissions will be necessary so long as important forms of treatment and follow-up care are only available through hospitals. Given this, a zero readmission rate may be seen to indicate poor quality of care rather than the reverse. Using hospital readmission rates as an index for evaluating quality of care is thus complicated by the fact that those assessments must take into account whether the correct balance between avoidable and unavoidable readmissions has been reached. These studies therefore employ normative standards, whether a particular type of readmission ought to have occurred, alongside contextualising information, regarding the conditions relating to different types of readmissions in different places, in order to arrive at conclusions about the ways in which care is being provided to those who go through readmission. The different ways in which the division between avoidable and unavoidable readmission is drawn provides the focus of this review as well as the starting point for the research more broadly.

As part of the process of examining acute medical patients' journeys from the hospital to the community and back, researchers have begun to ask whether large numbers of patients with manageable medical conditions should be readmitted to hospital instead when such conditions could potentially be managed at home or treated in alternative health care settings. The occupancy of acute medical beds by older people in this position, they argue, has had a negative effect on the treatment of other patients with acute conditions by taking up much needed bed space – so called 'bed blocking' – and so leading to delays in treatment, complications and, at the extreme, death. In what follows, I further explore and highlight issues relating to the issue of readmission focussing particularly on quality of care in hospital and the community. As became clear in the course of conducting the review, the evidence produced in support of a link between hospital readmissions and assessments of quality of care is often inconclusive.

2.2 Conducting a literature review: guiding rationale.

A literature review provides a researcher with the ideas and methods needed to justify an approach to their research and helps to facilitate theory development and tease out those elements of a topic understudied in the past (Hart 1999, Webster and Watson 2002). This was as true in the context of this study as in others. Literature review shows us what others have written, helps us to clarify what it is we are interested in studying and how to go about studying it. It also helps us to see why the research we want to do might be able to make a contribution in policy and practice in the care of older people in the community (Ngai and Wat, 2002).

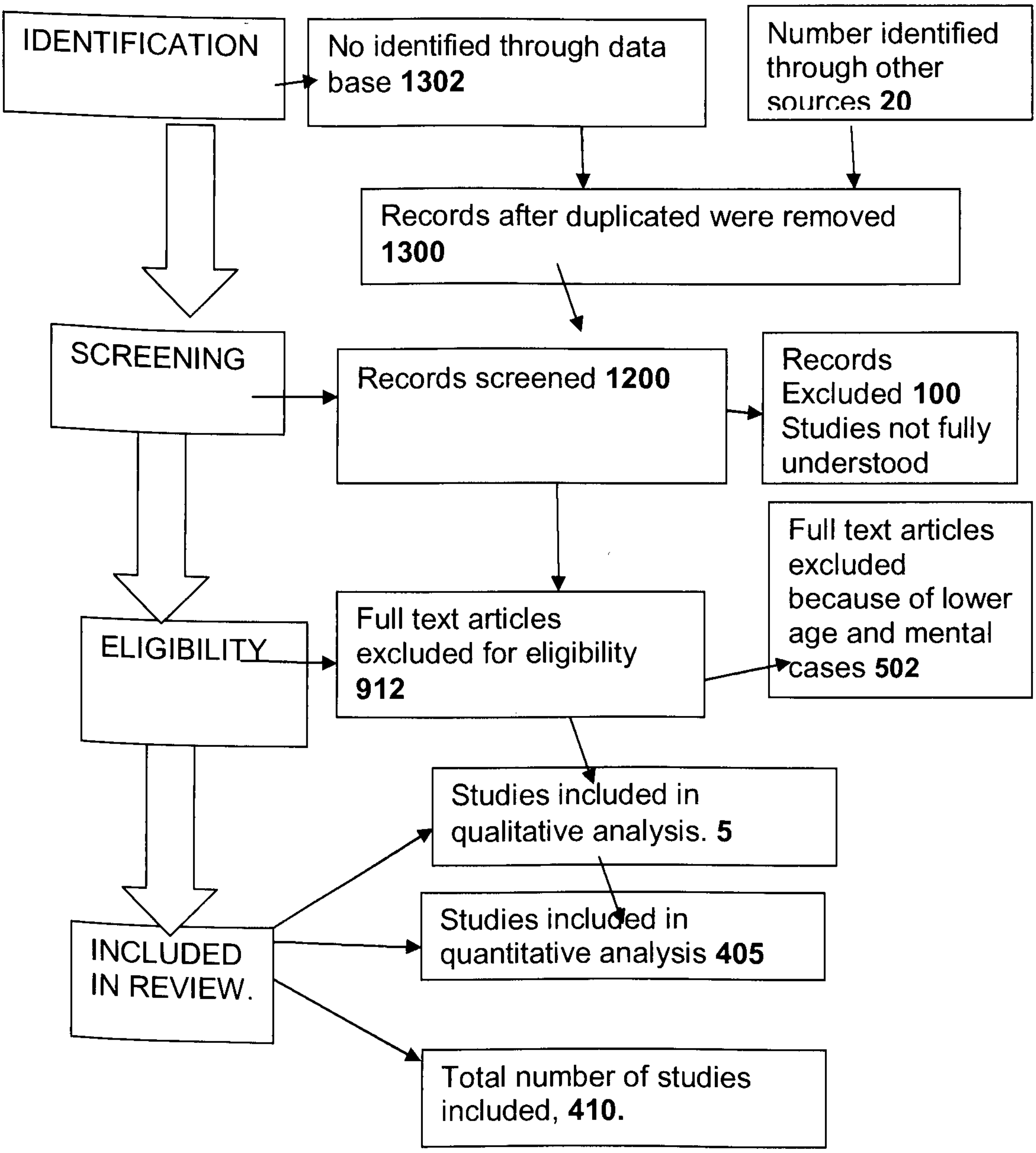
The aim of this review was to identify what aspects of the readmission of older people following hospital admission were being studied – what work was being done - and so identify the state-of-the-art in this area and explore those aspects of readmission that necessitated further research. The review helped gather together information regarding the key issues and problems that are currently being reported in relation to readmissions. Having done this it made it much easier to ask the question; were there areas of readmissions that require further exploration and how might we go about investigating them?

2.3 Search, retrieval and acquisition of materials.

A range of work relevant to the issue of readmissions was examined. It considered research conducted across North America, Europe and Anglophone countries, like the United Kingdom, Australia and the United States of America, so as to gain as wide a view of the issue as possible. Studies concentrating on these areas are, of,

course, far from representative of the situation around the world taken more broadly. Having been through the 'epidemiological transition' discussed in chapter one, these countries have far larger numbers of older people requiring much greater levels of support than in this case in developing nations (Omran 1971). There is growing evidence to suggest that long-term limiting illness rates among older people in developed nations is increasing in step with greater longevity (Jacobzone 2000).

Figure 1. Flow diagram showing information through the different phases of a medical and social scientific review



Adapted from Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

While this makes them unrepresentative, it also makes the issue of readmission all the more urgent. Thus, although the review is restricted to English language articles that does not represent a restriction as it has been in Anglophone countries that these issues have been thoroughly discussed.

Discussed below was the method used to search the literature, but it was also an inductive process. Many of the articles drawn upon were uncovered by chance, were recommended by colleagues or were unearthed by following lines of enquiry uncovered in the course of conducting the review.

As illustrated in the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) flow chart in figure 1, the literature review went through the following stages;

Identification; The strategy was based on the following techniques; keyword searches of electronic databases; hand searches of relevant journals; scanning of reference lists; and citation searching of key papers. Recurrent uses of combinations of a variety of key words were also investigated. The key words focussed on reflected the terms used to describe older people at the time the research was carried out and included such descriptors as; 'old people', 'elder people', 'older people', 'seniors', 'elderly people', 'geriatric(s)', etc. The search also covered terms relating to the substantive research topic; 'hospital readmission', 'unplanned readmission', 'readmissions', 'home care', 'hospital discharge to community', 'community rehabilitation', 'hospital to home' (Reed and Procter, 1994), etc. and materials were retrieved from both electronic databases and from the grey literature.

A wide range of electronic databases were consulted to reflect the wide scope of readmission, e.g. databases covering health management, nursing, medicine and social care. Also non-electronic methods were used, including looking at reference lists of articles and books to see what information sources the authors used. The following data bases were searched; OVID, Allied and Complementary Medicine,1985-May, 2009, British Nursing Index1985-2009, CINAHL (Cumulative Index to Nursing and Allied Health Literature) 1982-2009, International bibliography of Social sciences,1981-may 2009, OVID Medline1996-2009 and OVID Medline in process and other non indexed citations, OVID, Medline daily updates, 2009; A.S.S.I.A. (Applied Social Sciences and Index and Abstract); Cochrane library;

National Electronic library for health and Scopus. Policy and protocol documents were gathered e.g. Department of Health circulars and policy papers. Google was the primary search engine used. A total of one thousand, three hundred and twenty-two papers were identified (1322). However, some duplicated papers of twenty two were removed and remaining one thousand, three hundred that had to be screened.

Screening; A process of thematic content analysis was used, i.e. a method for recording the aspect of readmission to hospital addressed in any given paper. Each item was read and annotated, (using a standard data extraction form), according to characteristics such as; the author; year of publication; the identified risk factors; the actual causes of readmission; the type of publication (e.g. research journal or seminar); research materials, i.e. types of data, used; details about method, design and participants; the country of origin; the key outcomes addressed; and key phrases. Stoltz et al's (2004) seven-step method for analysing literature was initially employed. This involved the following; specifying the research question; specifying the inclusion/exclusion criteria used; devising a plan for searching and retrieval; conducting the search and retrieval; interpreting study evidence; integrating study evidence; and formulating recommendations for further research. The most relevant concepts identified within the bodies of work that were accessed in this way were subsequently isolated, highlighted and adapted so as to make them relevant to the topic of this particular project. Following the one thousand, three hundred screened, and one hundred papers did not report on risk or actual cause of readmissions, so that only one thousand, two hundred was further screened for eligibility criteria.

Eligibility criteria; Literature reviews enable a researcher to understand what kinds of work have already been done on their subject of interest (Straub, 1989), so this review concentrated on studies on readmission among older people that helped crystallise the issues at stake. Readmission is a multi-faceted phenomenon, and any adequate treatment of it must examine both endogenous and exogenous factors. In other words, readmission rates are not solely a result of 'structural' factors (the organisation and culture of health care, national forms of health service delivery, the training of medical professionals, the availability of resources both human and non-human) nor are they merely a function of the medical conditions that older people tend to suffer from in different parts of the world as they age. Rather, it is a product of both, a point where the bio-physiological intersects with social, cultural, political and economic organisation. The net has to be cast wide if these aspects are to be treated together. The studies consulted therefore included a range of quantitative and qualitative studies including; randomised controlled trials; systematic reviews in 'identified' problem areas; surveys and descriptive studies. The literature review also covered trials and studies designed to evaluate discharge planning, medication problems and co-morbid disease specific conditions, as well as studies that considered 'patient-specific' risk factors relating to hospital readmissions, including the home environments they returned to after hospital discharge. Only studies that included males and females over the age of 65 years were considered, those involving individuals of lower ages and children were excluded. The review also covered studies undertaken in inpatient hospital settings, such as teaching or district general hospitals, community hospitals or the community rehabilitation centres that provide care after discharge from inpatient hospital but ambulatory care settings, such as day hospitals and outpatient departments, were excluded since no formal admission was involved. A total of five hundred and six papers were excluded as they did not meet the eligibility criteria. Studies were excluded where they did not report on either the risks or causes of readmissions or where they included readmissions in ages lower than 65 years or reported on readmission pure caused by mental illness.

Review; Only 410 papers fell within the criteria specified and were included in the review.

2.4 Overview of the literature.

As discussed above, the review was organised into two broad sections; namely, studies of avoidable and unavoidable readmissions. Within the literature, some of the key care frameworks considered and used are; Kolcaba's 'Comfort Theory' (1991, 2003); Orem's 'Self Care-Deficit Nursing Theory', (1971) and Roy's 'Adaptation Model Based Theory'(1999) as these provided the main starting points for studies of the readmission of older people into hospital. These three theories are relevant to the study in that their epistemological stances are routed in a phenomenological approach to qualitative studies. Since the study is interested in hearing the views of older people and their carers, the perception of comfort, self care deficit and the level of adaptation required and have been met in their homes could only be possible through home visits. The social realities of the study participants, I believe could only be fully embraced through home visits, and the use of in-depth interview as a method. The chapter concludes with a discussion of the literature reviewed and provides an insight into choosing a phenomenological approach to the research. The majority of the studies discussed are quantitative in character and much less qualitative work has been done on the personal, social and cultural aspects of readmissions.

Studies of both avoidable and unavoidable readmissions reported here reflect the outcome of policy and practice here in the UK and elsewhere and can be considered to illustrate political approaches of their time. Moreover it seeks to address areas of gap in knowledge and how to utilise our available resources into full use.

Studies of unavoidable readmissions, which will be examined first, are discussed under four sub-sections; relapse of chronic disease, co-morbid diseases and the effect of Diagnostic Related Groups (DRG) of chronic conditions in older people; the effect of frailty with increasing age; changes in family life and caring; and the effect of limitation of primary care services on readmission of older people to hospitals.

Avoidable readmissions are then discussed under the following sub-sections; including non-involvement in care before discharge; unresolved health problems on discharge; lack of support in the homes; lack of accessible housing and limited or no uptake of rehabilitative services in the community; inadequate post discharge interventions from health trusts; lack of home visits from health professionals; poor communication across sectors of health care; as well as the effect of marginalisation and social exclusion on readmissions. Finally, a summary is provided on the principal findings from the literature.

The next section begins this systematic summary with an examination of studies that focussed on unavoidable readmissions.

2.4.1. Unavoidable Readmissions.

Unavoidable readmissions have been studied in some details (Buell 2008; Dai et al, 2002; Gravelle et al 2007; Sridhar et al, 2008). As routine aspect of healthcare provision, 'unavoidable readmissions' are those which have been pre-planned, and which take place under 'appropriate' circumstances variously defined. They occur primarily where medical professionals become aware of a change in the condition of an older person and typically relate to the normal course of treatment associated with the management of chronic disease; for example, where further or regular diagnostic checks must be completed or as a part of an ongoing treatment regime set out for an individual during an 'index', i.e. first, admission. Early discharge following index admission thus takes place on the basis that readmission may be necessary. Unavoidable readmission is, therefore, an extension of a patient's treatment over time and represents good medical practice.

This seemingly straightforward definition becomes progressively complicated when qualifications relating to 'appropriate' circumstances are considered. The category can be and is used to cover readmissions that result following diagnosis of disorders that are prone to relapse, following diagnosis of a disease or condition statistically, though not always definitely, associated with certain types of complication or following a different diagnosis from previous admissions. A case may also be classified as an 'unavoidable readmission' where a patient develops social or psychological problems as a result of increasing age and frailty over the course of treatment. Where an individual ceases to be able to look after themselves in the period of time after an initial spell in hospital, and while still under the hospital's care, readmission for management of personal care is often defined as necessary. Family is, of course, an important factor in this. Where personal support is unavailable at home, and the older person's capacity to look after themselves has notably deteriorated following hospitalisation, a return can come to be seen, and is subsequently treated as being inevitable, a self-fulfilling prophesy,
Additional complications in the definition as the timeframe between initial and subsequent readmissions can be as short as a day. As an example of short-term 'unavoidable' admission-readmission, consider the following. An older person may become ill, because their general practitioner is unavailable (GP). Locum doctors presented with the case lack knowledge of the existing health status of the older person. As a result of their personal uncertainty about underlying conditions coupled with institutionalised fear of litigation by the patient or their family should some condition go undiagnosed and untreated, it has become acceptable practice to send the patient to accident and emergency department. If the patient's condition does not improve within 24 hours, they are admitted onto the wards. Where this occurs, and it is especially frequent over the weekends and during the night, such short series of hospital visits are classified as unavoidable readmissions.

This brief discussion gives an initial flavour of what is meant by describing a readmission as 'unavoidable'. I now turn to the literature to provide greater depth. The concepts used in the literature to define and describe unavoidable readmissions are discussed under the following headings;

1. Relapse and the effect of Diagnostically Related Groups (DRG) of chronic conditions and co-morbidity in older people
2. The effect of frailty with increasing age
3. Changes to family life and caring

4. The effect of the limitation of primary care services

2.4.1.1 Relapse and effect of Diagnostically Related Groups (DRG) of chronic conditions and co-morbidity in older people.

Older people who are 65 years old or more will frequently have at least one or more chronic longstanding health problem; and the number of chronic diseases per individual increases with age (Harwood and Naylor, 1976). This claim is supported by research demonstrating that two-third of patients admitted as medical emergencies are so as a result of deterioration due to long-term conditions, due to the normal process of the disease or as a result of complications following them (Department of Health 2004).

The management of co morbid conditions amongst older people results in them being 'bounced' back and forth between home and hospital in the course of their care. In their review, Benbassat and Taragin (2000) showed that most researchers attribute readmissions of this kind to the weakness of the patient and the 'natural' progression of chronic conditions. Very much in this vein, Harwood and Naylor, (1976), Kosecoff et al (1990) and Osman et al (1997), for example, are confident in concluding that hospital readmissions are related to the clinical conditions that patients present with.

Yet some researchers have sought to examine claims concerning the impact of co-morbidities on patient risk for a variety of outcomes more critically. For example, Greenfield et al.(1988) hold up the case of a patient admitted with cancer of the colon, who had hypertension as co-morbid condition and intestinal obstruction as a complication of the entire situation, i.e. all three conditions and the way they had been treated (Greenfield et al 1988; Greenfield et at 1993; Iezzoni et al 1992;). Co-morbidity, which can be acute or chronic, as well as conditions that arise as complications thus worsens the patients' condition and predispose them to readmissions.

In another study, moreover, Morris et al (1990) showed that it would be a mistake to treat all pre-existing conditions as equal. According to them five pre-existing conditions in particular lead to significantly increased hospital readmission rates among older people; chronic obstructive pulmonary disease, ischaemic heart disease, diabetes mellitus, cirrhosis of the liver and congenital coagulopathy (1990). In cases where patients do not have these, readmission may arise in a variety of ways, not just as a function of whatever chronic condition they have been diagnosed as having. Medical professionals ought to look elsewhere, particularly to co-morbid conditions, in such cases. Thus, on measuring the level of effect of different co morbidities, such as hypertension, chronic respiratory conditions, stroke, chronic renal failure, cancerous conditions and arteriosclerotic heart diseases and their effect on older people, data from 30 randomly selected hospitals in the United States of America reported that they were equally sensitive to causing readmissions and death (Romano and Mark 1994).

The classification of unavoidable readmission and the International Classification of Diseases (ICD).

The International Classification of Disease (ICD) is a structured classification of diseases with associated codes that allows morbidity and mortality data to be systematically collected from different countries and statistically analysed by the World Health Organisation. Different diseases are classified according to ICD-10 (WHO International Classification of Diseases, 10th edition). This arena can be considered to be within a long standing tradition of sociological enquiry into knowledge where sociologists engage with rationalism. Such rationalism stances have it that classification schema are unproblematic reality descriptors. However, sociologist also argue that classifications should be understood from the results of the schema and in terms of the classification work that underpins their creation, as there could be some invisible categories (Bowker and Stars 1999). The ICD incorporates the 'Diagnostic Related Groups' (DRGs), meta-level classification schemes that provide a means of relating the type of patients which a hospital treats on the basis of their membership of one or another 'disease group'.

The DRGs supply a framework for monitoring quality of care and the utilisation of services in hospital settings. It does this by discriminating between aspects of chronic disease epidemiologically, clinically and pragmatically. The epidemiological element within the DRGs stresses that acute illnesses typically arise in the context of pre-existing conditions. On the other hand, DRGs also stress that persons having to cope with a range of chronic ailments are also, in clinical terms, often those most susceptible to the effect of acute illnesses, and so may require treatment for other reasons. Finally, the DRGs also stress the importance of pragmatic considerations, like making the best use of hospital data rather than following epidemiological or clinical considerations to the exclusion of other evidence, and emphasise the utility of, for example, discharge diagnoses and documentation relating to all conditions addressed during a particular hospital stay (Browner, 1992; Charlson 1993).

Still focusing on the Diagnostic Related Groups, research into patients readmitted within 28 days of an initial hospital stay in the city of Bristol, in the midlands of the UK, found that the proportion of readmissions rose sharply in people over 65.The illnesses most commonly associated with readmissions in the medical sector are cardiac disease, chronic obstructive pulmonary disease (COPD), diabetes and respiratory infections (Bound et al 2002). Similarly, another study, again in the UK, that was conducted in acute medical wards on the over-65s showed that readmitted patients were more likely to have chronic disabling diseases and more co morbid diseases, such as advanced malignancy, congestive cardiac failure, congestive obstructive airway diseases, and end stage renal failure. The study concluded that patients with advanced malignancy and cardiovascular diseases were more often readmitted compared to other disease groups as they were either for chemotherapy, or for diagnostic procedures (Dobrzanska, & Newell, 2006; Stewart et al 1999). For patients aged 65 years and older, admitted for congestive obstructive pulmonary diseases into intensive care units (ICUs) as a result of an 'acute exacerbation' in the UK, it was reported that they had a substantial hospital mortality rate of 24%, and that the mortality doubles in a year following hospital treatment from 30% to 59%. Acute exacerbation is a complication of COPD characterised with subjective increase breathlessness, increased sputum volume and coughing and does affect 85% of patients (Anthonisen et al 1987). Stewart et al (1999) further noted that hospital and longer-term mortality was closely associated with the development of non-respiratory organ system dysfunction. The severity of that underlying dysfunction influenced readmissions and mortality following hospital discharge. Research shows that hospitalisation for acute exacerbation usually occurs in the later stages of COPD and represents more than 70% of all COPD-related medical care expenditure (Garcia-Aymerich et al., 2003; Lau et al., 2001; Murata, 1992; Roberts et al., 2002; Sullivan et al 2000; Strassels et al 1998). In cases of patients with hypercapnia resulting from COPD on admission, half of them needed hospital readmission and 7% were readmitted 3 or more times within the ensuing 6 months (Connors et al 1996).

Clark (1996) identified several common self management tasks from a review of studies of patient education for chronic conditions in the UK. These included;

arthritis, diabetes, heart disease, asthma and COPD. The recognized core tasks that patients were being educated in included: recognising and responding to symptoms; using their medication, managing acute episodes; maintaining activity levels; smoking cessation where required and so life-style change more broadly; interacting with health care providers; as well as managing emotions and psychological responses to illness. Clark (1996) concluded that older people which chronic conditions who were not able to manage these daily tasks were more likely to be readmitted to hospital than those who could manage their conditions and activities of daily living. An increase frailty with increasing age could lead to such inability and could lead to unavoidable readmissions.

One of the domains of the body whose function is affected with increased frailty from co morbidity is the muscular skeletal system in that there is reduced muscle mass, joint pain with weak and painful hip and shoulder. These often lead to reduced mobility with it complication of deep venous thrombosis (DVT). Spyropouloa et al (2008) in their study of the effect of DVT as a complication of an existing chronic condition, discovered that the hospital readmission rate of DVT was 14% within a year of initial hospital discharge and that up to 45% of those readmissions occurred within the first 30 days, and were identified as unavoidable.

Similarly Moloney et al. (2004) examined data recorded in the Hospital Inpatient Enquiry system in an Irish hospital and observed that older age, male gender and clinical coding on discharge using Diagnostic Related Groups (DRG), strongly predicted readmissions. In particular, clinical coding of cardiovascular and respiratory conditions was associated with readmission. However, the researchers also stressed that many readmissions had to be treated as new illness in the chronic illness of older patients' co-morbidity, which often relapsed and cause unavoidable readmissions.

Some older people can have two to five co morbid disease conditions that can deteriorate rapidly and return them to hospital. However there are some specific disease and co morbid conditions that tend to increase the risk of readmissions of older people to hospital. These are grouped into DRGs. Recognising the relation between membership of a DRG and readmission allows hospitals with a complex case mix across DGRs to identify patients who require more hospital resources, experience greater difficulties around treatment difficulty, who have poorer prognoses and a greater need of intervention and so plan readmissions.

As a measure to improve the management of high-risk patients, like older people with co-morbidity, Essex Strategic Health Authority commissioned The King's Fund in 2005 to develop a case-finding algorithm on behalf of the Department of Health, the NHS Modernisation Agency and England's Strategic Health Authorities. The King's Fund has worked with Health Dialog and New York University to develop the Patients at Risk of Re-hospitalisation (PARR) tool. PARR is a software tool with an easy-to-use interface that uses inpatient data to identify patients at risk of re-hospitalisation within a year. The first version was developed in December 2006 while the latest amended versions PARR++ was released in November 2007, which is presently in use. PARR++ is used by the Primary Care Trusts to identify patients before their condition get worsened and consequently provide remedies that would prevent avoidable readmissions (Kings Fund 2009)

Also while chronic conditions contribute a great deal to readmission, it is not the sole reason why older people return repeatedly to hospital for further care. As will be discussed in the next section, many older people find it difficult to continue to care for themselves in their homes due to frailty. This is an important factor in readmission.

2.4.1.2 Effect of frailty with increasing age.

In reviewing data relating to the number of patients who regularly find themselves in acute hospital settings due to frailty and old age, a recent Department of Health Report suggested that patients aged 75years and over are at highest risk of readmission within 28days of medical discharge (Department of Health, 2008). Health and functional status tend to deteriorate with age and often deteriorate to the point where people are no longer capable of living independently in the community, although this is by no means inevitable. As they grow older, people experience a weakening of muscles, as well as weakened and less flexible joints, making movement difficult; they tire more easily; memory function tends to decline; and something which hampers recovery from illness. In many cases, these processes are unrelated to disease conditions but a concomitant of old age. Frailty becomes increasingly common as people reach their late seventies and eighties. This makes the performance of daily activities very difficult. As the old grow older, individuals are more likely to be housebound and dependent on the help of others for the performance of such essential activities as dressing, feeding or toileting (Cox 1987; Department of Health 2008; Hunt 1978; Martin 1988,; Parker 1997). This general decline in health usually leads to readmissions following hospital treatment, especially if the older person is living alone and without support. This problem was explored in a qualitative study by Roe et al. (2001) which investigated older people's experiences of support at home following hospitalization in the USA. Interviews with 16 women and four men aged 65 years and over in Washington DC, They noted that older people adjusted in different ways to the changes in their lives following hospitalization. Some older people responded positively while others passively accepted the situation. Many of the respondents were simply not aware of the community services available to them, whereas, some participants found it difficult to seek help. Their major problems were invasion of their privacy and loss of independence and it all led to unavoidable readmissions (Roe et al., 2001).

It is in consideration of the co morbidity and frailty accompanying older people that in 1997, the new UK government under labour was elected with a commitment to change. The new government published a policy document in 1998 entitled; A first Class Service, Quality in the new NHS (Department of Health 1998a). Standard 3 focused on monitoring health outcome of NHS for which readmissions was introduced as one of the performance indicators. Evidence suggests that readmission to hospital has been a problem with a wide variation across the UK (Department of Health 2002). Following this, further government policies have been introduced to improve standard of care for older people. *The National Service Framework for older people,* (Department of Health 2001) further set standard for older peoples care whether in homes or hospital, so that their health and independence can be maintained so that readmissions arising from frailty and co-morbidity can be minimised. Moreover, the development of high level clinical care and intermediate care (short stay centres) in the community, now enables older people with disability and long-term co morbidities to remain in their own homes. For those older people in the care system before first admission as well as for those who will need ongoing support when they are discharged home, the discharge process is more characterised by a transfer of care process so that the continuity of the right care is in place before discharge. This is facilitated through using person-centred approach assessment to determine the person's usual situation and what extra care are needed in the community (Lees and Emmerson 2006). Moreover the department of Health also produced a common assessment framework (CAT) for adults set out to deliver a better experience for those who use health and social care services (Department of Health 2009). In as much as older people face the problem of readmission as a result of frailty and co morbidity, it may be necessary to examine situations that trigger readmissions, which I suppose, the individual older people in this study are able to identify by reflecting on their experiences of readmissions. For planned admissions, a systemic approach as part of the pre-admission assessment; that has documented functional abilities and the existing care plan and home environment; will flag up any potential problem during discharge. Assessment involves putting together all information on older person's needs and circumstances, making sense of the information in order to identify needs and agree on what advice, treatment and support to provide (Lees and Emmerson 2006).

The gradual decline in health and functional status of an older person in a family setting is much less of a problem where they can rely on support from those around them. However, the changing nature of family relationships means that many older people either live alone, or may only be able to rely on family members for limited forms of support. These issues are taken up in greater detail in the following section.

2.4.1.3 Changes in family life and caring.

Family and informal carers are important source of support to older people. However, they in turn need support and information regarding older people and how best to care for them. Reflecting changes in society, the role of the family, as well as the norms and cultural expectations associated with participation within it, have changed over time, generating tension around the provision of care. Munday (1996) drew on the 1992 European Commission Observatory on Social Exclusion to argue that the institution of the family had weakened substantially over thirty years so that a good number of older people now live apart from their children, may be widows or widowers, tend to live alone towards the end of life, and increasingly rely on informal carers or formal carers.

The effects of caring for older people on carers have been explored in a number of UK studies. These studies, which examined the pressures experienced by carers, highlight the difficulties associated with caring, such as isolation, stress and tiredness. It was reported, for instance, that two-thirds of carers reported stress and half reported depression as a problem (Liston et al. 1995; National Assembly for Wales 2000b; Twigg, 1992;). Levin et al (1993) also noted that some informal carers are in full-time jobs leaving them with limited time to deal with those under their care while increasing the pressure upon them. Care-giving by informal care-givers engaged in full time employment is more likely to result in relapse, the development of new problems and so to readmission. Furthermore, family care-givers encounter many difficulties preparing themselves, both physically and mentally, for the return of an older family member from hospital. Unfortunately, those who experience the greatest difficulties are those whose relatives are most likely to relapse and undergo readmission.

Support for caregivers was another area of the literature that was explored. Respite care is perceived to facilitate informal care and enable care to continue at home for longer than would otherwise be possible. A range of services are provided under the heading of respite care in the UK to give carers periods of rest to enable them recuperate in readiness for their roles. Regular respite care has been shown to reduce stress in carers and is perceived by them to be the most needed community service (Nolan and Grant 1992; Shope et. al. 1993; Sperlinger and Furst 1994). Indeed, symptoms of stress were most commonly reported amongst carers where they could not access respite care (Nolan and Grant 1992). Ashworth and Baker (1996) have argued that women who are in poor health and spent eight or more hours every day caring for relatives aged 80 and over are at high risk of developing 'caregiver stress', something which in turn exposes those they care for to hospital readmission.

Carers' needs were similarly found to be of low priority in an Australian study by Driscoll (2000). Using focus group discussion with five sets of patients and their carers to explore perception of level of involvement before discharge from hospital, Driscoll found that carers received little information concerning the health problems of those they cared for, their care needs at home and even the possible complications of their conditions and the treatments they were receiving for them.

Support for family carers has been the subject of a systematic review by Stoltz et al (2004). Twenty six studies of both quantitative and qualitative studies were reviewed. While, most of the studies reviewed were conducted in the US, the findings resonate with findings from studies conducted elsewhere in the world. In this case, the review found that the paramount issues for family carers were fear of isolation, a wish to network with others and a desire for respite care; recurrent themes in the literature more broadly.

The Carers Recognition and Services Act (1995) in the UK gives carers providing regular and substantial care to older people the right to ask social services for a carers assessment on their capability to care and what support they require to perform such roles. These are combined with the assessment of the older persons needs before a care package can be arranged. Furthermore, the Carers and

Disabled Children Act (2000) further extents carers rights to an assessment with the person they care for, as well as give local authority the power to provide carers with services that help them to care; like payments, vouchers for break services, and other supports required by individual carers. Moreover, the Commission for Social Care Inspection (CSCI) recommended a strategy where carers are placed at the centre of adult care services but the government argued that carers are not to be overstressed but rather remain to be able to be willing to care and fully supported (CSCI ;2006). The evidence from the literature points to problems experienced by carers of older people. The explorations of view of carers of older people in this study are to highlight if these difficulties are still being experienced by them and they are able to discuss how they can be better supported if the problem still persists.

Application of Kolcaba's Comfort theory. This theory was developed as a patient-family centred theory. It is seen as central to both patients and their family carers (Kolcaba, 2003, Kolcaba 1991). Kolcaba identified three types of comfort; -relief; the meeting of a specific need for comfort; -ease; a state of calm and contentment and ;-transcendence, a state in which one rises above problems. Comfort is experienced in physical, psycho-spiritual, socio-cultural and environmental contexts and promotes engagement of internal and external health seeking behaviours. The three types of comfort are central to older people's care, the identification of their needs, the management of symptoms, the maintenance of interactions, homeostasis, holism and healing environment. According to Kolcaba, any alteration in the comfort of an older person at any level will make them seek such comfort in the hospital resulting to readmission (Kolcaba, 2003, Kolcaba 1991). According to comfort theory, patients experience the need for comfort in stressful health situations. Patients and their families may meet some of that need while other aspects of it remain unmet. Kolcaba believes that the needs of a patient should therefore be assessed *physically;* in terms of bodily sensation and the physiological problems associated with old age and chronic conditions; *psycho spiritually,* in terms of an individual's internal awareness of self and self esteem, their sexuality and their relationship with higher being; *environmentally,* in terms of the embodied human experience of life at home; and *socio-culturally,* in terms of interpersonal, family and societal relationships (Kolcaba et al 2006; Kolcaba and DiMarco 2005). Comfort must be viewed as individualistic and provided in a holistic manner to enhance wellbeing.

The practical use of comfort theory for older people after initial hospital admission is of multidisciplinary concern. Kolcaba and Dimarco (2005) argue for the need to comprehensively and consistently assess the needs of an older person and design interventions to enhance the comfort of the patient and their family. Older people may experience discomfort after initial hospitalisation in relation to bodily pains, cold, anxiety from diagnosis and prognosis relating to chronic conditions, anxiety about the future and isolation. For Kolcaba, each older person and their carer has to be assessed in order to identify their 'comfort zone' and measures must be put in place to maintain it through professionalism and collaboration based on constant monitoring.

The difficulties associated with caring for an older person in the family are made worse when the family of the older person lack knowledge of how to manage acute symptoms. When at a loss, families often send older person back to their GP, their first port of call. However, problems begin to arise when GPs are not available. This problem will be addressed in the next section.

2.4.1.4 Limitation of primary care services.

The development of acute symptoms that require prompt management in older people can occur when the GP surgeries are closed and are often referred to as out-of-hours-illnesses. Under NHS guidelines, out-of-hours services are for medical emergencies and should only be contacted if one cannot wait until the next day to be treated by a GP. Nonetheless, despite the existence of alternative points of contact with G.P consultation there are reasons for questioning their effectiveness. For example, a recent study in the UK showed that older people whose conditions deteriorated during out of hours periods were much more likely to be readmitted to hospital because their GPs, who knew the patients and their conditions and may have been able to provide treatment at home, were unavailable (Dobrzanska and Newell, 2006). This is because, primary care services are polarised falling short of ideal shared care. The primary services at the moment are fragmented across multiple providers with no clear managerial or professional hierarchy through which clinical governance can be implemented (Rossen 2000). This has frequently led to unavoidable readmissions. Even when admitted, they spend longer days in the hospital because there are minimal diagnostic and therapeutic efforts over the weekend. If referral occurred during the week, by contrast, greater resources were devoted to such efforts. Under these conditions older people were often discharged without having to be formally admitted (Maurer and Ballmer 2004). Just to buttress the effect of the limitations of primary services further, Hart (1971) described what he termed the 'inverse care law' which he described as the availability of good medical service to the population as limited, those in greatest needs receive relatively the least amount of health care. Granvelle and Sutton (2001) confirmed it by writing that the deprived areas with the worst health have fewer GPs. Also Leese and Bosanquet (1995) are of the view that GP surgeries are less well organised offering fewer services. As a measure to tackle these problems, Gulliford et al (2004) reported that greater availability of primary medical care practitioners do contribute to better population health. There is also strong evidence that better supply of general practice with easy access and larger practices that are relevance and effective to population health, tend to provide better quality care that may be associated with reduced readmissions (Audit Commission 2000; Wilkin et al 2000; Wye et al 2000). However reorganisation and extending the period of work for GP practices will in no doubt minimise readmissions. Still, some authors have argued that primary care has relatively weak influence on population health but that consideration should be given to socio-economic and environmental influences on older people like housing, transport and nutrition in addition to health care (Periere, 1997, Roland and Baker 1999).

Unavoidable readmissions still frequently arise due to the frailty of older people, coupled with the chronic and co morbid conditions, often worsened by the character of the diseases that accompany older age. This situation is aggravated when older peoples or their carers lack the knowledge and skills in the management of any relapse that occurs during out-of-hours-periods, something which can sometimes lead to readmissions. Readmission can be considered to be beyond the control of both older people and their carers.

That said, it is important to look at the patterning of different forms of readmission before arriving at judgement. For this reason, avoidable readmissions will be examined next.

2.4.2 Avoidable Readmissions.

As mentioned above, 'avoidable readmissions' are classified as those which were not planned in advance and which could have been avoided by observing good practice (Buell 2008; Dai et al 2002; Gravelle et al 2007; Sridhar et al 2008). Most of what is reported here are the results of the literature review and the opinion of the

authors. It still leaves a gap that only the older person in his or her given situation will be able to describe his or her readmission as avoidable or unavoidable. As a category, high levels of avoidable readmissions are an index for poor health care, failures to take into account how to properly support older people after discharge from hospital. Avoidable readmissions thus represent breaks in the 'care continuum' that links the hospital and the community (Burns and Nichols 2002). High levels of avoidable readmission are a product of problems at each stage of the patient's transition from one care setting to the next. These range from poor preparation for discharge, poor health on discharge, lack of visits at home, to poor care communication across health and social care sectors. The unexpected, emergency returns to hospital that are the result of these breakdowns, frequently have grave clinical and public health implications (Burns and Nichols 2002).
In what follows, empirical research on avoidable readmissions will be discussed under the following headings.

1. Non-involvement in care before discharge.
2. Unresolved health problems on discharge.
3. Poor accessible housing and limited use of rehabilitative services in the community.
4. Inadequate post discharge interventions from Primary Care Trusts.
6. Lack of home visits from health professionals.
7. Poor communication across hospital and community care for older people
8. Effects of marginalisation and social exclusion on readmissions.

2.4. 2.1 Non-involvement in care before discharge.

Returning home from hospital following admission due to a medical problem is not always a smooth process and many older people encounter serious problems in the first weeks of their return. This raises the question; do hospital trusts in the United Kingdom have a uniform discharge planning process in place? That is, discharge planning that involves patients and their families in a strategic way that bolsters autonomy and individual control and thus contributes to the preservation of dignity in older people.

Discharge planning and aftercare initiatives more broadly have received increasing attention in recent years. It has been recognised that what happens during both hospital discharge and the immediate period surrounding return to the community after discharge are critical to the well-being of older people (Armitage and Kavanagh 1998, Chapman and Jack 1996, Henwood and Wistow 1993, Roberts 2001, Waters 1987). Such post-discharge problems seem to be more common with increased age and have sometimes lead to further complications and avoidable hospital readmissions, (Mistianem at al 1999). Discharge planning has also been viewed as the development of an individualised plan for the patient which needs to be followed at home, with the aim of containing costs and improving patient outcomes. The process involves assessing patients' needs so that follow up care provision is arranged based on the needs identified (Bull 2000)

Discharge planning practices has been explored by some scholars. Clark et al (1996) in their study of discharge practices in the United Kingdom discovered that few hospitals start planning older patients' discharge early enough. Most do not, an organisational short-coming which results in 'bed blocking'. Taraborelli et al (1998) review of the literature on the discharge of frail older people from hospital cites a number of small-scale reviews of discharge policy and practice in the United Kingdom Health Councils. From their reading, they concluded that there is variability and discrepancy in the implementation of discharge plans across regions in the United Kingdom.

The amount of information given to older people on discharge from hospital in the United Kingdom was the focus of a review by (Bull 2002). It found evidence indicating that older people were not being given what the report's authors considered, or the NHS suggested is enough information at discharge. Patients were ill-informed about medication and their condition. They were unclear about what activities they could or could not participate in and had difficulty managing special diets (Bull 2000).

Roberts (2002), on the other hand, who explored the concept of partnership with older patients in the process of being discharged and in the period shortly after discharge from hospital in the UK, arrived at a rather different set of conclusions. Roberts sent out questionnaires to 518 patients and conducted follow-up interviews with 30 patients over 70 years. The majority of those he interviewed felt involved in decisions regarding their care and all welcomed the advice of professionals. Indeed, some expressed a preference for service providers to make decisions about their care on their behalf. However, Roberts observed that older people, whose family or friends became involved in their care, were found to be in a stronger position to participate in decision making. The diversity of viewpoints that Roberts documents reinforces the importance of considering the ability and willingness of each individual to play an active role in the stages of their care including discharge planning (Roberts, 2002). Loss of autonomy and control is a pervasive experience for older people with advancing illnesses (Chochinov 2002). Older people and their carers need to be given adequate information to enable them to make the most informed choices they can about care after hospitalisation. It can then involve choosing to be taken care of in their homes or elsewhere and the informal carers may decline to be involved in a caring role depending on their personal circumstances. Because of this, the provision of information needs to be seen as a fundamental principle of quality health care.

An Australian study by Heine et al. (2004) explored the thoughts and concerns of older people going home following total hip replacement (2004). Five older people were interviewed prior to discharge from a hospital-based treatment unit and the analysis of the data showed that patients had a number of concerns about their own ability to properly look after themselves. They were also concerned about the level of support they would require from their families and friends and whether they would feel safe at home. The authors argue that good practice in patient care means recognising and responding to the concerns of patients before discharge. Without making such provisions, return to hospital may be inevitable.

Also in a Canadian study, LeClerc et al. (2002) used structured interviews conducted with14 older women in their own homes 6–8 weeks after their discharge from hospital, to explore the issues and challenges they had to deal with. According to participants, their basic physical and medical needs took precedence over other issues of their recovery. The participants felt that the discharge plans they had been issued with did not reflect the complexities of their return home (LeClerc et al. 2002).

Using 'discharge liaison officers' to coordinate the discharge process and so minimise problems has been the practice in some hospitals in the United Kingdom. A systematic review assessing the outcomes of patients moving from hospital to home found that discharge planning may lead to, reduced levels of readmission to hospital and increased patient satisfaction (Parker et al 2002). Hyde et al (2000) review cited evidence from both Randomised Controlled Trials and quasi-RCTs in the UK. It investigated the effects of supported hospital discharge, the actual additional support provided to patients and carers from health and social care after discharge from hospital. The review found evidence that supported hospital discharge was of value, but its effect on readmission was unclear (Hyde et al. 2000).

The rise in co morbidity with older people in the western society due to having aging society, has resulted in an increasing self care initiatives like the Expert Patient introduced in the United Kingdom; *Our Healthier nation-Saving Lives* (Department of Health, 1999). The initiative recognised older people as individuals with expertise and knowledge in their conditions which require active participation in their care. However, Conway, (1996) believes that expertise is culturally, socially and politically constructed. Saving lives publication is based on the present age of enlightenment where older people are to apply the scientific rules and analysis to self-manage their chronic conditions. Expert patient initiative is embedded in empowering older people to retain control of their lives. The issue of independence and enabling older people to retain control over their own lives was seen as fundamental, and these objectives need to be central to community care in which participation in their care make them responsive to their cares (Department of Health, 2001). Evidence abound where involvement of service users has improved their self-esteem and a sense of empowerment (Carr 2004). Empowering older people would definitely denote participation, involvement and engagement during their first hospitalisation and at the time of planning their discharge (Carter and Beresford 2000; Carr 2004). However, studies also confirm that older patients are often less engaged in decision making than younger patients (Hamalainem et al 2002). Some authors have related this to the symmetry of the relationship of unwritten rules between patients and the health care professionals which has sometimes hindered the power to transfer certain information to expert patients (Freenan, 1997; Wilkinson1999,), however, the present practice of concordance where a patients decision not to accept any treatment are no longer perceived as negative behaviour is presently upheld as it reduces resources wastage (Connect 2000) so that patients are given all information relating to their care so as to make informed choices (Connect, 2000; Wilkinson 1999). Moreover, between 2007 and 2008, the Department of Health Local Authority circular, *Partnerships for older people project (POPP);* awarded ring-fenced funding of £60 million for Councils with Social Services Responsibilities (CSSRs) to establish innovative pilot projects in partnership with the Primary Care Trusts, the voluntary, community and independent sectors, aimed at large-scale reform across health and care services. The grant is to change the pattern of service delivery from acute and intensive care package to greater investment on preventative interventions aimed at improved outcome for older people (Department of Health, 2007-2008). However, only six local authorities are being used for the pilot study; such as Calderdale, Croydon, Devon, Gloucestershire, Kent and Leicestershire; which still require expansion to other local authorities.

Also, the NHS UK developed best practice guidelines for discharge from hospital, (Department of Health 2003) and this was followed by a tool kit which provides practical steps for health and social care workers in any organisation to adopt in order to improve discharge of older people (Department of health 2004). This policy is accompanied by a matrix of training competencies for timely discharge to help practitioners assess their level of discharge practices. Early discharge planning is recognised to empower and prepare patients for going home. Ensuring that patients participate in decision making around their discharge is recognised part of good practice in this area, as policy guidelines in the UK demonstrate (Department of Health, 2003). Both strategies help patients feel more empowered before discharge, and the evidence from the literature suggests that where this strategic thinking is lacking readmissions increase. Unplanned, disorganised discharge is, in other words, a problem. Since this policy is there, a comprehensive review of discharge practices amongst hospital trusts in the UK will further highlight the problems and advice further on best practice guidelines.

A recognised theory of care; Orem's Self-Care Theory (1971) is based on the idea that older people should be enabled so that they can take the initiative in managing their own health. According to this theory, self management promotes well being and reduces readmissions. Older people have to be able to function on their own if they are to remain healthy and retain their autonomy as individuals (Compley 1994). Orem formulated her theory when looking at the unique features of nursing as a profession. She arrived at three related theories; the theory of self care, the theory of self care deficit and the theory of nursing systems (Eben et al 1994; Orem and Taylor, 1986). For Orem, each older person has to be viewed as an agent, endowed with the ability to take care of themselves. 'Self-care agency', as Orem termed it, is essential to the maintenance of a healthy life over time.

According to Orem (1985), the role of the health care team during first hospital admissions is to facilitate and increase the self-care abilities of the individual, to 'empower' them to look after themselves in their new condition. Empowerment involves the creation of an equal partnership between the patient and health care practitioners. However, decisions concerning what health care to provide ought to take cultural and social factors into account (Chamorro 1985, Kavanah. 1996). Moreover, as individuals differ, the care provided and level of participation ought to vary from person to person. Individual older people have different priorities and preferences and ought to receive assistance in those areas. Individual assessments of the needs of older people are, therefore, paramount on this model (Faucett et al 1990; Resnick and Daly, 1998; Orem, 1985). According to Orem, self care has been achieved when an older person no longer takes the passive, dependent patient role they perforce adopt during early hospitalisation and rehabilitation, and starts to take on the role of an active partner, something exhibited during latter periods of hospitalisation and rehabilitation and which Orem associates with positive health outcomes (Frank-Stromberg et al 1990; Scwerter Kyle and Pitzer, 1990). However this is still debatable.

When an older person, as a result of poor health or frailty is no longer able to maintain self care, Orem argues that carers, formal or informal, are required even where the patient is to be discharged home. However, as will be highlighted in the next session, some patients have been discharged home due to pressure on acute beds for those perceived to have more serious acute conditions.

2.4. 2.2. Un-resolved health problems on discharge.

The health of older people on discharge from hospital determines how long it will be before they are likely to be readmitted. In the United Kingdom, intermediate care settings serve as stop-over places for older people who have recovered but are not well enough to return home. For those in this position, part of their convalescence periods are spent in such settings to enable them regain control of their health before returning home. Intermediate care services are usually provided for six weeks, and include a review date within that period (Department of Health 2001b). However, the Audit Commission (1997) found variations in the time from the assessment to the development of the care package, ranging from five days to twenty-six weeks - something which reflects the differences in working practices found across the UK. There are, for instance, important differences between trusts on when patients are to be discharged and where they are to be discharged to. In a literature review from 1990-2003 databases which examined the causes of hospital readmission of older people in the United Kingdom, one of the risk factors associated with readmission was an index admission stay of less than 72 hours due to pressure on acute beds (Dobrzanska and Newell, 2006). Similarly, Pearson et al.

(2004) using interviews with (GPs) in the United Kingdom reported that some patients were simply not fit to leave hospital and GPs often found themselves 'picking up the pieces' following discharge. Little information and chaotic management of discharge was also reported, with some patients being referred incorrectly ,for example, instead of being referred to a dietician, they are referred to physiotherapist and vice versa (Pearson et al., 2004).

It is generally assumed that the longer the time between discharge and readmission, the less likely it is that the way in which the first admission was managed played a significant role in the readmission. This hypothesis is supported by Clarke (2004) who showed that more avoidable readmissions occurred within 0 to 6 days of discharge than within 21 to 27 days. Patients who were admitted on a Sunday had shorter stays than those admitted on a Friday since they had access to treatment that was unavailable over the weekend. Older people require a lot of support from social and health care systems to be able to take control of their lives at home. They may require support with respect to adequate nutrition, everyday activities, managing symptoms and the adaptation of their homes. They may also require visits from health and social care personnel to ensure they are adhering to the enabling strategies they learnt on discharge from hospital or from an intermediate care unit. There is also a need to modify risk factors for disease in older people as such interventions have health benefits for individuals; for example, prolonging life, maintaining levels of functional ability, preventing disease, increasing control and improving states of well being.

Still exploring health on discharge, authors like; Burness et al (1996); D'Erasmo et al (1997); Friedmann et al (1997); Marinnella and Markert (1998);Sullivan and Walls (1995); have identified that older people have experienced hospital readmission due to unresolved malnutrition while in hospital. Among hospitalised older people, energy intake of less that 30% of estimated need and low serum albumin of 3.5gms/dl predicted adverse events such as in-hospital complications, longer hospital stay, in-hospital mortality, and frequent readmissions - all as a result of pressure on acute beds (D'Erasmo et al 1997). Hypoalbuminaemia is a medical condition characterised by low albumin in blood that is less than 3.5gms/dl in which case, drugs and other chemical that should be released to be made biological active are impaired. In Sweden, the nutritional status of 80 elderly people living in service flat complexes in the community was investigated by some researchers. Among the frail and chronically ill, 30% were malnourished and 59% were at risk. The malnourished residents had worse cognitive capacity and well-being, lower functional ability and a greater need for daily assistance. These were all factors in readmission (Olin et al 2004). Failure to thrive increases with age, it is not considered a normal consequence of aging, but may be due to protein-energy malnutrition, loss of muscle mass, problems with balance and endurance, declining cognitive ability and depression (Robertson and Montagnini, 2004) There is evidence that good nutrition is a key factor in the quality of life of older people. Despite such evidence, malnutrition in older people is not only common, but frequently overlooked. The prevalence of malnutrition increases with frailty and levels of physical dependence. In the United Kingdom (UK), an estimated 500,000 elderly are malnourished, or are at severe risk of malnutrition, and so are more likely to require readmission to hospital (Age Concern 2004). According to this publication, almost two million pensioners in the United Kingdom live in poverty and are facing ill health because of an inadequate diet .The study suggested that social isolation, loneliness, depression, minority status, caregiver burnout, lack of cooking and shopping skills, and economic concerns placed older people at higher risk. When severe enough, nutritional deficiencies can necessitate readmission to hospital (William et al., 1990). Nutritional deficiencies can arise from a variety of physiological, pathological and social factors, such as age-related changes in smell and taste, concurrent medical illness and isolation, and they have a variety of adverse consequences, including poor health, poor immune system functioning and increased disability (Brownie 2006). They increase the risk of respiratory and cardiac problems, infections, deep venous thrombosis, pressure ulcers, and multi-organ failure (Omran and Morley 2000), leading to readmissions. Such readmissions are viewed as avoidable.

Admission to hospital can be a particularly frightening and confusing experience for older people. Some early discharges have occurred at a time when patients require more information about their diseases and how to live with chronic conditions. Patients' education standards are therefore being challenged by going home with unresolved medical conditions, as they often lack the physical and mental abilities to concentrate on learning how to manage their symptoms control before going home. The effective communication of patient's disease condition and management strategies at home is the most important tool the health care practitioners have. The practical Guide, *Passing the baton,* provides practitioners with useful advice on how health practitioners can review their communication skill and build empathy with patients and their families (Welsh Assembly Government 2008). Coupled with lack of good nutrition in the home, these problems become all the more pronounced. Support in everyday activities including adequate nutrition is paramount in the recovery of older people after hospital admissions. However, on its own it is not enough. Well maintained, accessible housing with proper heating is also of crucial importance, especially in older people with impaired mobility. As part of providing rehabilitative service for older people, it may be necessary to recommend adaptations in the home depending on the situation. The next section, which explores studies of rehabilitative services and the effect of poor housing on readmission rates, takes up this point in more detail.

2.4.2.3 Inappropriate housing and the limited use of rehabilitative services in the community.

In assessing the use of rehabilitative services in the community and how it affected readmissions in the UK, Young et al. (2006) investigated medium-term outcomes and service use among older people seeking treatment at an Accident and Emergency (A&E) department in a District General Hospital. The goal of the study was to provide a needs estimate for intermediate care. 823 older people suffering from such things as falls, confusion and incontinence were recruited. The study revealed a high mortality rate - 36% during the 12 months - and evidence of a gradual decline in the general health in those who survived beyond that. The findings revealed that only one-third of participants used community services and only 5% used rehabilitation services. The researchers recommended a more appropriate and longer term model of care and rehabilitation for frail older people; one with more emphasis on supportive care (Young et al., 2006). Provision of timely and suitable rehabilitative services will minimise avoidable hospital readmissions.

Other studies found that the overall level of rehabilitation for people with strokes was low, especially for those who were not admitted to hospital, and that there were variations in regional access in the United Kingdom (Beach et al 2005; Tribe 2001; Wolfe et al. 1993). Also, according to the Audit Commission (2000a), standards of equipment services provided by occupational therapists are unacceptably low in some parts of the United Kingdom and generally do not meet peoples need effectively. Without appropriate adaptations, the likelihood of readmission sharply increases and such readmissions are avoidable.

A multidisciplinary approach to the provision of rehabilitation services for patients following discharge is now viewed as best practice in the UK (Department of Health, 2003; Department of Health and Children, 2003). The configuration of those teams is crucial. In a review of patient case-notes, Healy et al. (2002) explored factors that affected the services that older people received in their communities by comparing the work of three different multidisciplinary teams. Healy et al. (2002) noted that different professionals - nurses, occupational therapists and social workers specifically - took the lead in co-ordinating the care assessment process in each case. The nurse-led team was least likely to refer patients for care assessment. Those patients for whom this team was responsible received the least post hospital support and had correspondingly higher levels of readmission. The team led by the occupational therapist (OT) concentrated mainly on providing OT services and equipment. Their patients were found to receive the most home care, something which minimised readmissions. The team lead by social workers referred patients for care assessment the most and patients in their care received the greatest range of services but not the greatest amount. It appears the social worker put up a harder fight that other staff to get NHS resources. The study thus suggests that professional preoccupation can influence services after discharge from hospital (Healy et al. 2002). The appropriate referral of older people at any given time, depending on their needs, will minimise avoidable readmissions.

Good quality accessible housing has a powerful and positive impact on older age, while poor, inappropriately designed housing and an unsupportive environment discourages the maintenance of an active lifestyle and social participation. In a very real way, the physical surroundings in which older people live impacts on their need for services. Those living in inaccessible, damp and cold housing, those who live in fear of falling, those who have been or worry about becoming victims of crime, and those who live in isolated places with no local services may all require support from social services (Salvage, 1996). Lack of heating has been found to be implicated in increased hospital admissions in the winter (Morgan, Blair and King, 1996). The Royal Commission on Long Term Care of the Elderly, found that discharge from hospital is hindered by unsuitable housing. However, they also found that it was hindered due to the fact that occupational therapists were frequently unavailable to assess homes (as required), or, where they were available, delays in the scheduled and sometimes abandoned repairs and home adaptations those occupational therapists had recommended (Allen et al 2006; Great Britain Royal Commission on Long Term Care 1999). A number of reports in the UK have pointed to serious problems with rehabilitative service provision across certain institutional settings, across certain parts of the country and for certain conditions all of which arise because that provision is patchy and under-resourced (Audit Commission 1998; Hallet 2001)

Yet, a recognised model of care well documented in literature; Roy's adaptation model (RAM) (Roy and Andrew, 1999) is based on scientific assumptions drawn from Bertalanffy's general systems theory (1965) and Henlson's adaptation level theory (1964). From general system theory are the following concept; holism of an individual made from sets of units and systems; the interdependence of systems to function; a system with control processes, system has information feedback and the complexity of living system. And from the adaptation level theory are the following assumptions; behaviour is adaptive to focal, contractile, and residual environment stimuli, and positive adaptation is determined by the properties of the stimuli (Bertalanffy, 1965 and Henlson'1964). RAM is one of the most widely used conceptual models in nursing that focuses on environmental stimuli and bio-psycho-social responses. Roy postulates that humans interact with the environment and respond to stimuli in ways which initiate a coping process (Riehl and Roy 1980; Shin et al 2006; Tourville and Ingals 2003,). This process leads to responses that are either adaptive or ineffective (Perrett 2007; Tsai et al 2003; Whittemore and Roy 2002). The focus of research which uses the RAM model is adaptation. To understand older people using this model they need to be seen in the various situations which make up their daily lives (Roy and Andrew 1999). People's subjective experiences are central to the ways in which they come to evaluate their needs. As will be illustrated in chapter three, this focus on subjective experience makes qualitative methods an ideal choice for researchers who wish to employ the Ram model. According to RAM, environmental stimuli include focal, contextual and residual stimuli. Focal stimuli confront the older person while contextual stimuli are all other stimuli that contribute directly to adaptation in older people. On the other hand, residual stimuli may be grouped as focal or contextual depending on how they manifest (Gagliardi, 2003; Tsai, 2005). For older people, severity of disease, social support and frailty may be focal stimuli, and when confronted with one or more of these stimuli, their coping processes are activated and manifest in one or more of Roy's four inter-related modes; physiologic, self-concept, interdependence and role function modes. The physiologic mode relates to the maintenance of the older person's physiologic integrity, while self concept relates to older peoples conception of their physical and personal selves. The interdependence mode deals with social support and the maintenance of satisfying relationships with others, while the role function mode focuses on older peoples activities' particularly those associated with their roles in life and the social integrity they derive from them (Burns 2004; Pearson et al 1998; Yeh 2002;).

Rehabilitation of an older person after initial hospitalisation therefore requires a mixture of interventions that address issues relevant to a person's surroundings and needs, to be able to adapt to living and coping with chronic conditions. Mastery, survival and growth are the goal of adaptation which in turn promotes integrity, the adaptive response. On the other hand, ineffective responses undermine mastery and integrity. The strength of RAM in this is that it highlights the need to create a supportive environment for older people, while caring for them in their homes, providing them with as much independence as possible, particularly where they suffer from disability.

The provision of rehabilitative services, preferably in the home, is essential for full restoration of an older person after discharge from hospital. Moreover, the services provided should differ from one older person to the next depending on the outcome of their individual assessments. Services should reflect need. However, some older people, even after their homes have been adapted in line with their conditions, may still require other forms of post discharge intervention to avoid avoidable readmissions. This will be examined in more detail in the next section.

2.4.2.4 Inadequate post discharge interventions from Primary Care Trusts.

Discharge support arrangements are schemes that are designed to provide support for older people after discharge from inpatient hospital care. They incorporate interventions in which hospital and community staffs are put in contact with the patient around the time of their discharge with the specific intention of providing support during the period immediately after their hospital stay so as to minimise readmissions. The interventions they offer may be limited to telephone contact at one extreme, or, at the other extreme, may involve teams of professionals providing services in the patient's home, including continuing education on the management of manifested acute symptoms. As has been touched upon many times to, a patient who experiences difficulties following their discharge from hospital is associated with future readmission (Bull 2000), the effect of interventions based on discharge support arrangements have been studied by various researchers.

Richards and Coast (2003) evaluated the effectiveness of organizational interventions that influence access to health and social care after discharge in the UK. It was difficult for them to determine the effect due to the differences in the patient groups and the interventions required by them. They also identified two trials that reported on functional status within 3 months of discharge, but both of these were inconclusive and did not suggest any improvement. Elsewhere, Sheppard et al. (2004) assessed the effects of providing acute care for a patient in her home compared with transferring the patient to the hospital in the UK. Sixteen studies were included in their review, eight of which measured functional status in elderly medical patients and two trials of patients following elective surgery. Areas of functional status assesses were mobility and development pressure sore, being able to breathe with ease, levels of cognition, and social activities. There were no indications that functional status in the intervention groups was better at 3 months post discharge.

In another study, Teasell et al. (2003) studied the effectiveness of early supported discharge programs in stroke patients in the UK. Ten studies were included, eight of which reported some kind of functional outcome. None of these studies reported statistically significant differences between the treatment groups, indicating that functional outcome was not affected negatively or positively by the intervention.
Whereas Rosswurm and Lanham (1998), using experimental design, conducted a study of 507 hospital patients, aged over 65 years, who were divided into control and experimental groups in the UK. The control group was discharged as normal while the experimental group's discharge was co-ordinated by a team of nurses and social workers. To be able to ascertain patients' functional ability and their home care needs, the researchers telephoned the patients 30 days after discharge. The majority of respondents in the control group had functional dependence which required the help of another person. Home care referral only occurred 50% of the time. The combined nurse/social worker team, by contrast, was found to provide effective screening and co-ordination of home care. The study suggested that increased functional dependence was associated with higher levels of readmission and recommended that comprehensive functional assessment should become part of discharge planning in order to prevent early re-admissions (Rosswurm and Lanham, 1998).

The effect of educational interventions on physical status like; the temperature, pulse, respiration and blood pressure, assessment of pain perception, height and weight; after discharge, was researched into. Richards and Coast (2003) studied the role of discharge co-ordinator, a role which may incorporate responsibility for educational interventions in the UK. Five studies were included, four of which contained data on physical status after discharge. None of these found significant differences between experimental and control groups. According to the authors there were no clear indications that educational interventions have an effect on physical status after discharge and no effect on avoidable readmissions.

Furthermore, Parker et al. (2002), in a review of 54 RCTs, sought evidence on the effects of interventions intended to improve post discharge arrangements for older people. Included in the review were discharge support schemes, geriatric assessment programmes and educational programmes in the UK. The review revealed no significant difference in mortality and no effect on length of stay in hospital as a result of the interventions but there was evidence of slightly reduced readmission rates, suggesting some beneficial effect. Parker et al. (2004) also conducted another systematic review of literature and meta-analysis for the Health Evidence Network (HEN) of the WHO's Regional Office for Europe, entitled 'Evidence for Decision Makers' (September 2005) it sought to provide an update on the previous review based on studies that specifically considered discharge arrangements across the hospital-community divide and reported readmission outcomes. Seventy-one trials were reviewed and the interventions covered were classified into comprehensive discharge planning, comprehensive geriatric assessment, discharge support arrangements and education interventions. The evidence gathered showed that the effective and safe interventions delivered across the hospital-community interface which were associated with a reduction in the rate of readmission included; multidisciplinary teams using the principles of comprehensive geriatric assessment; discharge co-ordination using defined protocols; and patient empowerment using educational approaches (Parker et al.2004). Richards and Coast (2003), on the other hand, included five RCT's dealing with comprehensive discharge planning in the UK and came to the opposite conclusion: that no differences had been shown with regard to physical status. Shepperd et al. (2004) included 11 RCT's in their review, six of which presented data concerning physical status in the UK. Here too no effects of discharge planning on physical status were found. These reviews, which discuss the impact of discharge planning on physical status after discharge, all conclude discharge planning has no demonstrable effect on physical status and no effect on avoidable readmissions. Elsewhere, Cameron et al. (2002) examined the effects of coordinated multidisciplinary inpatient rehabilitation led by a rehabilitation physician compared with the usual care received by older patients with hip fractures in the UK. They concluded that the trials reviewed had a variety of aims, interventions and outcomes, making them difficult to compare. On the basis of evidence from nine trials they concluded that functional status did not improve consistently and that, therefore, coordinated multidisciplinary rehabilitation had no effect on readmissions. Houghton et al. (1996) assessed the quality of discharge planning before and after the appointment of a discharge co-ordinator in the UK in an intervention study with 600 older people which ran for a period of months. Structured interviews were used to measure readmission rates, duration of hospital stay, patient's health and satisfaction after discharge, and receipt of services. In this study the discharge co-ordinator was reported to have made a difference. Their presence raised the quality of care received at discharge and reduced the problems experienced by the patient after discharge, including readmission. However, improvements came at additional cost. On the other hand, Handol et al. (2004) studied mobilisation strategies in hip fracture surgery patients. They concluded that there is insufficient evidence from randomized trials to determine the effect of various mobilization strategies on readmissions.

The effect of interventions from the 'Comprehensive Geriatric Assessment' category on emotional status after discharge was covered by two reviews. Parker et al. (2002) found eight studies reporting on aspects of emotional status, only one of which reported a significantly greater improvement in cognitive scores in the intervention group than found in the controls. On the whole, however, the outcomes of intervention and control group patients were broadly similar, with no obvious benefit observable for patients undergoing comprehensive geriatric assessment. However, Richards and Coast (2003) included three studies in which some emotional outcome was reported within 3 months of discharge, but none of the three found differences between intervention and control groups. On the basis of these two reviews, therefore, there are no indications that comprehensive geriatric assessment has a positive impact on emotional status after discharge.

Most of these reviews and trials found no significant differences in readmission and mortality except Day and Rasmussen (2004) who concluded that stroke units showed significant benefits in terms of readmissions and mortality reduction, but did not specify the trials on which this conclusion was based. Gwadry-Sridhar et al. (2004) evaluated the effectiveness of multidisciplinary heart failure management programmes on hospital readmission rates and found a significant decrease in readmission rates. Also, Phillips et al. (2004) conclude that comprehensive discharge planning plus post-discharge support for older people with chronic heart failure significantly reduced readmission rates. They argued it could improve health outcomes such as survival and quality of life without increasing costs.

It appears that readmissions among older patients for medical chronic conditions like COPD, heart failure, and renal failure, can be reduced by various kinds of intervention after discharge in which case could minimise avoidable readmissions. Some of these interventions may require a visit from a team of health professionals who are specialise in particular types of chronic conditions. When patients lack support from professionals, the effect can be devastating. This problem is examined in what follows.

2.4.2.5 Lack of home visits from health professionals.

The evidence on whether home visits after discharge from hospital are effective ways of controlling readmissions is split and researchers take various different lines on the question, something which will be illustrated with respect to the following studies;

Stuck et al (1993) performed a meta-analysis of 28 controlled trials that evaluated the outcomes of comprehensive geriatric assessment in the UK. The 28 studies wee each allocated to one of five types of assessment, two of which involved home visits to older people. They found significant positive effects of home visiting on mortality, hospital admission and readmission, and nursing home placements. Elkan et al (2001), in their systematic review of this area, looked at eight studies that assessed readmission and mortality in members of the general older population on the basis of home visits received in the UK. Once again they concluded that home visiting was associated with a significant reduction in mortality. Another five studies of home visiting to frail older people who were at risk of adverse outcomes also showed a significant reduction in mortality. Home visiting was associated with a significant reduction in admissions to long term care among the elderly. Elkan et al (2001) study demonstrates that patients who have access to specialist nurses are more knowledgeable, more proficient in self-care and more satisfied with the care they received at home. They argued that in the long run home visits also minimised avoidable readmissions (Mcsharry 1995, Naylor 1996; Wade and Moyer1989).

Similarly, research by a group of Australian and American researchers such as Naylor et. al. (1999, 2004); Stewart et. al. (1999, 2003); showed that home visits 1-2 weeks after discharge from hospital by qualified specialist and GPs reduced hospital readmission compared with those who had not received such follow ups .The work of the practitioners in this particular study concentrated on patients education in the areas of self care and drug counselling (Naylor et al 1999, 2004; Stewart et. al. 1999; Stewart et al 2002, 2003).

Furthermore, a systematic review of 15 trials of preventive home visits to older people was undertaken by vanSuch et al (2006) in the UK who found consistent evidence that preventive home visits had a significant effect on reducing avoidable readmissions.

The social environment of older people plays a crucial role in their survival in the community. Tsuchihashi et al' (2001) study of the medical and social-environmental predictors of hospital readmissions for heart failure patients in United States of America lends further support to some of these conclusions. Eighty percent of the participants had care-giver support and 21% lived alone with no care-giver support. The major predictors of hospital readmissions that emerged from the study were; poor compliance with follow-up visits; older people without home care follow-up visits; previous hospital admission for heart failure; and a history of hypertension. There was a readmission rate of over 40% in two years. The study concluded that social environment of older people are important in predicting hospital readmissions and that professional home care and care-giver support may reduce hospital readmission in patients with chronic conditions such as heart failure. The assessment of older people's social environment before hospital discharge will control avoidable readmissions.

In another study, Stewart and Horowitz (2002) explored the long-term effects of home health care multidisciplinary interventions on heart failure patients in United States of America in order to determine whether hospital readmissions and hospital costs were lower when heart failure patients received home health care interventions. Two hundred participants were randomly placed in the home health intervention group, while others were managed as they normally would be. Nurses and pharmacists visited the home health intervention groups in their homes within 7 to 14 days of their hospital discharge, and they were given education on heart failure symptoms and management. Patients in both groups received physical examinations and their use of medications was reviewed. The result showed a hospital readmissions reduction from 8.8% in the usual care group to 8,2% for the home health intervention group. The patients in the home intervention group visited the clinic more while the control group had a higher level of hospital readmission – a much more costly option than dealing with the patients in primary care settings.

In another study in this area of practice, Naylor et al. (1999) conducted a randomized clinical trial in two hospitals in Philadelphia in order to examine the effectiveness of a comprehensive advanced practice nurse (APN) centred discharge planning and home follow-up intervention package that had been specifically designed for older people at risk of hospital readmissions. A total of 363 patients aged 70 years and over were enrolled in the study. The outcomes measured included hospital readmissions, acute care visits after discharge, costs and functional status. The APN-centred discharge was found to reduce readmissions, lengthen time between discharge and readmission and decrease costs. Although the patients' functional status was not found to improve with the APN intervention, the researchers argued that it provided benefits to patients by enhancing their capacity to cope with functional disabilities at home and so by minimising their need to be readmitted (Naylor et al., 1999). Yet, Dellasega and Fisher (2001) conducted an examination of the patterns of post-discharge home care use by 70 frail older people in the rural USA. Findings revealed that non-professional services were used most frequently. The most intense period for use of services was the first 2 weeks following discharge, during which time more supports were required by older patients returning home.

A RCT was conducted in Denmark by Avlund et al. (2000) to examine whether interdisciplinary home visits and follow-up had any effect on the functional ability of older people following discharge and on subsequent readmission rates. 149 older people aged 65 and above were recruited for the study. Outcome measures included the ability to engage in everyday activities before and after discharge. Findings suggested significant differences in patients discharged from medical wards but no significant differences in patients discharged from geriatric wards. This led the researchers to conclude that some but not all older patients will benefit from the interdisciplinary home visits following discharge (Avlund et al., 2000). In another study Li, Marrow-Howell and Proctor (2004) examined the relationship between the number of hospital readmissions in heart failure patients and receipt of home health care services after discharge from hospital in the UK. The study included 192 participants, aged 65 years and over. These individual were followed for the 14 weeks that followed their discharge from hospital. The research focussed on the services provided by home care nurses and care givers in that time. The nurse monitored blood pressure, respiratory status, provided needed injections and also obtained blood samples, while the care givers provided assistance with ordinary activities, shopping and meals, medication monitoring and house keeping. Participants were asked questions about how many times they used each service - both the formal home health nursing service and the informal care giving service. The result showed a relationship between hospital readmission rate and the services received. There was not, however, a significant relationship between medication compliance and hospital readmission.

Whether pharmacists should extend their services to home visits so as to aid medication compliance was the focus of the next study. Holland et al (2005) performed a randomised study of home based interventions by pharmacists to determine their effect on hospital readmission rates in the UK. The participants were 80 years and older and were dived into a control group and an intervention group, who received at-home pharmacist assistance after hospital discharge. During their first visits, the pharmacists provided patients with educational materials relating to proper use of medication. They also assessed their patients' abilities to adhere to their medication schedules. Further follow-up visits were made in the six to eight weeks that followed to review medication management. Results from the study suggested a significant correlation between medication compliance and hospital readmissions.

However, in opposition to the consensus emerging out of operational studies of discrete interventions, Godfrey (2004) and the Older People's Steering Group, (2004) have argued that living at home with no human contact apart from the comings and goings of different professionals can be as isolating and disempowering for older people as living in a nursing home. The studies reviewed reveal both positive and negative effects of home-visiting. What is clear is that communication between care providers, social or medical, is central to the provision of good services to older people. It may be argued that visits by primary care trust workers and visits from various health professionals to older peoples home is a way of keeping them under constant surveillance described as 'clinical gaze' which in a way objectifies older people (Foucault 1976). Such clinical gaze in the time past was restricted to the hospital environments with their homes being a place where some privacy could be maintained and less scrutinised (Twigg 1977). However, since a good number of older people are living with chronic conditions, there is a need to subjectify older people through such surveillance otherwise called 'pastoral power' so that expert patients (older people) judge themselves by the standard of the experts (health professionals) to maintain healthy living in their homes (Wilkinson 1999). By this, most intimate lives of older people are now open to scrutiny which in a way could be seen as encroaching on their privacy.

Some older people have complex needs and the Ministry of Health in the UK has produced best practice guide on assessing such older people so that they are provided with complex case managers in the community, otherwise known as community matrons, responsible for providing them with high level of clinical support (Department of Health 2007). Once the relevant information relating to such individual older people are recorded, they are kept in place for easy access by all the team involved in the care of the patient so that those with complex needs, which may involve insecure accommodation are taken care of (Department of Communities and Local Government 2006). The aim is to enable older people attain self care level as early as possible to minimise the disruption of their lives and those of their families through readmissions. For this reason, the next section looks at studies that examine communication across hospital and community care sectors.

2.4.2.6 Poor communication across hospital and community care for older people.

Proper communication across various health sectors is important in the continuing care of patients, especially for older people that require continuing support in the community. Breakdowns in communication are breakdowns in the continuity of care provided to older people and adversely affect their health and social status and so the need for readmission to hospital. Outlined below are some studies that explored communication across health sectors and its implication for "revolving door syndrome" among older people.

The transfer of information relating to patients diagnosis and treatment between hospital and GP practices in the community following a patient's discharge from a hospital in Ireland was examined by Cahill (2005) over an 18-month period. The basis of the research was a retrospective audit discharge summaries for 73 patients from the hospital. The audit focused on the areas of information relating to the patient received by individual GP practices and if all the recent medications of the patients have been passed on. Findings from the study indicated that although the GPs received some form of written post-discharge information on 93% of patients, 52% of the reports were incomplete. This had implications for the prescription of medication, something which could have contributed to readmissions in a number of cases and was suppose to be avoidable (Cahill, 2005). In order to ascertain perceptions of discharge planning as well as communication between sectors, Dunnion and Kelly (2005) conducted a survey of 222 professionals drawn from all grades of medical and nursing staff. The result revealed that community-based and hospital-based staff felt that levels of communication between them were unsatisfactory. Complaints centred on inconsistencies in documentation relating to patient referral and the coordination of follow-up arrangements. The study concluded that poor communication led to readmission. Tackling this problem, according to the researchers, could best be done by encouraging greater collaboration across care settings and by the introduction of a liaison nurse in emergency departments.

Research show that gaps in communication to vulnerable older people lead to misunderstanding, mistrust, non adherence to management of chronic condition management regimen and other health care problems like readmissions (Cooper et al. 2003). Gaps in communication also attributes to a lot of medical errors and increased costs of care provision with the overall result of poor quality of health care delivery (Bernstein 2005, Flores et al. 2003; Jacobs 2004, Schillinger 2004). It then means that communication gaps have a negative impact on health outcomes and may be a root cause of some health care disparities with adverse effect on older people (Berkman et al. 2004; Fiscella et al. 2002; Jacobs et al. 2005, Taylor and Lurie 2004; Schillinger et al. 2002; Schneider 2002). Evidence abounds that patient satisfaction increases when communication is clear, understandable and respectful (Beach et al. 2005; Morales et al. 2006; Wanzer et al. 2004). The problem of linkage and to promote a better communication between the geriatric team in the hospital and those in the community was investigated by Robinson and Street (2004) in Australia. They discovered that the geriatric team in the hospital had limited knowledge of community care and how older people could access services in the community after discharge because they were too busy. As a remedy, an interactive forum was introduced as part of action research project to build the links between care setting and the community worker in that an immediate feedback of any discharge process was encouraged. However, the health service strategy in the UK is committed to improving the linkages and working relationship between the key players of health and social care but it seems a lot of work is still required to bridge the gap (Department of Health and Children 2001, Department of Health 2001).

In addition to the problems associated with poor communication across sectors, some older people are refused help and treatment on the grounds that they do not meet eligibility criteria used by health and social services to determine need. Given the importance of professional support to older people, incorrect, inaccurate and misleading assessments are major problems, contributing to marginalisation and social exclusion. This problem is explored in the next section.

2.4.2.7 Effect of marginalisation and social exclusion on readmissions.

In order to qualify for certain types of health care, older people must have their needs assessed. The 'needs' assessed are regarded as a measure of an individual's reliance on assistance and support. Many older people have to live with un-met need because they do not fit the criteria which entitle them to services. In the United Kingdom, needs assessments have been the subject of heated debate since the mid-1980s (Department of Health, 1993; Meltzer, 1992). The criteria used to define needs have to highly flexible so that they can accommodate a diverse range of cases. However, this flexibility makes it difficult to ascertain the exact basis on which resources are being allocated through the needs assessment mechanism (Audit Commission, 1996; Godden et al 1995; Leicester and Pollock, 1993;). Many older people do not fall within the remit of social care services. Individuals in this situation have limited access to crucial forms of low-level support such as help with shopping, cleaning or gardening. On the other hand, some older people believe that accepting support is stigmatising and may therefore prefer to stay without. The existence of individuals in both types of situation makes determining the extent of unmet need problematic – something which is particularly troubling as it is these individuals who turn to hospitals in times of need (Caldock, 1995; Godfrey, 2004; Kerr and Kerr 2003; Petch, 2003; Quinn, et al, 2003;)

There are two broad sets of factors which influence the degree to which individuals who might be eligible for services receive those services in practice in the UK. The first set is related to the personal circumstances of the individual; while the second problem relates to policy and practice constraints in operation at the time the need for those services was identified. Research for the Scottish Office found that the eligibility criteria used by service providers created a significant barrier to meeting needs in many cases (Scottish Executive 2001).

A great deal of research shows that people's health is affected, positively or negatively, by their standard of living and their interactions with others, at home, at work and in other public settings (Adler et al 1994; MacIntyre 1986; Townsend et al 1990; Williams and Fritton, 1988). There is evidence to suggest that uptake of some community-based services is fairly uneven across different social and ethnic groups in the UK as a result of differences in the affordability of the care those services provide (Krieger et al 1997; Scottish Executive 2001). Increasing social inequalities in health in the UK and elsewhere, coupled with growing inequalities in income and wealth, have refocused attention on social class as a key determinant of population health (Krieger et al 1997).

There is also evidence for the hypothesis that the problem is not just one of linguistic and cultural barriers. Provider behaviours also contribute to ethnic disparities in the standard of care received (van Ryn, 2002). During the discharge of the older people they cared for from hospital, research found that carers from ethnic minorities were not consulted, did not have their concerns taken into account and were not actively involved in the discharge planning process as a result of social marginalisation and discrimination. Generally speaking, evidence in the UK on access to services for older people from ethnic minorities is mixed and complex. As a result, some older people, like those at the lower end of the social-economic spectrum, were at high risk of readmission, "bouncing back" repeatedly form hospital to home (Chau et al, 2002; Kerr, 2003; Thornton and Tozer 1992).

2.5 Association of physical illness in older people with depression and readmissions.

The association between depression and physical illness in older people is complex. Also Co morbid medical illnesses are a key feature of geriatric mood disorders, yet the specificity of such associations remains unclear. Evidence abound that number of medical conditions increase the risk of depression such as hypo/hyperthyroidism, Cushing's disease, hypercalcaemia, pernicious anaemia, cerebro-vascular disease, Parkinson's disease Alzheimer's disease, SLE, HIV-AIDS, cancer, to list but a few, and such a physical illness and certain drugs can cause or exacerbate depression. Conversely depression may worsen or cause a physical illness, (Ariyo et al 2000, Jonas and Mussolino 2000) Also depressive symptoms also add to the disability from physical illness and are associated with physical decline (Penninx et al 2000). A study that examined the prevalence and associated risk factors of depression in older patients discharged home from acute medical care and their influence on duration of survival in the community was undertaken. The study involved three hundred and eleven patients aged 75 and older discharged from the Countess of Chester Hospital and Wirral Hospitals Trusts in England. The result showed a depression prevalence rate of 17.4% Age (*p 0.049*, CI; 0.813, 0.999), and handicap (*p 0.000*, CI; 1.268, 1.723) were associated with depression but depression (*p 0.040*, CI; 1.039, 4.915) was the only base-line variable associated with reduced survival in the community as defined by mortality and re-admission (Wilson et al 2007). Also in a sample of 546 primary care patients age 65 years and above, with pathology in several organ systems (respiratory, eye/ear/nose/throat, gastrointestinal, central nervous system, endocrine) and several chronic conditions (neurological disease, low vision, chronic obstructive pulmonary disease, diabetes) were associated with depression caused by both functional status failure and the medical burden of the disease and subsequently led to readmissions (Gerson et al 2007, Tsuchihashi et al 2001). In another study where the objective was to analyse the association between nutritional deficit and the presence of depression among community-dwelling elderly people, the results showed that there was an independent association between nutritional deficit and depression in this population of older people, which emphasizes the importance of early identification of depression among individuals with nutritional disorders (Jeffrey et al 2006). This implies that in general primary care populations, the relationship of medical illness to depression may be multimodal and may involve shared path biological and psychosocial mechanisms.

This section looked at a large number of quantitative studies with few available qualitative studies supported by various theoretical positions. The research that will be reported on in later chapters takes a qualitative approach to the question of readmission. That approach has been informed by theories relating to the care of older people in the community.

2.6 Summary

The literature reviewed has revealed that unavoidable hospital readmissions are a problem for older people with chronic and co morbid conditions, especially those in diagnostic related groups, that worsen over time. Part of the problem can also be attributed to the changing role of the family in modern society. Family ties are weaker today and many older people live alone. Moreover some older people have been admitted and readmitted because of the unavailability of those medical professionals with greatest knowledge of their cases.

In the literature, avoidable readmissions have been attributed to, on the one hand, insufficient preparation for discharge and, on the other, the fact that older people are discharged prematurely due to pressure on acute beds. The literature also revealed inadequate support for disease conditions as well as inadequate personal care. Inaccessible damp houses are another problem, especially during winter.

The lacks of post discharge interventions were also highlighted. Findings relating to the receipt of support and home visits by older people were shown to be equivocal. Some researchers argued they had no effect, while others concluded that they led to reductions in hospital readmissions. The fact that some older people have been marginalised because they do not meet the eligibility criteria that govern access to support was also discussed. Those in this position were argued to be improperly excluded from care services and at much greater risk of readmission. Evidence of poor communication and the absence of coordination between professionals in the acute medical-community interface were explored. It was argued that these problems made discharge from hospital more difficult for older people.

The literature review has shown how the burden of disease and uncontrolled risk factors associated with old age generates high levels of hospital readmission among older people. Such factors revolve around the home and the community environment. Health and social care services, however, are only a small part of the support that older people need and only a small part of the experience of growing older. Efficient discharge planning involving patients, carers, social services and occupational therapists appears to be the best way to reduce readmissions. Readmission increases the vulnerability of older people and every possible measure must be put in place to minimise it. The active involvement of patients and their carers in the discharge process is recommended so as to ensure that continuous care can be provided in the community. This review has revealed that difficulties persist with many aspects of hospital readmission. It also highlights opportunities for further research and practice development. The review has shown that the cost of hospital readmission to the health care system as well as to the nation's economy is massive and growing. Exploring patients' views on the support they believe would best enable them to cope at home is, I suggest, a crucial missing piece of the evidential jigsaw. The hope is that understanding this neglected dimension of the 'readmission problem' will help us understand the process better and perhaps take concrete steps to better guarantee the well-being of older people.

Having considered the major themes in the literature, gaps in our knowledge will be highlighted in the next section.

2.7 Gaps in the literature and contribution of the research.

In attempting to study phenomena that include multiple realities, like an older persons experiences of hospital readmissions, the investigator is often directly involved in both data gathering from those who have the experienced readmission and interpretation of the data. My review of the literature showed that, while data were collected in relation to readmission, the quantitative methods used in the majority of the studies conducted within the field did not capture the lived experience of readmissions. Only a small number of qualitative studies have been conducted at present. Accessing those who can describe real world experiences of readmissions to hospital has the capacity to contribute new insights into this area of research. As Congdon (1994) has suggested, because older people and their families are expert informants, the discharge process must be addressed from their perspectives. It could be argued that the review I have conducted does not give a complete picture of the state of art. As stated by Cameron et al. (2002) the studies of readmissions that were cited had different aims, looked at different interventions and outcomes and were of variable quality. Any overview of studies of this kind can, therefore, only reach tentative conclusions. From a practical point of view, however, this simply points to the fact that, while readmission continues to be an important issue, it is poorly understood as things stand. Professionals and organisations must consider new ways of preventing and solving post-discharge problems. Further exploration of the issues is needed using methods that move beyond the positivistic and reductionist approach to measuring relationships between readmission and causal factors.

Gaps remain in our knowledge regarding patient perceptions and views on why they have been readmitted and on measures that could have been put in place to minimise the need for hospital treatment. Some of the studies in the literature conclude that exploring older people's point of view on the causes of their readmission to hospital would offer further answers to the problems of readmission. One strategy proposed is to broaden research plans to include qualitative data collection from patients, family and other care givers. Since older people are often vulnerable and must deal with many chronic conditions with often diminished resources, they are in the best position to give valuable information about how to improve care. Conducting personal in-depth interviews with patients and their care givers could, for these reasons, provide a more complete understanding of what needs to be done to reduce the incidence of readmissions (Dobrzanska, and Newell, 2006). Exploring older people's experiences of hospital readmissions involves reflecting upon and describing experience. It involves, for example, ascertaining whether patients and their carers were involved in discharge planning, and, if so, at what stage and how? If the home environment is critical to maintaining quality of life, how do patients and carers articulate that? Despite the use of readmission as an indicator of the quality of hospital care, the empirical evidence linking it to process-of-care problems after hospitalization is still inconsistent. Moreover studies undertaken on older people and their carers' perspectives have been at best limited. Research of the kind reported on below is needed to determine the reality of the situation.

Qualitative methods of inquiry stem from the in existentialist and humanist philosophies that attempt to explore and understand how people perceive their situations. This is compatible with the three theories discussed above; Orem's-self-care-deficit theory, Kolcaba's Comfort theory and Roy's Adaptation Model. The study reported on below employed a qualitative design, and took a phenomenological approach – a methodological position that will be examined in more detail below.

2.8 Phenomenological studies of Aging and Care.

In this section I look at various phenomenological studies of aging and care-giving and how they helped to shape the present study. Studies cited here are qualitative in nature with phenomenological approach which the present study has adopted in order to fill the gap from the literature review. Majority of the studies cited explored experiences of the patients and their carers as discussed below;

Elofsson and Ohlen (2004) interviewed 6 elderly persons with chronic obstructive pulmonary disease in the UK to explore their experience of life with a severe illness and reliance on the daily care of others. Those they interviewed talked about the problems they encountered in coping with their conditions on a day-to-day basis, and their experience of resignation, disconnectedness, loneliness, and an inability to feel at home. According to Elofsson and Ohlen the experience of aging is just as important as the experience of illness when it comes to understanding how older people navigate life with a chronic condition (Elofsson and Ohlen 2004). In another study, Franklin et al (2006) explored the question of dignity at the end of life with 12 elderly people living in two nursing homes in Sweden through repeated qualitative interviews. Their analysis revealed three themes; the 'unrecognisable body; 'fragility and dependency'; and 'inner strength', which they felt was expressed when dignity has been threatened or violated from losses of bodily control and higher dependency. Those interviewed told Franklin et al that in order to keep a sense of dignity, people need to be seen and respected for whom they are. Retaining identity was thus extremely important to them (Franklin et al 2006). Also, Sand and Strang (2006) interviewed 20 patients and 20 of their family members to explore experiences of social interaction and isolation in the UK. The study revealed that older people experienced a kind of existential loneliness that accompanied awareness of one's impending death. Experiencing being alone in 'a world of one's own' was common. Older people, particularly those suffering from illnesses, saw fewer and fewer people over time, losing any sense of community that may have protected them from feelings of isolation. Those interviewed felt isolated at certain moments; upon being left alone when in need to support; when treated disrespectfully; and when they become aware that people were avoiding contact with them due to uneasiness (Sand and Strang 2006). Also Andersted and Ternestedt (1998) used qualitative interviews to examine family members' and carers' sense of their own involvement in the care of dying patients in Sweden. Based on their interviews, Andersted and Ternestedt identify two main forms of involvement which they termed "involvement in the light" and "involvement in the dark". Involvement in the light is based on relationships of trust between the family and medical professionals while involvement in the dark arises where there is insufficient interaction and collaboration family members and medical professionals, and where relatives are not properly acknowledged. The study revealed that relatives' sense of the coherence of their involvement increased under what Andersted and Ternestedt term humanistic care regimes (Andersted and Ternestedt 1998). In a small-scale qualitative study, Appelin and Bertero (2004) interviewed six patients with cancer who were receiving palliative care at home to obtain an understanding of their experiences of the treatment they were getting Sweden. They identified four themes; feelings of being safe but unsafe at home; the sense of powerlessness patients felt; the impact of illness on everyday life; and patients' hopes and beliefs about the future. The authors of the study point out the importance of teamwork and resources in increasing patient's sense of safety in their own homes (Appelin and Bertero 2004). Similarly, Benzein et al (2001) interviewed 11 patients aged between 54 and 83 years in order to explore the experience of hope in patients with cancer receiving palliative home care in the UK. The study revealed a tension between hopes of a cure and hoping to reconcile oneself with death. The study showed that hope is a dynamic emotion that is important to both a meaningful life and a dignified death for patients suffering from incurable cancer (Benzein et al 2001). In another related study, Broback and Bertero (2003) used qualitative interviews cancer patients' next of kin of to explore their experiences of a perspective on palliative care in the home in the UK. The study focussed on five themes; feelings of insufficiency, adjustment awareness, being perceived as a person, emotional effect and feeling of uncertainty. Because the informal carer/next of kin is a significant contributor to palliative care in the home, the authors concluded that it is important to promote feelings of control and control and self-efficacy (Broback and Bertero 2003).

Since these studies are exploratory in nature and adopted interviews, they gave the patients and their cares the opportunity to express their views which were quite informative and have added immense knowledge to the various concepts investigated into. It is with this understanding that I have similarly adopted this approach for the present study. As mentioned earlier, the present research used qualitative methods because it is concerned with exploring the experience of life with chronic conditions and hospital readmissions. Qualitative studies on the management of chronic conditions confirmed the importance of recognising patients' autonomy and respecting the views and experiences of older people with chronic conditions. It also showed that individuals are now expected to take a much more active role in their own care (Kirk and Gledinning, 1998). Co-morbid diseases and chronic conditions are widely acknowledged to be among the principal causes of readmissions. To prevent readmissions, patients must be able to manage some aspects of those conditions themselves. In a review of the literature on self care and self management, Chapple and Rogers (1999) noted that people wish to participate in self care practices; that significant others like the family and carers have a notable influence on self care; that social contexts, work place and other aspect of life-style impact on peoples' abilities to take advice about self management; and that timing and the progress of the condition affect the efficiency of self care interventions (Chapple and Rogers 1999). The involvement of patients and their carers in decisions regarding their health has been promoted as a key element of best practice in policy guidelines (DOH 2003; DOH and Children, 2003). Family and informal carers are increasingly involved in the care of older people at home following hospital discharge.

2.9 Towards a phenomenological inquiry.

Most of the studies included in the literature review belong to the positivist tradition within medical research. The present study, by contrast, adopted a phenomenological approach to gain a better understanding of the phenomena in question (Lincoln and Guba 1985). Those who adopt a phenomenological approach to empirical research emphasise concrete descriptions of the phenomenon under investigation in terms of lived experience. For this reason, phenomenology stresses the study of how things appear from the perspective of those under study.

The assumptions underlying phenomenology are quite different from the assumptions underlying positivism. The phenomenologist believes that individuals need to be understood as they operate within a situational context, not separated off from the environments in which they function. Human experience, in other words, needs to be studied as, when and where it unfolds. Phenomenology is often associated with constructionist epistemologies and the idea that social phenomena, like readmissions, are products of social practices rather than objective facts about the world (Lincoln and Guba 1985).

In the context of this research, adopting a phenomenological approach meant visiting patients at home in order to gain an understanding of the situation from their perspective. The social conditions under which older people live inevitably have a profound bearing on their needs. The onset, as well as the problems associated with living with chronic illness also has a profound effect on older people's self concepts, role function, interdependence and their physiological mode adaptations (Gagliardi 2003). However, these effects should not be defined exclusively from positions outside the circumstances in which they become issues for older people themselves.

2.10 Limitations

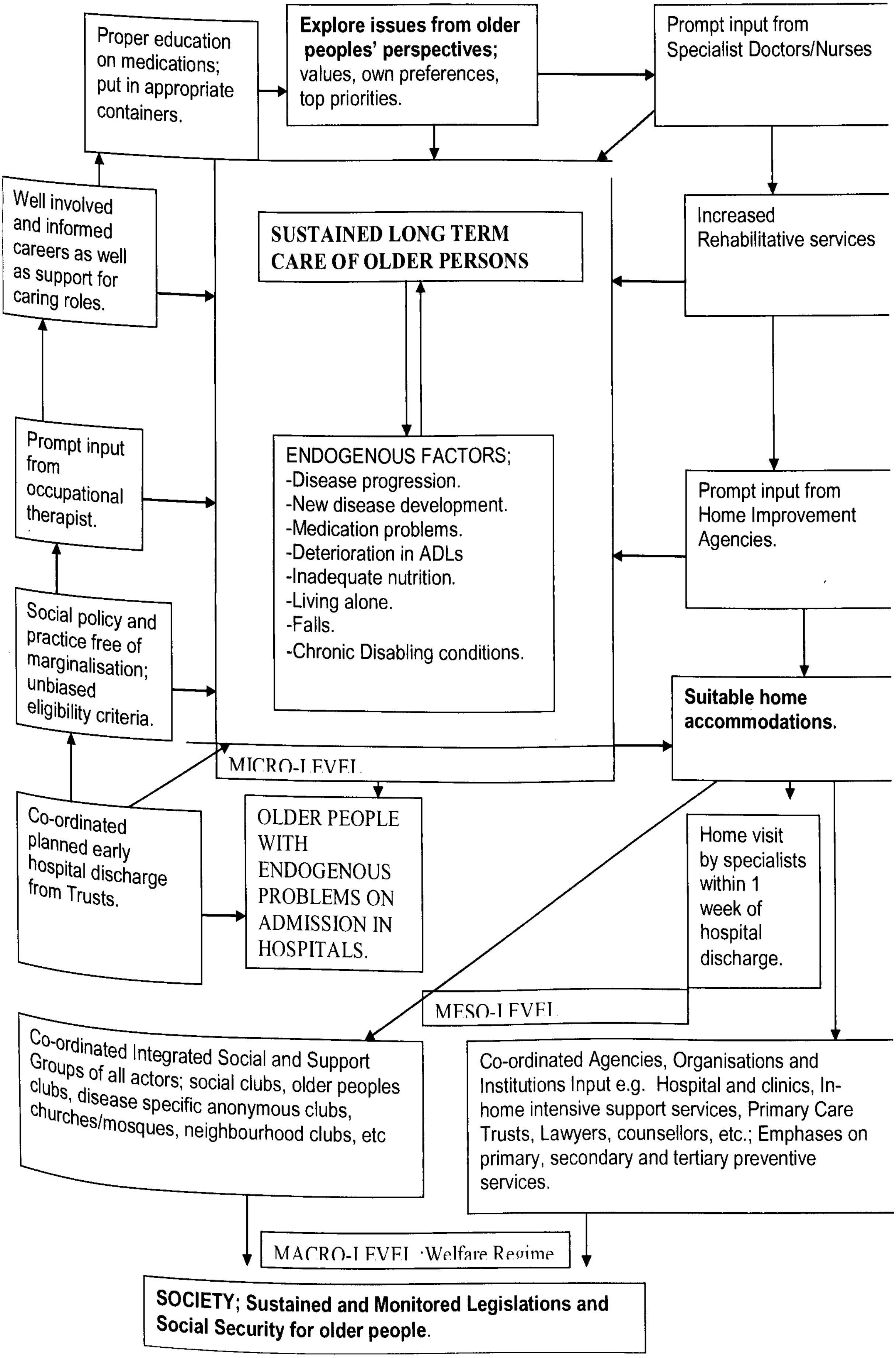
Although the literature search was conducted in a systematic manner it is possible that all relevant sources of literature may not have been accessed. Methodological issues in combining qualitative and quantitative studies were not considered. There may also be other theories relating to care of older people in their homes and prevention of readmissions but only the three highlighted ones were considered for the purposes of this thesis.

2.11 Final synthesis; line of argument translation of literature to achieve sustained long term care at individuals' home to minimise avoidable readmissions.

Following the literature review and themes/concepts that emerged, it appears that the successful implementation of sustained long term care at home can therefore be achieved through the use of this line of argument synthesis so as to minimise 59% of readmissions thought to be avoidable. Looking at the illustration in figure 2, individual older person admitted into hospital may have come with one or more micro-level problems also known as endogenous factor which may include progression of an existing disease, new disease development, medication problems, deterioration in the activities of daily living, inadequate nutrition, lives alone and may have experienced several falls. It is expected that from the first admission of the older people to hospital with such existing endogenous factors, a co-ordinated planned early hospital discharge that is practiced by all Trusts is commenced, This should involve all actors in patients discharge (the multidisciplinary team), such as doctors, nurses, social workers, occupational therapists, patients' family/carers etc, with the aim to assess this individual based on his 'need' and free from bias and marginalisation. There is a high need for the Occupational Therapists to promptly review older people's residents and involve the Home Improvement Agencies for necessary innovations in the home to support independence living at home. Patients' carers should be well involved and informed right from time of planning discharge to ascertain their readiness to care and provisions made for their respite care.

A good education of patients' medication is necessary to patients and their carers' with the medications put in appropriate easy to use containers and proper labels. There should be emphases on taking the medications as at when due.

FIGURE 1; FINAL SYNTHESIS; LINE OF ARGUMENT TRANSLATION TO ACHIEVE SUSTAINED LONG TERM CARE AT HOME & REDUCE READMISSIONS.



The need to send patients to rehabilitation centres will obviously ease off pressure on acute beds so there is a high need to acquire more rehabilitative centres for enablement and recuperation of older people before going home. It is also hoped that occasional home visits from the rehabilitation centres to their homes will enable the social workers and the occupational therapists to further assess the patients and determine their successful discharge home. After successful discharge home, home visits by specialist team relating to patients conditions is necessary within 1week of discharge for necessary advice and correction of newly cropped up issues that would have warranted readmission.

The successful stay at home will be further enhanced by involving older people in social activities of their interest to prevent boredom and isolation; hence introduce them to local social clubs, older peoples clubs, specific disease anonymous groups, churches, mosques, etc.

The co-ordinated integrated social and support groups of all agencies, organisations and institutions input such as in-home intensive support services, Primary Care Trusts, Lawyers, counsellors, etc.; involved in the continuing care of older people will prevent repetition of care, waste of time and resources, by clearly tracking the risk factors to avoid readmissions.

Above all these is a Social Policy that has older people at heart at the macro-level. This will be achieved by sustaining and maintaining policies that seek to protect the vulnerable older people as well as monitoring legislations and Social Security issues for older people.

This line of argument will not be complete without exploring issues that lead to readmission from older people perspective, especially from the ones who have experienced readmission after what we thought to have been a successful discharge home. It will provide a practical recommendation to services nationally about team work model, procedures, policies and resources to respond flexibly to heartfelt personal priorities expressed by older service users, which is the focus of the present research.

2.12. Summary.

The studies examined in the review in this chapter have provided a background and foundation for research into avoidable and non-avoidable causes of readmissions to hospital. All of the cited work has helped inform the design of this research. The rationale driving the present research is clear: the basic insight being that discussing readmissions with older people themselves will offer a distinctive take on the subject. The research reported on below was designed to provide an alternative to the other studies in the field by seeking rich descriptions of the causes of readmissions. Nonetheless, it shares a goal with most of the work in the field: a desire to identify and find ways of responding to the menace of 'revolving door syndrome'. How this was done through the research, as well as further explanation of the role of phenomenology in addressing the research questions will be outlined in the following chapters.

Chapter Three: Methodology and Methods.

> "A lived experience does not confront me as something perceived or represented; it is not given to me, but the reality of lived experience is there-for-me because I have a reflective awareness of it, because I possess it immediately as belonging to me in some sense. Only in thought does it become objective." (Dilthey 1985:223)

3.1 Overview.

This chapter has a number of intentions. Firstly, it sets out the aim and objectives of the study. Secondly, it provides an overview of the philosophical approach which has informed the research, namely phenomenology. Particular emphasis is given to the work of Alfred Schutz (1967) and the basic principles of phenomenology as it has been adopted here. It also provides a theoretical framework for thinking, in phenomenological terms, about the methods and outcomes of the present research. By relating phenomenology to the literature on the readmission of patients to hospital, the rationale for a phenomenological study in this particular area is further developed. The chapter furthermore details the methods used in the study, highlighting the sampling method and the strategies used to recruit patients and their carers. It also outlines the research techniques used and the way they were developed, as well as the approach taken to analysing the data.

3.2 Aim of study.

To explore older people and their carers' perceived reasons for readmissions to hospital, within three months of hospital discharge, in Merseyside in the North-West of England.

As earlier explained in the literature review, gaps remain in our knowledge regarding patient perceptions and views on the cause of their readmissions. This therefore necessitates further exploration of the issues. By exploring what older people had to say about their experiences of readmission, often a traumatic and disorienting moment in their lives, I wanted to show that we can learn important lessons when we listen to older people themselves.. My goal was to allow the people I interviewed, people whose voices are rarely heard on these subjects, to tell their own story, in their own terms (Daniel 2000).

3.3 Objectives.

1. To explore older peoples' perception of receiving care in their homes.
2. To explore the views of older people regarding the quality of care received.
3. To assess the views of carers on how adequate care-packages are and how caring for a chronically ill older person affects them.
4. To identify supports received by family and other carers in their roles.
5. To identify, in the home setting, the reasons that older people and their carers give as to why they were admitted to hospital and their views of what the future might hold for them.
6. To make recommendations to policy makers and practitioners based on the results from the study.

3.4. The Phenomenological Approach to studying hospital readmissions.

My PhD research was an attempt to engage older people who had experienced hospital readmissions on questions relating to their care. Focussing on first-hand accounts from older people and their carers, it explored their experiences of readmission and their suggestions for improving the services they received. In this chapter I am going to explain why I adopted this approach and how it helps us better understand the problem of readmission. The goal of phenomenological research is to produce descriptions of lived experience and in so doing, disclose the essence or character of those experiences. The term 'phenomenology' is derived from two Greek words: *phainomenon* which means 'that which appears' and *logos* meaning reason, word or reasoned inquiry. Phenomenology is, then, a form of reasoned inquiry into that which appears, that which is experienced. More particularly, it is an investigation of experiences from the perspective of those who experience them. The term Phenomenology was coined in the mid-eighteenth century by Husserl, who is commonly referred to as the father of phenomenology (Spinelli, 1989) Since then, many other philosophers have employed it at various times of their writing. Understanding how older people experience hospital admission and readmission requires exploration using qualitative methods. In chapter two, I argued that we know very little about patients and their carers' perspectives on the causes of hospital readmissions. Research of this kind will help to ensure that policy makers and health care practitioners have the best evidence-base upon which to base patient-centred practice in hospitals and in the community. As a number of researchers writing in this area have argued, exploring the perspectives and views of patients, particularly in the context of research on chronic conditions, will help inform preventive strategies for dealing with the problem of avoidable readmission (Charmaz, 1987; Kaufman, 1988; McWilliam et al 1996, Skilbeck, et al, 1998). In this study, understanding readmissions means understanding what older people and their carers value or find to be desirable, a kind of understanding that emerges out of people's subjectivities. As Alfred Schutz more neatly puts it, it is the study of the everyday world as it is experienced by the ordinary person. The study I conducted looked at what older people and their carers had to say about the experience of hospital readmission. I wanted to find out from them why they had ended up back in hospital and what that experience had been like. I also wanted to find out their thoughts on the nature and quality of the care they received, at home and in the hospital, and their views on how things could be improved. Rather than think about readmission in abstract terms, I wanted to find out about how it affected individual lives. For this reason I paid particular attention to the personal histories of those I interviewed and how readmission had affected them (Dahlberg and Dahlberg 2004).

There are two conceptual propositions supporting phenomenological method within qualitative research design. The first is that the reality of a set of human experiences will be uncovered through the detailed yet subjective descriptions provided by the people being studied (Creswell 1994) and second, that "establishing the truth of things" begins with the researcher's perception (Moustakas, 1994). Phenomenology is concerned with identifying that which is inherent and unchanging in the meaning of an item or idea under scrutiny. The three main schools of phenomenology are Husserl's (1963) descriptive approach, Heidegger's (1962) interpretive hermeneutic approach and the Dutch Utrecht School of phenomenology which combines characteristics of both (Given, 2008; Groenewald, 2004; Hamill 2010). The phenomenology of Husserl and the hermeneutic phenomenology of Heidegger and Gadamer share some similar components. Both of these traditions arose out of German philosophy, with their creators having worked with and influenced one another and each philosopher sought to uncover the life world or human experience as it is lived (Laverty, 2003).They sought to reclaim what they perceived had been lost through the use of empirical scientific explorations within the human realm. Both Husserl and Heidegger were convinced that the world that scientists believed as the world, based on Cartesian dualism, is simply one life world among many worlds. Both men called for a fresh look at our world and ourselves (Jones 1975; Laverty, 2003). Despite shared beginnings and common interest in lived experience from a perspective other than a Cartesian one, differences in direction arise between these two traditions. These differences emerge within ontological, epistemological, and methodological realms.

Heideggers hermeneutic phenomenology operates between a researcher's awareness of past experiences and the units of meaning identified in the data accounts of the research respondents. Each is kept apart from each other or held in suspension by *epoche*. The two states are taken through to reintegration when the items held in *epoche* are assessed for any synthesis with the flagged items data collected from the respondents. This revealed how the bracketed data would stand in relation to the respondents' data in order to suggest conclusion. The literature has generally treated bracketing and *epoche* as interchangeable or synonymous (Gearing, 2004; Beech, 1999; Ray, 1990; Spiegelberg, 1973). Gearing (2004) however, declared there are some underlying philosophical differences between the two terms, but they can be described or defined interchangeably "to reflect the similarity of their core essences". Gearing (2004) is not alone in identifying practical distinctions between *epoche* and bracketing. Variations of function and purpose are also argued by other researchers (Ahern 1999, Denzin and Lincoln 1994, Groenewald 2004 and Patton 1990). The distinctions emerge from how a researcher engages with data at the pre-empirical, collection stage and how that engagement shifts at the post-empirical stage. Patton (1990) described *epoche* separately from bracketing as "an-ongoing analytic process" which implies it should be dynamically integrated into the sequential progress of the whole research method from the very beginning of the study. A researcher then allows those personal ideas and feelings held in *epoche* to synthesise with those observations as interpretative conclusions. This is the process described by Gearing (2004) as 'reintegration' which consists of "...the unbracketing and subsequent reinvestment of the bracketed data into the larger investigation" *Epoche*, accordingly, allows for empathy and connection, not elimination, replacement or substitution of perceived researcher bias. Bracketing advances that process by facilitating recognition of the essence of meaning of the phenomenon under scrutiny. Gearing actually used the term 'unbracketing' to describe the event of removing the brackets which leads to a fusion between the two sets of information. The idea expressed in this fusion or *unbracketing* emerges as the interpretative statement. *Epoche* therefore is a habit of thinking which continues throughout the pre-empirical and post-empirical phases of the study. Bracketing is an event, the moment of an interpretative fusion and the emergence of the conclusion.

However, one major criticism of qualitative work has been the absence of clear-cut methodological descriptions and the failure of authors to describe the philosophy underpinning the methods employed in research (May and Pope 2000). It is for this reason that Schutz's methodological position has been highlighted. Schutz attempted first to clarify the nature of social reality, describing in depth what he termed ‘the phenomenology of the social world’, before moving on to indicate how actors sustain that reality based on an understanding of each other's “in-order-to motives” that is framed in typical terms. Given this account of social reality, it is one in which actors give meaning to their world by interpreting it (Schutz 1967), Schutz's methodological position is set out in three essays in Volume 1 of his Collected Papers, entitled ‘The Problem of Social Reality’ (Schutz 1962). His starting point is that social research differs from research in the physical sciences by virtue of the fact that, in the social sciences, one is dealing with 'research objects' that are themselves interpreting the social world that social scientists also wish to interpret. People are engaged in an on-going process of making sense of the world, in interaction with their fellows, and social scientists seek to make sense of their sense-making. In doing so, social scientists must inevitably make use of the same methods of interpretation as does the person in his or her 'common-sense world'. Schutz (1967) argues that the appropriate method for social science involves developing constructs of everyday actor's constructs (Endress et al. 2004; Natanson 1986;). It is with this understanding that Dilthey (1977) argued that human experience was to be understood and disclosed (through the operation of ‘verstehen’), rather than explained or measured. The new conceptualisation of the social sciences also involves encouraging previously unheard or marginalised voices like older people living in the communities.

Phenomenology has typically involved an examination of conscious experience from the subjective or first person point of view. It involves the study of the structures of various types of experience ranging from thought, memory, imagination, emotion, desire, volition, bodily awareness, embodied action and social activities including linguistic interaction (Given, 2008; Hamill 2010). Phenomenology, per se, is a branch of philosophy, owing its origin to the work of Husserl (1962). Phenomenology seeks to understand how persons construct meaning and a key concept in that effort is ‘intersubjectivity’. The challenge for a researcher is to allow the voices of subjectivity to emerge authentically in coming to an understanding of what essentially the research respondents mean in their personal accounts expressed through the data collection devices. My phenomenological preference for this study is Husserl's approach--the description of ordinary human experiences as perceived by each individual and it involves four main steps: bracketing, intuiting, analysing and describing (Given, 2008; Hamill 2010). This placed upon me as the researcher, the obligation to separate any past knowledge or experience I might have had readmissions but then to legitimise that experience by connecting it to the descriptions of the participants. Such a connected relationship was only made possible by the concepts of bracketing. Gearing's (2004) identified six typology for *epoche* and bracketing which was applied in this study as follows;

Stage one: Iterative reading and 'flagging' items; in this stage each interview transcript was read repeatedly. I flagged items in terms of their relevance to the general areas canvassed by the interview questions, including the probe and follow-up questions.

Stage two: Establishing topics of significance; the flagged items constituted a preliminary list for clustering into topics of significance. A strict discipline was applied not to allow flagged units from one interview to influence selections of units from any other. A substantial degree of coding was applied during Stage 2, and later decisions to flag further items were seen as part of the progressive development of data.

Stage three: Establishing thematic linkages; common ideas or themes surrounding the topics of significance were then re-assessed and subsequently identified and clustered by coding them together as the major contextual issues. I remained alert not to allow my own professional experiences to contaminate the distinctive voice of the participants.

Stage four: Examining the flagged items for meaning. In hermeneutic phenomenology, this stage would involve inserting hypothetical ideas and random thoughts based on my past experiences on readmissions but for descriptive, I am to remain faithful to the rich descriptions of the study participants and later rename them in readiness for the write up. Themes not assigned to a topic of significance, were not discarded from the data but transferred to a miscellaneous category in case their significance to the holistic impact of any aspect of readmissions may became important. Minority voices were thereby retained because they are important counterpoints to bring out regarding the phenomenon researched.

Stage five: Reintegration This phase represented the climax of the *epoche* and bracketing application and included an additional test as to its authenticity. At this stage, the relationship of all the respondents' data was finally selected and all insignificant ones removed.

Stage six: Fashioning the unity of the study. Direct quotations from the interview transcripts were used to amplify and illustrate each theme and subthemes. These summaries were then gradually integrated into the text of the four descriptive chapters of the result section...

By going through these stages many of my own implicit assumptions about the capacities of older people were challenged. Even those with the best intentions can find it difficult to break free from stereotypical views of older people, what they are capable of doing and what we can learn from them. Nonetheless, as I hope to show, it is extremely important that we do so. There is a need for a public examination of the ways in which older people are treated within the health service, particularly at the point of readmission when they are often most vulnerable and older people can make one of the most significant contributions to that debate. Qualitative research designs are particularly useful for exploratory inquiry and for understanding context from an individual's perspective (Cresswell 1998, Denzin & Lincoln 1994). In the literature on health and health care, qualitative research is alone in attempting to focus on specific experiences of illness and chronic condition and to reflect the interaction between a health care professional and the patient (Thorne 1993; Hair et al 2000). Qualitative research aims to understand people's experiences and interpretations of life events. Qualitative research explicitly acknowledges the complexity of life and human relationships (Murphy and Dingwall 2003). Drawing on these studies and the philosophical and methodological literature discussed above, I argue that there is a need to include the views and experiences of people who have experienced readmission in research. Exploring different methods is one of the ways in which a qualitative methodologist matures, where that process is driven by an investigation of the philosophies that underpin various types of studies (Fine 1994). The social scientist believes that people, including those who participate in research, should be treated as persons rather than as natural objects (Schutz 1967; Van Langenhove 1995;).

3.5. Pilot Study.

Before embarking on the study proper, I conducted a pilot (Colaizzi 1978). In-depth interviews were initially conducted with five older people and two carers who had experienced readmissions to hospital in an intermediate care unit in a care home situated in Liverpool. The purpose of this was to test out the questions I planned to use in order to elicit accounts of readmissions. The pilot study was undertaken to establish the feasibility of sample recruited and to test the reliability of the methods of data collection from intermediate care units. On completion of the pilot study, the study methods were reviewed and the topic guide for the in-depth interviews was revised before the main study was conducted. Lines of questioning were introduced to verify the accuracy and consistency of responses. The deliberate sampling of subjects who are able to explain through experience the phenomenon being studied worked to ensure the validity of the study (Glaser and Strauss, 1967; Polit and Hungler, 1995). Older people and their carers who had experienced readmissions were the most credible sources of information about the experience of readmissions. These interviews were included in the final data analysis. Participants in the pilot study were recruited using the same methods described above. They were informed that they were participating in a pilot study for a larger piece of qualitative research and that results of both the pilot study and final qualitative study would be made available to them if they desired. The results of the pilot study interviews were systematically analysed according to the method described in more detail below. As hoped, the pilot showed that older people and their carers had a great deal to contribute on the question of readmission and were more than happy to share their experiences with someone they were not directly acquainted with. There were more pragmatic benefits too. Following the pilots, the main interview question was reconfigured in order to more effectively elicit accounts of experiences of readmissions to hospital.

3.6 The Research Questions.

The principal research questions that guided this study were:

What are the reasons leading to hospital readmissions among older people?
What are older people and their carer's perceptions of hospital readmissions?

Secondary research questions

After an older person has been admitted into hospital, if a return home is possible, support packages are put in place to provide the health and social care that person needs to remain there for as long as possible. These support packages are used to prevent unnecessary hospital admissions and the need for long term residential care. This raises the question;

what do older people and their carers feel about the care and support they receive at home?

Older people are supported at home by informal carers such as family members, friends or neighbours as well as formal carers and this study has explored their views on readmissions. This is captured in the next question; how does caring for chronically ill older people affect carers? Since carers need support too, it is important to ask another question; what support is received by family and other carers?

A pilot study was conducted and revealed that some older people have access to a form of home telecare, so, one of the objectives of the research was to find out why it was not being used.

3.7 Methods

3.7.1 Participant Selection. Sampling

Table -Description of study participants and their carers

The approach taken to sampling in qualitative research is flexible. It is guided, at the start, by questions that are fairly broad and unfocussed in scope. Whom should I talk to? What should I be looking for? Where am I likely to find the sources of information most relevant to my study? How might my understandings be challenged or enriched by what I might learn? (Cuba and Lincoln, 1989; Patton, 1990)

My aim was to learn about patients and their carers' perceptions of hospital readmission. Given my interest in older people, I specifically wanted to talk to those aged 65years and above. I was most interested in those who had actually experienced readmissions as well as the carers who had been with them during particular episodes (Creswell 1998; Flick 2006;).

Interested in contacting individuals in this position, I made contact with the Research Governance and Development Manager of Liverpool, where I practice and observed the problem, and that of Halton and St Helens Primary Care Trusts (PCTs), the region in which the research was to be conducted, who particularly showed interest to the research by providing part sponsorship for the research, to seek advice on how best to access possible research participants. I was informed that as a result of data protection policy in the NHS, a researcher can have no contact or access to details of participants until they have been introduced by the Trust and those contacted have indicated an interest in participating in the study being proposed. These guidance and protocols were strictly adhered to.

Purposeful sampling; in this study, selection of study participants was by Purposive sampling .This is a non-probability sampling which does not involve random selection of participant, unlike probability sampling that does. Also in probabilistic sample, there are the odds or probability that the population is well represented in which case, confidence intervals can be estimated for statistics but non-probability samples does not depend upon the rationale of probability theory. Non probability sampling could either be accidental or purposive. In accidental method, the researcher may ask for volunteers to participate in the study or use members of the population based on their relative ease of access (Given, 2008; Lincoln and Guba, 1985; Ritchie and Lewis 2003). On the other hand, purposive sampling permits the selection of interviewees whose qualities or experiences permit an understanding of the phenomena in question, and are therefore valuable. One of the first thing the researcher does is to verify that the respondent does in fact meet the criteria for being in the sample. It is a strategy where Lincoln and Guba (1985) describe as 'emergent and sequential

Other methods of purposive non-probability sampling are; *snowball sampling,* in which people who meet the criteria for inclusion in the study are first identified and they in turn recommend others who they may know who also meet the criteria. *Stratified Purposeful sampling* Illustrates characteristics of particular subgroups of interest and facilitates comparisons. *Critical Case purposive* permits logical generalization and maximum application of information to other cases because if it's true of this once case it's likely to be true of all other cases while *Criterion purposive* *sampling* includes all cases that meet some criterion for the study. On the other hand, *Deviant Case sampling selects* cases that substantially differ from the dominant pattern while in *Case study* the research is limited to one group, often with a similar characteristic and of small size (Given, 2008; Miles and Huberman, 1994; Polit & Hunglar, 1999; Ritchie and Lewis 2003)

This study utilised the criterion purposive sampling in which older people age 65years and above and who are able to recall their experiences of readmission to hospital are selected. It was difficult to estimate the sample size of this study at the outset because the strategy was to conduct interviews until a 'saturation' point was reached, i.e. when the accounts I was being given of readmission by participants no longer added anything new to the descriptions I had already had. In the end a total of 30 interviews were conducted.

The nineteen older individuals who eventually took part in the study suffered from various chronic disease conditions, like COPD, liver and kidney conditions, malignancies, arthritis with reduced mobility, and some were incontinent, while others suffered partial or double incontinences due to stress or bladder and rectal sphincter weaknesses, typical of older age. They also had widely differing experiences of hospital readmission. Also the eleven carers who were either wives or children to the older people gave their own view of the experiences of readmission for the older people they cared for. Interviews with them were recorded, and this allowed me to immerse myself in the data through repeated listening. This had two distinct analytical advantages. On the one hand, I could be sensitive to the ways in which each participant framed their own experience of readmission and gave reasons as to why it had occurred. On the other hand, familiarity with participants' accounts also enabled me to see commonalities across them (Atkin 1991; Cresswell 1998;).

Phenomenological studies are generally quite small scale, and phenomenological researchers generally do not normally specify participant numbers prior to commencing data collection. The question of how much data to collect is informed by the data collection itself and what it reveals cumulatively about the structure of the phenomenon in question (McIntosh, 1997). Sufficient data has been collected when a 'saturation' point has been reached: when the accounts the researcher is given in subsequent rounds of data collection do not vary significantly from the descriptions they had been given before. This is sometimes referred to in qualitative research as 'the principle of redundancy'. Phenomenological researchers have found that this 'saturation' point is often reached with about 5-8 participants (Simms, 1994; Fischer, 1995, cited in McIntosh, 1997). Apart from this research-based way of arriving at the number of participants required to describe essential features of a given phenomenon, the principle of comparatively small participant numbers is also grounded in theoretical elements of phenomenology. Phenomenological philosophers emphasise the 'shared' nature of consciousness, the inherent logic of human experience (Husserl, 1931; Merleau-Ponty, 1976). Therefore, any human subject is, in principle, able to access the logic of a given human phenomenon.

3.7.2 Recruitment strategies.

3.7.2.1 Patients.

I made contact with Primary Care Trusts for the identification of participants. Participants were identified through PCTs from the database of Rapid Access and Referral Service (RARS) of Halton PCT, and through the 'Enabling Team' at St Helen's PCT. Both RARS and Enabling Team are centres in Halton and St Helens respectively that arrange intermediate care for patients including older people so that rehabilitation service that aims to help people regain the best possible level of independence following illness are planned for them. The intermediate care units are often described as a bridge between hospital and home and also aid in the recuperative process following on from hospitalisation or to avoid hospital admissions.

An initial approach was made by staff from the intermediate care units and staff from Halton and St Helens Primary Care Trusts who explained the research to possible participants (see appendix 1and 2). They read through a covering letter from the PCT which outlined what the request was about and provided a package containing further information, an expression of interest from and a stamped addressed envelope to be returned by those who wanted to take part (see appendix 3 and 4). As part of the methodology, the information leaflets and the expression of interest forms were word processed with Arial 14 for easing reading for older people, and printed off in cream-coloured paper to make is easier for those that may be dyslexic (see appendix 1 and 2). After contact was made by PCT staff, I contacted those who had shown an interest in participating in the study to further explain the study as well as to give them details about the interview process.

Table 3; Description of study participants and their carers

Older People						Main Carers				
S no	Names	Sex	Age in years	Conditions	Locations	Names	Age / yrs	Sex	Relationships	occupations
1	Emma	F	92	Anaemia, Arthritis., Reduced mobility.	Widnes	nil				
2	Josie	F	88	Ca breast, DVT, Congestive Cardiac Failure (CCF) Multiple drug reactions.	St Helens	nil				
3	Jane	F	90	Ca uterus, Arthritis. Reduced Mobility, Hypertension	Halton	Davina	44	F	Daughter	Teacher
4	John	M	89	Cerebro-Vascular Accident (CVA), Anaemia, Ca Prostrate	Widnes	Matilda	82	f	Wife	Retired
5	Agnes	F	86	Mastectomy for Cancer breast, Reduced Mobility, CVA, Arthritis	Liverpool	Mrs Derrick	43	F	Daughter	Secretary
6	Martha	F	81	Arthritis, Anaemia, Chair bound	Halton	George	38	M	Son	Part time jobs

7.	Audrey	F	93	CVA, Arthritis. Immobile, hoist transfer	Halton	Tina	55	F	Daughter	Caring job
8	Janine	F	75	Fall with fracture Ulna and Radius CVA	Liverpool	Nil				
9	Mina	F	77	COPD. Anaemia, mild CVA	St Helen's	Nil				
10	David	M	83	Fall with fracture head and femur	Halton	Nil				
11	Daniel	M	93	. No mobility wheel chair board. CVA	St Helens	Nil				
12	Suan	M	90	Fall, arthritis reduced mobility Renal Failure.	Widnes	Nil			Shopping done by sons	
13	Margaret	F	89	Deceased	Widnes	Martin	M	62	son	Disabled
14	Jim	M	86	Deceased	Widnes	Mabel	F	85	wife	Retired
15	Victor	M		Deceased	Halton	Nadine	F	14	wife	Retired
16	Joan	F	89	Reduced mobility, Falls Fracture Humerus	Liverpool	Betty	F	59	daughter	Caring job
17	Emily	F	95	Chair bound, CVA, Renal Failure	Halton	Shedrack	M	56	Son in law	Handy man
18	Abigail	F	88	Insulin dependent diabetes, (IDDM) arthritis fall, reduced mobility	St Helens	Formal carers				
19	Allan	M		Deceased.	Liverpool	Vera	F	75	wife	retired
20	Eileen	F	87	COPD arthritis falls	St Helens	Nil				
21	Moss	M	88	Falls, Fractured neck of femur	St Helens	Nil				

22	Diane	F	92	Vertigo CCF IDDM	St Helens	Formal carers				
23	Leonard	M	89	Renal failure NIDD cancer of prostate	St Helens	Nil				

I explained that their participation was entirely voluntary and that they have a right to withdraw at any stage. Having obtained written consent, (see appendix 5 and 6), the interviews were set up. Fifteen interviews were conducted in participants' homes while five took place in intermediate care units.

Five of the patients visited at home were said to have died within six months of my visit and only four of the carer were interested in having an interview as regards the experiences of their patients' readmissions while one declined.

3.7.2.2 Carers.

The carers who participated in the study were identified through the older people I contacted via the PCTs. Those who had designated carers were asked if their carers could be approached for the study. The same procedure used to recruit older people was used in the recruitment of carers. While carers were interviewed in the same location as those they cared for, they were interviewed separately in order to maintain confidentiality and allow each party to express themselves freely. A total of eleven carers were interviewed including four of the carer whose patients were dead but were still interested in having an interview as regards the experiences of their patients' readmissions while one declined as she was still too emotional about it. Table 3 shows the distribution of the carers and their relationship to older people. The distribution show four daughters, who are also active in other employments, two sons, one of which does part time jobs and one that is disabled; four wives who are all retired; and one son-in-law.

3.7.2.3 The principle exclusion criteria.

1. Patients aged less than 65years.
2. Patients who had experienced admission but not readmitted to hospital.
3. Patients readmitted to hospital after 3 months of hospital admission.
4. Carers who have not seen patients experience readmission within 3months.

3.8 Rapport.

It is important to establish and maintain rapport between a researcher and participant in order to elicit good quality data (Hamersly and Atkinson 1991). I had the opportunity to meet each participant face-to-face on two occasions and I wanted to make best use of this personal contact to build relationships with those who had agreed to share their experiences of readmission with me. Following an initial phone call, I visited participants to further explain the study and arrange a time for the interview when I would return for a second time. These first contacts gave me a chance to get to know those I was talking to, and for them to get to know me, as well as to gain some insight into their personal situation ahead of the interview proper.

By background I am a nurse, an educationalist and a health-service manager. I am now a researcher. I am a person who tries to constantly question the world around them. I am also human, and so vulnerable. Nonetheless, whatever weaknesses I may have, I strive to be true to myself and others. This is reflected in my orientation to conducting this research. I have not personally experienced readmission but, through past work in an intermediate care unit, I have been in direct contact with older people who have. My objective was to describe what older people and their carers go through, being as true to their accounts as I could, to those who had neither direct nor indirect experience of hospital readmission and the impact it has on individual lives.

When I visited older people for interview, I made it clear to them that, although I was a nurse, the purpose of the meeting was not medical but to hear about their experiences of readmission. However, knowing that I was a nurse, someone with experience in this particular area, made them open up to me and relax more during the interview than they perhaps otherwise would. Whether a significant factor or not, during the interviews participants were certainly at ease and felt able to speak freely, something which added depth and richness to the stories they told because it provided scope for extended discussion around often sensitive matters (Holstein and Gabrium 1994).

Although much information was not actively solicited, through talking to participants I learnt a great deal about their extended relationships and family ties, the situation they found themselves in now, including where and how they were living, but also how life had changed for them over time. One participant took me on a tour of their back garden to see the flowers they had spent so much time cultivating. Another invited me to see their bedroom to admire decorations made for them by their children.

There were some problems. Occasionally it became difficult for me to separate my function as a nurse and as a researcher. When participants asked for my professional opinion, particularly around medication, I felt I had to respond by offering basic advice. Thus, for example, I tried to dispel confusions that had arisen because of the colour of different medications. At all times, however, I made sure to refer them back to guidance they had been by the medical staff they had already been in contact with.

3.9 The Interview Questions.

A list of questions designed to allow participants to express a broad range of views were at the centre of the in-depth interviews I conducted. Although these questions helped focus the interviews, keeping them on topic, there remained plenty of scope to explore ideas areas of participants' experiences that had not and could not have been anticipated at the beginning of the research (Ritchie and Spencer 1994; Spradley 1979,). The interview was a means of learning about the life world of the participants. Although I did have a topic guide (see appendix 7), I did not strictly adhere to it as the flow of the interview was directed by the manner in which participants responded to the questions I put to them. Some participants were more interested in some concepts than others, and dwelt more on them (Flick 2006).

I was guided by Holstein and Gubrium's account of good practice in the 'active interview' (1995). Within this approach to interviewing, the interviewee is treated as an active rather than passive participant who contributes equally to the interview process and shapes its results. The idea of the interviews was, therefore, to treat the interviewee as a co-inquirer rather than an object of study.

As part of purposive sampling, none of the participants in the study suffered from dementia. They were perfectly able to talk at length about their experiences, to communicate their feelings and to reflect thoughtfully on their situation. From my perspective, it was they who had the expertise in readmission and it was my role to access and communicate something of what that expertise rested on (Gough and Madill 2007). Given this emphasis on the knowledge possessed by the participants, it was important that the interviews faithfully captured their perspective. In-depth interviews were chosen over focus groups because I felt there would be more opportunity to listen to the views of older people, and to relate those views back to the experiences they were shaped by, on a one-to-one rather than group level. They also seemed more appropriate given the sensitive and private nature of the matters I wanted to discuss.

My experience of working in intermediate care unit also helped me in the choice of the topic guide for the interview and on what prompts to use. Indeed, more generally, my particular background made it easier for me to do research of this kind with older people (Hollway and Jefferson 2000). Phenomenological research emphasises approaching the topic afresh without preconceived notions about what one will find in the investigation (Polkinghorne, 1989). Therefore, following Fischer and Wertz's (1979) self-reflective method of conducting interview, I began by reflecting back on the knowledge of readmissions I gained through working in an intermediate care unit. This self-reflective process, which Colaizzi (1973) terms 'individual phenomenological reflection', helped me to become more aware of and to 'bracket out' my presuppositions and assumptions. It also increased my awareness of my own biases, biases which may otherwise have 'bridled' how I thought about the research (Dahlberg and Dahlberg 2004; Drew, and Nystrom 2002).

With respect to analysing the data what this meant in practice was as follows: if a similarity was noted between what was said by participants in the interviews and aspects of my own experience or the knowledge of readmissions I gained through my review of the literature and my understanding of this area, I looked at the interview materials again. I asked myself: is this interpretation arising from the material or am I imposing my understandings on it? This process was conducted in a repeat fashion throughout the research as a whole.

The interviews with older people were meant to provide a way of exploring their experiences and perspectives on hospital readmissions and the tangle of issues surround them, and were structured as shown in appendix 6. Similarly, the interviews with carers were designed to explore readmission from their perspective as significant others within those processes. See appendix 8.

A summary of the points made by participants was presented to them at the end. Each participant was asked whether that summary captured what they had to say and whether they wanted to add anything they may have forgotten. The interviews generally ended on a positive note. I thanked them for taking part in the study and the participants in turn thanked me for the opportunity to voice their opinions.

3.10. Data Analysis. Phenomenological approaches to data analysis.

The current section examines the models and specific forms of analysis used in phenomenological and qualitative studies more broadly. There is no single 'phenomenological method' of analysis used in every case. Phenomenological psychology advocates processes of analysis that evolve in contact with the phenomena in question, here readmissions (Wertz, 1983). The method of analysis used in this study is based on McIntosh's (1997) combination of Giorgi's (1975) classic technique of phenomenological analysis for qualitative studies and orthodox thematic analysis (Braun and Clark 2006; Pope et al 2003). Phenomenology relies on two main techniques to prevent bias. The first is bracketing, which involves suspending one's preconceptions and presuppositions. This is done by laying those preconceptions and presuppositions out in as clear and complete a form as possible (Valle et al., 1989). Polkinghorne (1989) describes bracketing as a process self-reflection whereby the investigator comes to examine her own beliefs, in order to become aware of any hidden or potential presuppositions and biases that could change the way they obtain the data and interprets the results. It is one of the key features of phenomenological methodology and is done not only before the interviews are performed but also repeatedly throughout the data analysis. The second way of preventing bias is the use of imaginative variation. This involves playing with the sentences to see if they could have more than one possible meaning. Where a sentence was found which had more than one possible meaning, the protocol was checked to see if other sentences clarified it. When the meaning of a statement made, through reflection, remained in doubt, participants were asked during the course of the interview to please explain what they meant in the form of debriefing since there were no other contacts with the residents.

As Polkinghorne's (1989) points out in an account of phenomenological analysis, analysis has both a nomothetic and idiographic aspect. In the philosophy of science, scientific analysis has typically been described in either of these two ways. Basing its name on the Latin root, *nomos,* this means; laws, consistencies, or regularities. Nomothetic science is concerned with the search for patterns and uniformities in social life (Crotty, 1998). By contrast, the Latin root *idios* is used to mean individual or idiosyncratic aspects of reality. Idiographic science is therefore concerned with the analysis of the individual in order to understand that which is unique and is concerned with the variability of individual behaviour. Qualitative research involves either idiographic or nomothetic investigation, or some combination of the two. This study had elements of both. The purpose of the analysis was to derive a description of key features or 'logic' of the experience of readmission from the collection of individual interviews I collected (Polkinghorne, 1989). This was done by unravelling, for each in-depth interview, the constituents of the experience and the interrelationship between, resulting in a description of their 'individual structure'. This was an idiographic analysis. I then began to look at patterns across individual cases, looking for what was common to them, in an attempt to identify the 'general structure'. This was a nomothetic analysis. The process by which I arrived at an account of individual and general structures will be addressed in turn.

The Analysis Leading to Individual and General Structures.

The starting point for reflection was the individual phenomenal description, the naïve description of the phenomenon provided by participants about their experiences of readmissions, the affect it had on them and the alternatives to readmission they talked about. After reading transcripts of the interviews several times to get a sense of the whole, the text was broken down into 'meaning units'. (Giorgi, 1975). This process requires the researcher's judgement and care has to be taken to treat the text in its own right. It was vital that I immersed myself in the data so that I could become familiar with the depth and breadth of the content. Immersion involved transcribing and repeated readings of the data, actively searching for meanings and patterns (Edwards, 1993; Poland, 2002; Riessman, 1993). I read through the entire data-set three times before I began coding sections within the transcripts. My ideas were shaped as I read along and this reading and rereading provided the bedrock for the rest of the analysis. During this phase, I also started jotting down notes that I went back to in subsequent phases.

In coding the data I was attempting to identify features of the data that were germane to my topic and interested me. The process of coding the data into meaningful groups and the coded sections became the basic building blocks that I built my analysis out of (Boyatzis, 1998; Miles and Huberman, 1994; Tuckett, 2005;). The codes I used related back to both my research questions and themes whose importance became clear in the course of the interviews. Coding was performed both manually and through NVIVO '08 software programme (Kelle, 2004; Seale, 2000)

I worked systematically through the entire data set, giving full and equal attention to individual items, and identifying aspects of interest. I worked by writing notes on the transcript texts and by using highlighters to indicate potential patterns or themes. All the data extracts I identified in this way were coded, and then collated. This enabled me to write out a preliminary thematic mind 'map', a sketch of the data patterns, and relationships between them.

Next, I re-focused the analysis at the broader level of themes, rather than codes, a process which involved sorting the different codes into thematic areas, and linking all the relevant extracts to those areas where they fit best. This was undertaken following Wertz's (1983) approach of: empathic immersion in the world of the description; slowing down and dwelling; magnification and amplification of all details related to participants' situations; suspension of disbelief; employment of intense interest and careful reflection; and the turn to the meanings attributed by participants to their situation rather than the facts of the situation alone. A broader analytical scheme emerged naturally from this process.

By using induction, I elaborated and initially classified themes into factors that directly connected to individual participants, i.e. *micro-level factors*, factors arising from the organisation of health care, i.e. *meso-level factors*, and wider societal factors, i.e. *macro-level factors*. This process was iterative, in the sense that I would return to individual interviews to check my analysis. Any new themes that emerged were considered and used to refine my overall analytical scheme. This process was repeated until the researcher felt satisfied that the themes reflected the nature of the participant's experience of readmission to hospital, when the structure of individual cases could be clearly discerned.

Analysis was then conducted across cases in order to arrive at the general structure. The aim of developing a general structure was to 'see past' the specific, situated context of the individual structures in order to provide a detailed description of those aspects of readmission that hold across individual situations. The process of analysis used to arrive at the general structure was similar to the analysis used to arrive at the individual structures. The analysis proceeded along the four stages proposed by Wertz (1983) for nomothetic analysis. As with the analysis for the individual structures the stages overlapped with each other rather than remaining clearly distinct. The stages included:

Seeing general insights in individual structures; the goal of this phase was to determine which features of the individual structures were common across cases and which were not. This involved reflecting on constituents of the individual structures and considering whether these constituents refer only to the particular case or whether they refer to all of the available cases.

Comparison of individual descriptions: This involved looking for evidence of each of the constituents in all of the individual cases, thus establishing convergences and divergences between the descriptions. The convergences provided the basis for a general statement about readmissions. Essentially, I was starting to analyse the codes and consider how different codes might combine to form overarching themes. Both tables and mind-maps were used. I also started thinking about the relationship between codes, between themes, and between different levels of themes (e.g., the main overarching themes and sub-themes within them). Some initial codes went on to form main themes, whereas others formed sub-themes. At this stage, a 'miscellaneous' theme was initially created to house the codes that did not seem to fit into any other themes. Based on this work, I started to gain a sense of the significance of individual themes. This was the point at which I interpreted the data in relation to arguments concerning how older people and their carers perceive readmission (Boyatzis, 1998). This process consists of a recursive movement between the structures of each individual transcript. It was this that enabled me to arrive at higher-order themes.

Imaginative variation: As in the individual analyses, imaginative variation is employed to achieve the desired generality. Imaginative variation at this general level helped to clarify how far I could legitimately generalise from individual cases to shared structures.

Explicit formulation of generality: This phase involved two levels of reviewing and refining the themes. Level one involved reviewing at the level of the coded data extracts, in order to work out whether they formed a coherent pattern. If not, they were used to create a new theme. Level two involved a similar process, but in relation to the entire data set. At this level, I considered the validity of individual themes in relation to the data set but I also examined whether or not each candidate thematic map 'accurately' reflected the meanings evident in the data set as a whole. The entire data set was reread to ascertain whether the themes worked in relation to it and to code any additional data within themes that has been missed in earlier coding stages. Some re-coding needed as coding is an ongoing organic process.

Themes were then further refined. I looked at each theme in relation to the others and thought about whether or not a theme contained any sub-themes. In most qualitative research, there is a tension between the accounts of those whose experiences are being studied (i.e., 'the emic') and the outsider perspectives of the researcher or observer who is conducting that study (i.e. 'the etic'). The way we as researchers align ourselves with these perspectives has profound implications for how we conduct analysis. The emic perspective most closely aligns with an idiographic approach, a case-based position that, in this case, foregrounds the specifics and constraints of everyday life following hospitalisation (Denzin and Lincoln, 2003). Adopting an emic perspective meant seeking to understand the multiple ways in which older people view the reality of which they are a part. Adopting an etic perspective, by contrast, means placing a greater emphasis on the ways in which pre-existing theory, empirical findings and existing policies shape how researchers orient their own inquiry and make sense of the results. Both emic and etic perspectives are necessary for good analysis. The qualitative researcher should start with the "native's" emic point of view but then attempt to make sense of that point of view in relation to the etic tools of scientific theory and prior research and policies formulated following other studies. How the researcher comes to think about the products of her analysis is contingent on her epistemological beliefs. Since I have taken a phenomenological approach, there is some blurring of the boundaries between these different modes of interpretation, something which reflects the fact that the etic and emic interact in older people's accounts (Daly, 1997; Geertz, 1983) Having conducted my analysis, an initial categories, themes and subthemes were formulated which were later renamed and I decided to write my report under the following five main themes as illustrated in table 4. These are:

Information, Engagement and Choice of Care
Inadequate service provision
Service provision from health and social care.
Nutrition, Co-morbidity and Social Isolation
Nightmare of social care without social ties

Findings organised according to these themes and their subthemes will be reported in the next section.

Table 4; Showing the process of arriving at main themes and renamed subthemes for the results write up

CATEGORIES	INNITIAL THEMES	SUBTHEMES
1.Mezzo-level Problems (Problems from Health and social services.	1.1, Ignorance of available services.	1.1.1. Lack of information 1.1.1.1 Changing health and social policies. 1.2 .1. Care at home, otherwise loss of extended self]
	1.2 Preference of where to receive care	I.2.1.1. Home is mine 1.2.1.2 .Safety 1.2.1.3. Comfort 1.2.1.4. Self care 1.2.1.5. Security 1.2.1.6. Independence 1.2.1.7. Freedom
	1.3.Caring problems.	1.3.1. Caring stressful 1.3.2 lack of respite care 1.3.3. No support for informal carers 1.3.4.Training for formal carers 1.3.5.Short time of caring for formal carers 1.3.6 No sustained care after hospitalisation 1.3.7 non involvement in care
	1.4 Problems with mean-tested social care	1.4.1 Expensive 1.4.2 Living with Unmet needs 1.4.3 Prescribed care 1.4.4 Attitudinal problem 1.4.5, Short time of caring
	1.5 Introduction of	1.5.1 Early discharge from hospital

	re-imbursements.	1.5.2 Pressure on acute beds 1.5.3.Acute unbearable pain
	1.6 Treatment and medication problems.	1.6.1 Polypharmacy 1.6.2 Compliance 1.6.3 Mental confusion 1.6 4 Reactions 1.6.5 Wrong treatments 1.6.6 Reaction to treatments 1.6.7 Patients own strategy 1.6.8 Medication education.
	1.7 Lack of information across acute and community care	1.7 1 Delay in support for independence living at home 1.7.2. Lack of care continuity.
<u>2.Micro-level problems (From individual older person)</u>	2.1.Frailty with increasing age.	2.1.1 No energy for activities
	2..2 Inadequate nutrition	2.2.1 Inability to cook 2.2.2 Late and lack of delivery of meals-on-wheels
	2.3 Progression of chronic disabling conditions	2.3.1 No social life outside home
	2.4 New disease development	2.4.1 Co-morbid conditions.
	2,5 Living alone with unmet needs	2.5.1 Help from sons/daughters/ 2.5.2 Help from cousins/nephews/neighbours 2.5.3 Social care provision.

3. Macro-level problems (National problems)	3.1 Changing national policy on health and social care	3.1.1 Confusion on sources of help. 3.1.2 Need for sustained national policy 3.1.3 Need for transparent eligibility criteria for care provision system on grounds of need.
CATEGORIES	RENAMED THEMES	RENAMED SUBTHEMES
4.Mezzo-level /Macro-level issues	4.1 Information, Engagement and Choice of Care	4.1.2.Dilema in getting help with care 4.1.3. Involvement in Care 4.1.4 Preferred Priority of Care.
	4.2 Inadequate service provision	4.2.1 Stressed families 4.2.2 Respite care 4..2.3 Support for family carers 4.2.4. Service from formal carers.
	5. Service provision from health and social care.	5.2 Pressure on acute bed 5.3 Prescribed care 5.4 High cost of Care 5.5.1 Support for independence living 5,5,2 Supporting independence with home telecare 5.6 Investigation and treatment 5.7 Care Communication.
Micro-level issues	6. Nutrition, Co-morbidity and Social Isolation	6.2 Nutrition 6.3 Chronic Disabling Conditions 6.4. Social Isolation and Marginalisation
	7. Nightmare of social care without social ties	7.2. Support from immediate family 7.3 Support from significant others

		7.4. Care package provision. 7.5 Suggestion on where to care for older people.

3.11 Ethical Considerations.

As earlier written, the ethical approval from COREC and the local approval from Halton and St Helen;s Primary Care Trusts are part of the ethical considerations of the research, In addition, in order to maintain confidentiality, all documents relating to the study – biographic details of participants; research participants' information sheets; signed expression of interest forms; signed consent forms; audio-taped interviews and transcribed interview sheets – were kept physically in a secure office in a locked cupboard in the University of Liverpool, only to be accessed by the researcher, and electronically on a password protected account on The University of Liverpool server.

3.12 Reliability and validity.

The validity and reliability of this study was gained first of all through the development of the study instrument, which was first of all tested through pilot study and revised for the main study. Also during the interview, prompts were used and study participants were often asked to clarify issues raised to confirm what they meant. Issues of method have been vigorously debated in the human science literature over the last several decades. The writings of Giorgi (1970, and 1988) and Polkinghorne (1989) are outlined here. These have included such questions as: how should notions of validity and reliability is construed in the phenomenological context? What is the role of subject numbers? What are the limits of description as data? Clearly, given the different philosophical outlooks of the natural sciences and phenomenology, these approaches differ in various issues of method (Giorgi, 1970, 1988). The phenomenological researcher, as with all empirical researchers, is concerned throughout the investigative process that the findings are valid – that they are well grounded, well supported, and that one can have confidence in them. The main issue of validity within the natural science framework is whether one can have confidence in the instruments used, for example, the in-depth interview. Phenomenological research adopts a more general perspective towards validity by inspiring confidence (Polkinghorne, 1989). The validity of a phenomenological study depends on the power of its presentation to convince the reader that its findings are accurate. This has been achieved in this study through the cut and paste system where the exact quotes of the patients and their carers are used to illustrate the themes. It works in the linguistic realm, rather than being able to draw on the reader's commitment to the conclusive power of statistically based arguments. Polkinghorne (1989) notes that the reader must be persuaded that two key inferences made by the phenomenological researcher are powerfully supported by the transformation of the raw data into a phenomenological study. The reader must be able to follow and be convinced by the thought processes that have led to the conclusions, agreeing that the general description reflects the common features and structural connections manifest in the examples of data collected.

At the heart of the reliability issue is replication. However, the goal of the qualitative researcher is not to replicate results, but rather to produce an illuminating description and perspective on a situation that is based on a consistent and detailed study of that situation (Eisner and Peshkin 1990; Firestone 1987,). A qualitative study is credible when the participants recognize the descriptions and interpretations of the experience as their own (Sandelowski, 1986; 1995). For this reason, a reliability check was used at the end of interviews to ensure there was agreement on what had been discussed. When differences arose these were resolved by discussion aiming at reaching consensus. Reflexivity was carried out throughout the interview sections, for instance, one of my interviewees was a 90year old woman, 'Doris, who I talked to in an intermediate care unit. She had been diagnosed with COPD, complicated by 'ataxic tremors', and has been readmitted so she could be treated and further receive guidance on the use of her medications. At the beginning of the interview, I could actually see these intermittent tremors. Nonetheless, 'Doris' was ready to share her experiences of readmission with me. However as the interview continued, the tremors got worse, coming on with greater frequency and intensity. I stopped the interview and offered her a cup of tea, which she accepted, and she calmed down a little bit. We continued for a while longer but towards the end she told me she could not go on any longer and asked me to send for an ambulance to take her home. When I asked Doris why she needed an ambulance, she explained that she could do as she pleased at home. She had been told that she could not smoke in the care unit but she really wanted to smoke. She wanted to go back home to die, where she could smoke to her satisfaction rather than being forced to quit. She claimed she started smoking at 15 and knew how to manage herself. She always, for instance, made sure she took her medication before going to bed so she could have a good sleep. She said if the ambulance team were too busy, I should get a taxi and that she had the money to pay and began looking for her purse in her hand bag.

At this juncture, I stopped the interview and promised I was going to take her to the smoke room meant for nursing patients. She asked me if I meant what I had just said and I said yes. I took her to the smoke room, lit the cigarette and handed it over to her. I could see that the tremors gradually reduced and she was able to hold unto the cigarette without dropping it. I told her I could not stay with her, not being a smoker, but that I would keep an eye out through the glass window while outside the smoke room. After the first cigarette, she quickly lit a second one. She spent the rest of the night in a much happier frame of mind.

The following morning I told my head of unit what I observed. I suggested Doris ought to be allowed to smoke in the smoke room despite her status as an intermediate care patient. I argued that if the purpose of the unit was to rehabilitate the patient, allowance had to be made for her lifestyle, including smoking. I advised that we discuss the issue with the matron. When the matron heard the full story, the lady was allowed to use the smoke room until discharged.

3.13 Summary.

This chapter outlined the aims and objectives of the study. Drawing on the philosophical writings of Shutz, it emphasized the importance of understanding patient's experiences of readmission from their perspectives. Following that, primary and secondary research questions were formulated for the study. I also outlined the methods used in the research itself and the process employed in the data analysis The next chapter discusses the results of the data analysis.

Chapter Four: Findings and Discussions

Information, Engagement, Choice and Adequacy of Care.

> "For the unique distinguishing feature of aesthetic experience is exactly the fact that no such distinction of self and object exists in it, since it is aesthetic in the degree in which organism and environment co operate to institute an experience in which the two are so fully integrated that each disappears" (Dewey 1934;249).

4.1. Introduction.

This chapter concentrates on the voices of the older people and the carers who participated in this study. It presents extracts taken from my interviews with participants that describe their experiences of readmission and what led up to them, as well as their accounts of life with chronic conditions at older age. It is worth noting that in as much as interview schedule was developed for this study, majority of the participants only discussed in areas that affected them and not necessarily on all the questions raised. Table 5 in pages 201-242 shows the responses of all study participants but in topics of their choice but only one or two quotes is used to illustrate the subthemes identified.

As discussed in chapter 1.4, recent changes in UK health care policy have had a major impact on the health and social care of older people.

The first theme I want to examine concerns information, engagement, choice and adequacy of care. How medical professionals engage with and provide information to patients and their carers has attracted a great deal of attention in the past decade in Europe and in the United Kingdom (European Social Network 2004). Orem's Self-Care Theory (1971) suggests that older people should take some of the initiative in relation to their own health and should learn how to manage routine aspects of their illnesses themselves. By so doing, they can avoid the need for readmission (Compley 1994). Those who provide information and support to them have a crucial role to play in this. When the needs of older people and their carers are not met, when they are not given the resources they need to look after themselves, the result is increased readmission rates. This further reinforces Kolcobas comfort theory where any alteration in the comfort of an older person, at any levels of comfort will make him or her seek such comfort in the hospital resulting in readmission (Kolcaba, 2003).

This chapter examines information provision and how to engage older people in making the right choices for their care. The following three sub-themes will be discussed under this category:

4.1.2. Dilemmas in getting help with care.
4.1.3. Involvement in care.
4.1.4. Preferred priorities.

A second theme, inadequate service provision, is considered in connection with the following sub-headings;

4.2.1. Stressed families
4.2.2. Respite care.
4.2.3. Support for family carers
4.2.4. Service from formal carers;

4.1.2 Dilemmas in getting help with care.

The boundaries between health and social services are contentious and are repeatedly re-negotiated and re-interpreted (Lewis 2001a, Mean et al 2002), a process that directly affects the support older people receives. As a result of the shift in the functions of the NHS and Local Authorities, previously highlighted in chapter 1.4, their work is considered to be inefficient, and there are ongoing conflicts between the social and healthcare professionals relating to their exact responsibilities. Many of the patients interviewed have become extremely frustrated with the poor quality of the services delivered.

A major part of the problem is that older people and their carer's have become confused about how to access health and/or social services. The needs of many of those I interviewed had not been met and this led to readmission into hospital.

Emma, aged 92years, lives alone in her own home in the Merseyside town of Widnes, close to Liverpool. She has two children; a son who lives in the nearby town of Warrington and a daughter who has migrated to America. She had been diagnosed with anaemia and arthritis affecting her limbs and neck: problems which greatly reduced her mobility. She had undergone readmission three times within a month because she was unable to cope at home without a support. She jokingly mentioned that after her third admission she promised the consultant that she would not come back.

Emma told me she felt isolated at home. She had not been able to go out to play bingo, one of her main leisure activities. She felt increasingly detached from the lives of her children and grandchildren. Emma expressed her frustration about how difficult it was to get in touch with the right people to help her at home and feared she would soon be admitted for a fourth time, something she was struggling to avoid. As she put it:

> "I've asked Age Concern... they won't clean the windows. I've asked the Council ... [and] Housing Trust to get someone to change the bed for me, because I can't lift the mattress up, you know ... Couldn't get any one. I fought for 2 years to get someone to cut the grass at the back, and the grass was that high, it was that high. I fought for 2 years to get the grass cut and it was that high and they told me I would have to see to it myself, and I said I would have to write a letter to someone." (Emma, 92years, Widnes).

Despite the difficulties she encountered at every turn, Emma refused to give up. She continued to seek help, calling a national advocacy on behalf of older people, the local Council and Housing Trust, and continued struggling for a period of two years before her grass could be cut. Despite repeated admissions to hospital, Emma has not still been informed of the necessary contacts she needs to enable her to live comfortably at home.

Similarly, Josie aged 88years experienced first admission with a diagnosis of Congestive Cardiac Failure and returned within 4weeks with Deep Venous Thrombosis, multiple drug reaction and erythema with dermatitis. She had been prescribed 13 different medications. Josie lives alone in the town of St Helens and her only son lives in London. She felt she had had to be readmitted because she was not in contact with the people who might have been able to help her live at home. She could not understand what happened with respect to her discharge arrangements as she was discharged without a care package. When I asked Josie about whether help at home was discussed with her, she said;

> "I had no contact with anybody and it, it was as though I was dropped in the middle of nowhere. And when the doctor came out he said you're not well, you look absolutely exhausted. I said I feel absolutely exhausted. I just felt as though I couldn't carry on doing anything else and also there's been no housework done since I'd done it in November. And I know it's only dust and stuff like that, but I'm looking at knowing that it's not clean and needs to be cleaned. I couldn't, I tried ringing numbers that I found for people to come and clean but they didn't come for some reason. And they just won't come out so I couldn't get anyone out to do my cleaning for me." (Josie, 88years, St Helens).

Josie was not discharged with a care package and she could not get help at home because she did not have the information she needed to contact the right people. Josie needed help with personal hygiene and the cleaning of her home, as well as help with cooking. Her son had helped her in the past, but he had recently been transferred to a job in London. Without due consideration of her needs, Josie struggled on her own to check the directories and ring the telephone numbers of people who might have been able to help. She realised eventually that she had the wrong numbers, and so she was left without support. As a result, her disabilities worsened. She was only able to struggle on for a short while before experiencing three hospital admissions within one month; readmissions she felt were entirely avoidable.

Davina, the main carer of Jane, her 90year old mother, explained that their experience had also been one of conflicting information and wrong phone numbers. They tried all the contacts they had been given without success. In the absence of support, her mother gave up on help from health or social care services. Although she could little afford it, she relied upon expensive private home care provision;

> "They've come on to give her this phone call, and somebody's given her this phone number. Oh no try this one, no that's wrong love, you want to try this one. And she's just hit a brick wall, nobody knows what it's for and yet he's paying £35 a week out of his lousy money. That's what I mean, it's our name, A and B must have a hex on it ...I don't know. This is why I am ready for a break down" (Davina, 44years, main carer to Jane 90years, Halton)

Another main carer, Matilda, also expressed her anger at the difficulty they had in getting people to help her husband, John, 89yers, when he was discharged from hospital following a stroke. Matilda's husband had died some time before the interview was conducted. When asked to reflect on her experience of getting help with his care, she said;

> "I found it difficult to get in touch with the right people"
> (Matilda, 82years, main carer to John 89years, Widnes)

As the main carer to her husband she did not know who to contact after his discharge from hospital, Matilda had suffered a great deal from stress. Her husband had to be readmitted to hospital several times. Matilda felt that she was never given appropriate guidance.

Older people and their carers confirmed how difficult it was to get the information they needed to help them cope better at home. Some even felt that such resources were reserved for the affluent. Asked about home telecare Josie had the following to say.

> Ya, Ya. But you know, that sort of thing (home telecare) is pie in the sky, it's not for someone like me, something I can't reach." (she laughs)
> (Josie, 88 years, St Helens)

Some carers explained that they had only been able to get things done for those they cared for by putting intense pressure on health and social service personnel. The question is, what happens to older people without carers?. Mrs Derrick, a carer for her mother, blamed herself for not having enough time to pressurise health and social care personnel so that her mother, Agnes, 86 years, could get the care she needed.

> "I do push to a degree but sometimes I think maybe I haven't pushed to the extent I should and that's the way you get anything done because if you just sit back you will not get the help that you really need."
> (Mrs Derrick, 43years, main carer to Agnes, 86years, Liverpool)

On the other hand, George, a carer for his mother, explained that he tended to fish around for information before informing his mother about the options. It was by doing so that he was able to secure a wheel chair for the mother;

> “She didn’t even know she could be helped with walking, she had a bad fall and it’s only because I told him to ring the doctors ... got help with wheelchairs and things, she didn’t even know she could do that, but there is no information given out at all.”
> (George, 38, main carer to Martha, 81,Halton)

In discussions with participants it became clear that older people and their carers find accessing information about health and social care difficult and confusing. The care funding system varies across the United Kingdom and it is constantly changing. As a result, many older people and their carers are struggling to navigate a maze of information. Many are not aware of their entitlements and the different options available to them. As a result they often end up receiving care unsuited to their needs or miss out on help altogether, a major factor in readmission.

One of the carers made a useful suggestion when asked what he thought should be done to help people in her situation access the right information;

> “There must be someone in the hospital that can advise you, mustn’t there, or the Rapid Access and Referral Service (RARS) team could give us a booklet thing, with some ideas of what you could claim and stuff. No. It’s stupid but they have got these patient liaison officers, what do they do? You would have thought that they would have a booklet or something that they could give out. Even just to say here you are, a couple of pages stapled together with some information
> (Tina, 55years, Main carer to mother Audrey, 93years, Halton)

Tina wondered about the function that patients’ liaison officers in hospitals perform. She suggested that they should provide discharge information explaining where to receive help. Based on this suggestion, service for older people should include advice on a wide range of topics such as funding care fees, social care provision, as well as the rights and benefits of patients and carers.

Patients need clear information about their disease conditions and about their management after hospital discharge. Symptom distress is a central concern to many older people with co morbid conditions, because pain is positively associated with depression, anxiety, mood disturbance and psychological maladjustments (Lichter 1991; Cochinov et al 1999).

The idea that older people can and should have a role in the development of policy which affects them has received strong endorsement at national and local government levels. It is now common practice to make arrangements for older people to contribute through participation, partnership working, consultation, and information giving (Department of Health, 1999; 2001; 2009). An older person about to be discharged from hospital should therefore be informed about his/her condition, the treatment regime, given a full explanation about why they have been prescribed It is important to empower older people by involving them in their care, and health and social workers are meant to place great emphasis on enabling older people to adapt to changes arising from old age by providing them with the assistance they need to live in the community. Older people and their families ought to be involved in all decisions relating to their care. Ideally patients should participate in decision making around treatment and continuing care at home medication as well as when they are to be taken. Providing older people with the right information on where to get help during their first hospital admission, will help to minimise avoidable hospital readmissions.

4.1.3 Involvement in care.

In exploring the views of patients and their carers as regards their involvement in care and the management of their health, a number of issues came to the fore.
Josie had the following to say on this issue;

> "During my second admission, I mean I'd spoken to the lady who assured me that people from the hospital like her should have spoken to me before I came out. But they didn't and she said she was going to take all the details this time and hopefully you know come home with me and check everything is alright and that it won't happen again. I don't think I could take it if it happened a third time, but it's so worrying trying to work out the medicine side of it as well. Because after a bit you don't know if you're doing right or wrong because you've got nobody to ask properly if it's right that I'm still doing this. I am still confused with my medicines, because when I was in the hospital it was getting it done for me and they just tell me when you go home, you just carry on with it." (Josie 88years, St Helens)

The result of not explaining Josie's medication to her, not just in first admission, but also in her second admission, was a third return to hospital within a month. From Josie's perspective, her readmissions were entirely avoidable. Facilitating self-management means helping individuals to find the combination of behaviours that best suit them. It is suggested that health educators should be trained in motivational methods, psychology, peer review and group working in order to facilitate this (Munro et al 2003). The last National Service Framework (NSF) for older people stressed how important preventive services, such as medication education, are when it comes to maximising and sustaining health and well-being (Ellis, 2001). Non-governmental research regularly highlights the value placed by older people on support of this kind (Clark et al., 1998; Help the Aged, 2002; Raynes et al., 2001;

The issue of supporting independence by enabling older people to retain control over their own lives was seen as fundamental by participants, and these objectives need to be central to community care in a way that has not been the case to-date (Department of Health, 2001). In 1998, the Better Government for Older People (BGOP) programme was set up to promote better coordination and responsiveness in public services across government so that older people's interests could be prioritised. It is widely acknowledged that user participation in service planning can ensure that services are accountable and responsive to users' needs (Department of Health 2001). Efforts to involve service users have increased considerably in recent years, and involvement has had important intrinsic benefits for participants, such as improved self-esteem and a sense of empowerment (Carr 2004). Empowering older people would definitely mean participation, involvement and engagement over range of sites and activities designed to enable users to have a say in how services are delivered to them. It could range from consultation approaches where users play a passive role, through to user control of services (Carter and Beresford 2000; Carr 2004). A number of ways in which older people could be involved include forums, consultation, pensioners' groups, and campaigning or user panels. This study confirms findings from other studies which have shown that older patients are often less engaged in decision making than younger patients (Hamalainem et al 2002).

When I asked carers about how involved they were, the picture varied. Mrs Derrick's mother, Agnes, was initially admitted for mastectomy following a diagnosis of breast cancer. She experienced a second admission after two weeks with irregular heartbeat, and a third admission the following week after being diagnosed with a cardiac problem. Agnes also has reduced mobility due to arthritis and uses a Gutter frame as a mobility aid. Agnes lives alone but Mrs Derrick visits on a daily basis before and after work. Mrs Derrick, who also had to take care of her family, had previously worked part-time so as to be able to have time for her mother. However, she was recently forced to seek full time work because she was unable to manage on part-time wages. After Agnes's third admission, she was discharged with a care package that covered morning and evenings. However, Mrs Derrick cancelled the care package for reasons that will be discussed in later sections. When asked if she was informed of her mother's discharge and involves in decisions relating to her care, this was her response;

> They said they couldn't contact me,------ that wasn't true because they had both my house and work number and I was contactable at anytime. They just didn't contact me.---- We can provide for her as a family ,myself and my brother we can provide some form of care ---- but not really the care that she needs ---- that's my concern really." (Mrs Derrick, 43 years, main carer to Agnes, 86years, Liverpool)

Mrs Derrick, the main carer in this case, was not informed that her mother was coming back from hospital. When her mother returned, she was unable to provide care to her as she had her own family to look after. She felt very upset as she had been unable to prepare for her mother's home-coming. She had two days to adapt the home to her mother's personal needs.

Agnes appreciates the fact that her daughter has other responsibilities and has no desire to be a burden or complain, so she puts up with whatever care she receives whether adequate or not.

> "No, my daughter does what she can. She has her own family so I don't like her to do so much. She is also working on the computer in her office so I don't like her to do so much". (Agnes 86, Liverpool)

Mrs Derrick is convinced that the care her mother receives is not adequate but feels it has been left to her to deal with. Together with her brother, she was ready to do her best to but was worried because she felt that inadequate care at home would send her mother back to hospital. Her mother was later readmitted for a fourth time within six weeks, an outcome her daughter felt could have been avoided had they received proper support.

The involvement of carers in preparations for the care of older people, especially family carers who do not receive training on how to care, is important in sustaining their stay at home. Studies in this area have shown that carers are all too often left to cope with unacceptable caring situations (Bull 2000; Harding et al 1989; Montgomery 1999; Parkin et al 1976; William et al 1988; William et al 1990). The NSFs which define responsibilities in this area have a strong focus on prevention and on the role of the individual and family in their own care (Department of Health, 2001). Within the NHS it is recognised, that the NSFs must be fully implemented if medical staff are to minimise avoidable readmissions. However, according to recent research, only one in four carers in England have been given a choice about whether or not to take on a caring role (Practice Research Awards Seminar 2004).

In 1998, the White Paper 'Modernising Social Services', reinforced the government's commitment to user participation in service planning. This was first introduced in 1990 when the National Health Service and Community Care Act made user involvement in service planning a legal requirement for local authorities. The publication of the NSF in 2001 again highlighted the need to engage older people and their carers. This strand of though also informed the launch of the Partnerships for Older People Projects (POPP), by the Department of Health in March 2005, a programme designed to evaluate innovative and sustainable initiatives aimed at improving outcomes for older people. In the same year the Department for Work and Pensions produced the first report of a long-term strategy for older people with the goal of ending inequalities among older people, of improving their quality of life and of supporting their independence, dignity and choice through the care system, especially after discharge from hospital. All the measures taken by the government have been aimed at empowering and improving the life of older people (see also Sure Start for Older People, and the 'Our Health, Our Care, Our Say' initiative, launched in 2006). Empowerment improves the efficiency of services an makes them more responsive to their users' needs.

While older people's experiences of chronic conditions differ according to the symptom and treatments they receive, there are sometimes commonalities in the day to day challenges they face. Adopting a patient-centred approach to providing care requires health professionals to obtain; information from each individual concerning their specific preferences, needs and values; relationship building skills for making connections and building trust with individuals; partnering skills for making decisions and solving problems together with individuals; and counselling skills (Cooper and Roter 2003). Self management and empowerment programmes should aim to equip older people and their carers with the knowledge, skills and support to cope with the challenges they face.

The transition in care of older people from long stay hospital care to community based alternatives, developed as part of community care, is presently in operation. Consensus has emerged that older people prefer to be supported to remain in their individual homes for as long as possible.

4.1.4 Preferred Priorities of Care (PPC).

It is, however, not enough to note that older people want to remain in their homes; care also has to be taken to explore the kind of care they want to receive and whether their preferences change with time. The NHS has made it clear it 'thinks patients and family care givers want choice over the kind of care they receive from health and social services (NHS 2003).

PPC is a patient-led advance care planning tool for patients to use with their families and carers. It is usually a catalyst for communication about wishes and preferences with respect to care. As things currently stand, before older people are discharged from an intermediate care unit or hospital, they are given a questionnaire that explores their circumstances and care preferences. I wanted to examine what older people thought about receiving care at home. The following portraits highlight the significance of home to the participants in this study.

Janine, aged 75years, who lives alone in Liverpool, was recently admitted to hospital due to a fall in which she fractured bones in her left leg.. She was readmitted 22days later due to acute pain from deep venous thrombosis. She no longer leaves her home for fear of being attacked. She had little knowledge of the home adaptations she might have benefitted from. She felt that such provisions were 'pie in the sky', simply unavailable to people 'like her'. She receives occasional visits from her children during festive periods and is occasionally taken to visit them in their homes. They do telephone regularly.

Her interview was conducted in an intermediate care unit while she was awaiting discharge after her second admission. Her son visited and took her out to look around. He asked her if she wanted to be taken home before going back to the unit.

> "My son took me out, to have a break from this place and he said "Mum, do you want to go home to see the house?", and I said no (both laughed). I couldn't face the pain of going and having to come out again. I said no, please don't take me home."
> (Janine, 75years, Liverpool).

Janine could not stand the pain of visiting her home just to leave it it again. She explained that had never enjoyed being away from home.

When Emma, 92 years old, was asked about her view of receiving care at home, she had the following to say;

> "You get old, you've lived all your life, you've seen wars out, you've brought your family up, you don't want to be going to hospital, you want to stay in your own home and try to live a life as best you can, well that's how I feel. I wouldn't go out of here, I want to stay here ---- Oh I wouldn't go in hospital again to receive care. The few occasions I've ever been in hospital, I'm not condemning them, they were good to me, but it wasn't like being at home. When I came home I got better quicker than all the while I was in hospital" (Emma, 92 years, Widnes)

Other participants expressed themselves in similar ways;

> "Erm well, home means everything to me because I'm independent, I'm as independent as I can be" (David 83,Halton)

> "Oh no, no thank you. No, I don't wanna go in one of those homes. Oh no, I've a friend that went in one and it's supposed to be a good, expensive one. Well, I had two friends actually. But no, they go, you go funny when you go in them places. You start to, you know, your mind goes and it's too ...no, I don't want to". (Mina, 75, Widnes)

> “I’m eating well in here, but this is not the answer for me. Yes. Such things should have been happening in my home.” (Jennie, 75, Liverpool)

> “Happiness to me, happiness. I shut my door and then I don’t go out, and people come to see to me and then they ask me say, are you alright? And I went “Yes “. My home is small you know. I can do what I like and please myself.” (Josie, 88years, St Helens).

> “You know, they like their own things around them. They have been so independent and they do not want to lose that independence”.
> (Mrs Derrick, 43, Main carer to Agnes 86, Liverpool)

> ”Home is my own. From my home, I am able to sensitize, which I have not been able to do all these since admission.” (Daniel, 83, Halton)

Those I spoke to clearly preferred to receive support to remain in their homes. Home is considered as a place of safety, refuge, happiness, freedom, independence and even a place to die. This confirms results from another qualitative study that explored the meaning of home to older people, highlighting its importance in terms of security and refuge, and as a place where older people could express individuality and where they could retain control over their lives and not be dependent (Means, 1997). Older people consider their homes as ”theirs” (Buckley1971). Usually home interiors contain a wide variety of objects which hold special importance in the lives of older people, functioning as reminders of their past as well as close relations and friends. Repeated hospital admissions or readmissions sever the connections that older people have with their homes. Severing these attachments is thought to play a role in high mortality rate from “transplantation shock” or “uprooting” (Howell 1983, Stafford 1988, Sherman and Newman 1977). This may well be another reason why readmission makes older peoples’ conditions worse;

> “Well I think readmission makes her worse, she is really traumatized” (Mrs Derrick, 43, Main Carer to Agnes, 86, Liverpool)

Mrs Derick observed that each time her mother was readmitted into hospital, her condition deteriorated, a expressed by the majority of the patients and the carers interviewed. They observed that when older people return home after hospital admission, they tended to become more relaxed, something which led to quicker recovery, especially when there was adequate support at home. Given this, it is important that we recognise the role that familiar environments play in the recovery of older people

While they wanted where possible to receive care in their own homes, some older people opted to move to smaller bungalows, sheltered accommodations or residential homes due to their desperate need for care and anxiety about social isolation. If people find it difficult to cope physically or psychologically at home, their views of residential care may be more positive than those of people without those difficulties. The following quotes illustrate some of the reasons participants gave for opting for other accommodation;

David, a retired Engineer, aged 83years, in Halton lives in a two bedroom bungalow, which he moved to from a four bedroom semi-detached house. He has two children, a son and a daughter, grandchildren and great-grandchildren, but lives alone. Following repeated falls after suffering a stroke, David is now chair bound and requires an electric wheel chair to get around. Local social services had however supplied him with a manual wheel chair. In the absence of social service support, David bought a scooter for moving about outside and for shopping, an electric wheel chair for getting around at home, and a Zimmer frame for transfers. One room in the bungalow, which he called 'the garage', contained all his mobility aids. His daughter visits regularly to offer what support she can. He loves his present home as it is manageable for him. His daughter had persuaded him to purchase a fall alarm, and he was happy to use it when required. When David was asked why he left his former accommodation, he responded as follows;

> "I found everything too much to cope with on my own. My wife died you see. I wouldn't have moved from the house if she'd lived. I would have had to stay there you know, because she loved it too much you know,.... Because.... But.... erm my only reason was that erm, I couldn't cope with things and I always said when it started to look neglected that's the time for me to pull out" (David, 83years, Halton)

David found his previous house too big to live in and maintain especially after the death of the wife. His mobility problems make it more difficult to live in a house that requires climbing the steps. Both his health and social situation informed his need for alternative accommodation.

Suan, aged 90years, moved away from his home in Liverpool to live in sheltered accommodation in Widnes along side with the wife. Prior to moving, he recalled how he experienced repeated readmission from falls as a result of frailty. He said it was only after his fourth fall and subsequent admission that he was provided with a Zimmer frame to use at home and a manual wheel chair to use outside. He used to receive meals-on-wheels but due to the irregularity of the delivery, he stopped the supply and his two sons, who live in Liverpool and Widnes, take turns to shop for him and his wife. He has a fall alarm in his flat and feels very happy at his present accommodation. When asked why he left his home in Liverpool he told me the following;

> "We moved on account of the area, we had a couple of break-ins in Liverpool you see. So erm ... it was that that decided the move out of Liverpool ... been here since. .. been here 7 years now." (Saun, 90 years, Widnes)

Suan moved to sheltered accommodation because they have been assaulted and burgled. Sheltered accommodation had given them respite.

4.2. Inadequate Service Provision and Readmissions

Older people who remain in their homes do, however, have to deal with numerous problems relating to those who care for them, whether they be family members or care staff.

4.2.1 Stressed families.

Almost six million people in Britain, one in eight adults, are carers (General Household Survey 1998) and the majority of those who took part in this study were family members. Carers are people who provide unpaid or paid care, looking after an ill, frail or disabled family member, friend, partner or client. They are the backbone of care provision. All the carers interviewed for this study were unpaid. According to research, three-quarters of all informal carers look after older people aged 65 and over and around half of all disabled older people in the UK rely exclusively on informal help (Comas-Hererra et al, 2004).

Family and friends provide care due to positive motivations like love, affection and emotional bonds while others perform caring roles out of a feeling of duty and of obligation towards the older people in their lives. This is particularly true when few affordable care alternatives are available (Lamura et al 2008).

As became clear in the course of this study, the type of care provided by the carer varied depending on whether the dependant lived in the same household or in a separate one. The following background descriptions and quotes reflect the experiences of family member in the course of caring for older people;

George, aged 38years, is the main carer of his mother, Martha, who is aged 81. They live together in Castlefield, Halton, another of the small towns near Liverpool. Martha was diagnosed with angina, anaemia, gout and a chest infection. Until the right diagnosis was made, Martha's experience was one of continuous, ongoing readmissions returning to hospital up to ten times within a single month.

Although George has an elder brother and sister, they are both married and live away, and only visit occasionally. In the absence of health and social care support, George was left with no option but to take care of Martha himself. During the period when Martha was experiencing the most pronounced difficulties, George lost his permanent job because of the amount of time he had to spend taking care of his mother. He now works part time on a greatly reduced wage. Having to assume the role of principal carer also put tremendous strain on his personal life and he has been in and out of relationships. George, who is doing his best to keep Martha out of hospital, summarised his experience of caring for her as follows;

> "I was just a zombie, just because I had to be up and down of a night with her. And when she was asleep, I would worry if she was dead because she had a really bad chest and heart and everything, so I would lay awake at night trying to, just trying to hear if she was breathing. And I would get up and I put a buzzer in her bedroom, so she could buzz me, because she couldn't shout, and I got a bell, but she couldn't ring the bell, she didn't have the muscle control and

> everything to do that, she was too weak, so I got a buzzer, like a door bell, and she used to do that. And in the morning I would get up, as long as she had buzzed me, because obviously I was tired because I had lain awake all night trying to hear if she was breathing or not. She would buzz me, I would have to get her up to go to the toilet, she could do that 6 times or more times of a night. And when it came to time for me to get up, I would get up, I would have to do her breakfast, make sure her tablets were there, get her to take her tablets, which she is very good with, she took them anyway. Jjust then what I would do is, I would tidy up a bit, look after myself, get myself washed and dressed and breakfast, feed the animals, then because she couldn't, because she had got up and had her breakfast and stuff, she took a little while to get her strength again. Normally I would just give her, I would take her in the bathroom in the wheelchair, and I would just give her a wash, just give her a wash, that's all she needed and then she could either go back to bed, because that was just too much for her. So she would need to go back to bed again or if I was lucky she would stay up in the kitchen for a while, but a lot of the times, most times, she would do that and then it was back to bed, and that was it, that was, it was like that for a long time. And slowly she got better. She is no good during the day, she can't be left. But when she is in bed, I can leave her. So what I did was I got a cleaning job in the morning when she's asleep, and then I could at least have an hour or two of life, get some contact, because I never saw a soul." (George 38years, main carer to Martha 81years, Castlefield, Halton)

George summarised his experience as that of a zombie, the result of sleep deprivation connected with having to attend Martha at all times of the day and night, his continuous worrying about her health, and carry out domestic tasks while working part-time in order to earn a living. This had been his daily routine for several years, without rest. He has little contact with people outside work, and feels intense social isolation.

Martin, 62 years old, was the main carer to his mother, Margaret, who passed away before the interview was conducted. Martin described the terrible stress that accompanied the routine tasks that a carer must perform. Here he describes some of the problems he had to deal with.

> "She got stuck behind the radiator; on that wall there love, yes. Her head was behind that and it was all grazed ... And the post on the stairs, her leg was stuck behind that ...So you can imagine, she was shouting, you know, ambulance. I had a heck of a job lifting her out you know, because it was the only way I could get her, by lifting her ... She [also] fell half way down, erm 2 falls she had on the stairs. But she didn't come all the way down I managed to stop [her fall]. So after that I slept on the landing by her bedroom door, till she went in hospital in case she did it again. (Martin, 62years, main carer to Margaret, deceased, Widnes, England)

As a personal measure to prevent further, potentially fatal falls, Martin slept on the landing outside his mother's bedroom door. He told me that the stress he was under was frequently unbearable. Despite his best efforts, he could not provide the care his mother needed. Margaret subsequently died following admission to hospital for the third time in a month.

Mabel, aged 85years in Widnes, had been the main carer to her husband, Jim, who passed away after being diagnosed with respiratory failure that required him to be on an independent oxygen supply 24hours a day. Mable had herself been admitted to hospital several times over short periods of time in the period before Jim's death having being diagnosed with congestive cardiac failure, asthma, tablet controlled diabetes and deep venous thrombosis. Her experience of hospital readmissions was therefore dual in nature, one of the few in the study who could be described both as a carer and a patient. I talked to her about both. When I asked Mabel about her experience of caring for her husband when she herself needed care, she told me;

> "Four times I had to call the ambulance because of his breathing and he'd shout me and I'd come rushing down different times of the night, can't breathe, get an ambulance ... I know that the struggle to take care of my husband has worn me down like this. Oh he wouldn't knock me. The only thing was when he was shouting me in the night .Sorry about this [crying]" (Mabel 85 years, Widnes, England)

Mabel attributed her poor health, and her need for hospital admission, to the accumulated stress connected with caring for her late husband. Being woken several times a night by shouts from her husband, without knowing just how bad his condition may have been, was a tremendous source of anxiety.

As became clear in the course of the research, problems of this kind were routine. Davina expresses this well;

> "He realized how very, very tired I was because I was up in the night with him ... It was hard, jolly hard work really, but I was determined he wasn't going to go into a home." (Nadine, 74years, main carer to Victor-deceased Halton)

Nadine, like the other family carers interviewed, expressed how tired and frustrated she became because she was unable to care properly for Victor. Nadine, like the other family carers, was under extreme stress as a result. The family carers I spoke to had all provided physical help, personal care, and assistance with medicines. They talked about how they slowly lost of control of situations that became ever more demanding. Unsurprisingly, they felt trapped, unable to provide the care needed but unable to call upon alternative sources of support. They associated their stress levels with the number of hours they spent looking after their dependants. Most of the carers interviewed juggled their caring role with paid work. This is a common predicament, as a study conducted by the Princes Royal Trust for Carers has shown (2003).

Carers must also prepare themselves for the unexpected, and spend a great deal of their time worrying about what would happen if they were in an emergency and needed to find replacement care. As a result of the anxiety associated with the caring role, carers lead ever more restricted lives, spending less and less time with anyone other than the person they are caring for. The physical and emotional demands placed on carers cannot be underestimated.

'Family stress theory' (Tomlinson 1986) emphasises how crises in a family can create chronic hardships that mean that a family's way of functioning is completely disrupted. According to Patterson and Garwick (1994), facing crisis events within the family involves a downward period of disorganisation, an upward period of recovery and a period in which families find new stabilities. All the carers in this study had to make adjustments in their lifestyles in order to cope with the demands of caring. They often had to deal with financial hardship. As the following quotes show, the financial implications of caring by family carers can be debilitating.

> "But of course by then we were down in income, down on money, so we lost, we used to have NTL because she is here all day, and it gave her something to watch, but we haven't got that now. We had to lose the landline telephone, because it's all money and I basically can't do everything. And then when the social security lady came out to see me, she said oh, she came to fill in forms for me, or with me, for me to become a full time carer. I said, I don't want to become a full time carer, thank you very much. I value my own life, I value my own life ... I took lots of little jobs, just cleaning jobs, making up an 8 hour day. Then if my mum's health deteriorates, as happened the last time she got ill, I can just lose a job here, lose a job there. Okay I lose money and my income drops down, the household income drops, but I am still with my mum and I have still got my jobs, I have still got my foot in both camps. Because I need to have my own life as well because being a full time carer, that will probably at some time happen, isn't really what I want at all, because I want my own life. You just want company, just somebody to talk to, because when you are stuck within these walls all the time, just caring, it's terrible." (George, 35 years, main carer to Martha 81year in Castlefield, Halton)

> "It's very, very hard because I've only been working part time but started full time work recently. And I've just got to do what I can do and I leave the rest. And it can be quite difficult sometimes."
> (Mrs Derrick, 38 years, main carer to Agnes 86years old, Liverpool)

George and Mrs Derrick did not want to become full time carers. They knew the money they would be given would not be enough to support their families. They also valued working, interacting with others and having their own sources of income. At one time or another, both had picked up several part time jobs, a pattern of working that gave them the flexibility to care for their mothers. However, working this way it was impossible for them to earn much.

Mrs Derrick, by contrast, continued to work a full time job to be able to fully support her family, something which left her with much less time to take care of her mother, Joan. Leaving her mother in the hands of formal carers, however, led to a series of hospital admissions. Mrs Derrick and her mother had argued about this. Agnes expressed her serious regret but explained that she could not help the situation.

> "And I was still going to work you see, my mum was expecting me to give up my work and sit in a chair talking to her. Well I'm a widow, I couldn't do that you know. I've had to take care of my finances." (Mrs Derrick 43years, daughter and carer to mother, Agnes, 86years, Liverpool)

The emotional pressures experienced by family and relative carers are again reflected here. Caring meant they had to work long hours, sometimes around-the-clock. Those who tried to keep jobs down invariably came into conflict with their employers, because of lateness and absence. Those who gave up working had to deal with financial difficulties. The carers I interviewed received only the most menial levels of support.

This research is in line with many other studies that have explored the pressures experienced by carers and which have pointed to the tiredness, isolation, stress and depression that is connected with the caring role. Becoming a carer has many, often negative, impacts on a person's life. Having to bear financial costs, deal with exclusion and discrimination at work, social isolation and poor health through stress and physical injury are among the most significant (Bauld et al, 2000; Carers UK 2004; Liston et al. 1995; National Assembly for Wales, 2000b; The Report 1995; Twigg, 1992; Philips et al 1997). Sadly, the emotional ties that connect family carers to those they care for can also fray as a result of the difficulties of the situation.

Systems of informal care undoubtedly save costs. None of the carers interviewed were paid to care for their relatives. Older people also benefit from increased contact with their family, and the emotional support it brings with it. However, the reliance on informal carers all too often becomes a substitute for formal care. Informal carers are not medical professionals and the demands placed upon them to do that work in place of medical professionals is unacceptable. Older people require both formal and informal care.

4.2.2 Respite care and readmissions.

There is much emphasis in current government policy on providing support for carers through specific carer-oriented services, such as breaks from caring or respite care. Regular respite care has been shown to reduce stress in carers (Nolan & Grant 1992), and is perceived by them to be the most needed community service (Banks & Cheeseman 1999, Caserta et. al. 1987, Furst 1994; Shope et. al. 1993)

Respite care is designed to ease the pressure on informal carers by substituting an alternative method of care for a period of time lasting from a few hours to several weeks. It may be arranged on a one-off basis or as a regular standing arrangement. The family carers I interviewed had the following to say about respite care;

> "In the end it got so bad, because I was sore, my back was really sore at this stage., My mum was still really ill, and I was asking them for help and what I asked them to do was to put her into ... Like because, I look after her, it's 24/7, and I manage, but because I have got myself bad as well, I couldn't look after myself, work and look after my mum, so I asked them for help, just to put her in for respite care, a nice one by the beach I said to her, just for a week, just for a week or two weeks at the most, just to help me get better ... Because I am the carer, if I am ill, you could have both of us in hospital. So to let me get better, so I could, then, look after my mum. And they said, no, a blank no. No help at all, so what I had to do then, I had to lose one of my jobs ... Me, I cried. I went bald, I got old. It wrecked me. My mum is not a small woman, and we asked for help at that time and we didn't get help ... And by then I had no patience, I was in pain, I was extremely tired, and stressed and I thought, right, I can't cope, I can't cope, I need help."
> (George, 38years, main carer to Martha, 81 years, Halton)

> "No, no, no, no, I have not had a holiday in like 10 long years. No, there was no time to rest, no good break. I can't take the time off work because I only get statutory sick pay, which is you get nothing

> for the first 3 days, and then for the following 2 days you get half pay, so really what that means is you get 1 days pay for a week. Sorry, I can't survive on that, bills have got to be paid."
> (Shedrack, 56 year, main carer to mother in-law, Emily, 95years, Widnes)

George did not receive respite care even when he desperately needed it. As a consequence, he was in no position to properly care for his mother and she experienced so many readmissions within short intervals over a month that he lost count. Shedrack, the main carer of his mother in-law, has been working for the past ten years without a break or holiday. He said he would continue, for as long as it takes, to take care of his mother in law at home, even if he has not been offered respite care. He had friends who had been denied respite care, and knew his situation was no different from theirs. Most family carers felt that taking a holiday or even getting a brief break was impossibility.

Respite care and counselling can be a cost-effective way of reducing the negative psychological effects of caring on carers. When these services are denied to those that need them, they burn out and are no longer able to support those they care for.

4.2.3. Support for family carers.

Apart from respite care, other sources of supports are supposed to be available to family carers. The services available to those caring for someone in their own home and those caring for someone living elsewhere differ.

It is important to understand something of the historical background to current government policy. In the 1970s and 1980s, the Carers Rights Movement was formed to address the issues of low income, social exclusion, damage to mental and physical health and lack of recognition suffered by carers (Carers Act 1995.) They suggested a wide definition of service provision should be adopted so as to properly recognise the work carers do. They also advocated the creation of support services such as increased day respite care, residential respite care, in-home respite, social work/counselling and improved home care to help them in their socially valuable role. Davies and Fernández (2000) have suggested that services such as these can be cost-effective ways of improving outcomes both for carers and those they care for.

The following are indicative of the responses I was given when I asked carers about the supports they received;

> "I thought, someone would have come to say, here you are, this is how you lift her out of bed, this is how you get her into the wheelchair, this is how you lift her from the wheelchair to the toilet, without hurting her. Because I mean, when there was only me on my own or my brother, she did say oh you are hurting, you are hurting, but we don't know if we were doing any more damage than what had happened. Because we hadn't been shown, so what we were doing was what we thought was best, but no one showed us anything, nothing at all."
> (Shedrack, 56years, main carer to mother in-law, Emily, 95 years)

Shedrack expressed frustration at not being shown how to care for his mother in-law after her discharge from hospital. He realised that when he and his brother attempted to move Lil they caused her pain. The majority of family carers were similarly frustrated by not being shown what to do. While they were responsible for providing care, often on their own, they received no formal instruction.

George, for example, talked about how health and social services had failed to provide him with any type of support. He had no other option but to carry on as best he could.

> "We didn't get any help that was a long time ago; we got no help at all. And we just had to cope, just had to get on with it. And as she got better, slowly, what I did, I thought, ok then, she is getting better now and I am feeling more confident so what I'll do is when she is in bed in the morning, I'll go to work, get myself a cleaning job because I was going stir crazy in here. I had cleaned the house from one end to the other, I had cleaned all the cupboards, I had painted the bin cupboard, I had taken the airing cupboard apart and painted all that, there was nothing else for me to do really I was going stir crazy."
> (George, 38 years, main carer of Martha 81 years, Halton).

George did not receive the help he needed when he needed it. Nor could he take a break. This is typical of the situation in the UK. Carers in general receive few breaks from caring and some never get any breaks at all, even for short periods of time (Parker and Clarke, 2002). The 2001-2002 General Household Survey (GHS) showed that less than 10 percent of disabled older people with a carer attend a day centre in Britain. Only around 20 percent of disabled older people living alone receive home care from someone other than a friend or family member (Wittenberg et al, 2006).

The Carers Recognition and Services Act (1995) gives carers providing regular and substantial care the right to ask social services to carry out an assessment of the help and support they are entitled to. These carer's assessments are meant to be combined with the assessment of the older person's needs so that a care package can be arranged. The Carers and Disabled Children Act (2000) further extends carers' rights to an assessment with the person they care for, as well as requiring local authorities to provide carers with services that help them to fulfil their role, including such things as payments and vouchers for break services. The evidence from this and other studies suggests, however, that theory and practice diverge alarmingly and policy changes at central level have not translated into improvements in the situation of those who give over much of their lives to care for members of their family. In the UK, organisations like Carers UK and the Princes Royal Trust for Carers provide support services for carers but those I interviewed were unaware of their existence.

The carers I interviewed for this study experienced frustration, isolation, guilt and anger, and caring had a negative effect on their health, privacy and life chances, especially in getting descent jobs.

Gertigab (2002) argues that carers can be provided support at the homes of the older people they care for, through informal education that is tailored to their needs. Gertigab also found that therapeutic social work is highly effective in reducing carer stress. However, less than 20 percent of those who care for frail older people actually received any such support (Davies and Fernández, 2000). In the context of current community care policies and practice in England and Wales, there is evidence that both day care and residential respite care have positive outcomes for carers, something supported by a systematic literature reviews in this field (Arksey et a, 2004).

Davies and Fernández (2000) have shown that day care reduced stress for about 85 percent of the carers of users of day care, and was particularly effective for carers of severely cognitively impaired older people. The national and international literature also shows that the provision of breaks from caring or respite care, such as day care and overnight respite in a residential care home, is often associated with very high levels of satisfaction on behalf of carers (Arksey et al, 2004; Levin et al, 1994;). Other methods that may be considered include the creation of individual casework relationships that address the expectations placed on carers. Carers may also benefit from attending supported evening classes, something that depends on the moment on having the money to pay, the time to go, and access to a competent sitter.

4.2.4. Services from formal carers.

Problems are, however, not restricted to family carers and it is important to think about the work that formal care providers do too. Formal carers differ from informal carers as they are acting in an agency-client relationship with older people, are often trained and are paid to perform their caring roles. The amount and type of care an older person is given is usually determined by an assessment procedure of his/her needs. We might expect, therefore, that older people would benefit from the training and knowledge that formal carers bring to the situation. Unfortunately, however, that expectation is frequently misplaced, as the following quotes show;

> "A carer came and she said, oh I have to come and help you to get him in the hoist. We had to show her how to get him in the hoist, she hadn't got a clue"
> (Mabel, 85 year, Widnes, former carer to husband Jim, deceased)

> "I left the carer to do her medication ... that kind of person ... who erm ... her appearance wasn't very nice, hygienic. She had long finger nails and burst about 5 bubble packs at the same time ..."
> (Tina, 55years, main carer to Audrey, 93, Halton)

> "My mum still wants to go home and be taken care at home ... but [that can only happen] if the carers can be properly educated on what to do."

> (Mrs Derick, 43years, main carer to Agnes, 86 years, Liverpool)

Mabel reported that the formal carer assigned to her husband had not been trained in manual handling tasks, while Tina reported long unhygienic finger nails which destroyed her mother's medication blister packs. Whether these are entirely fair assessments, they reflect a general lack of faith in the ability of formal carers. Mrs Derrick assessment of the lack of education and training among formal care staff is all too accurate.

Apart from a lack of training, formal carers often displayed disrespectful and disdainful attitudes to the work they were being asked to perform. Many turned up late to care for older people or refused to touch patients who were suffering from particular conditions.

> "They sent a carer and they were supposed to come in every morning early to wash me and to do my hair. And I was getting out of bed and sitting here, and the time was going on and going on and then, they would roll up, just before dinner. And I've struggled, struggled to wash myself and do my hair and everything and then when they come, all they did was sit there and fill forms in. So one day I was that mad, I said to my son, I'm not having them no more, so he said, well mum you're not able. I said I'll find a way, I've promised the consultant in hospital that I'm not coming back here." (Emma, 92 years, Widnes)

> "They're not as punctual as they might be. They're supposed to come between 9am and 9.30am, and sometimes it's nearly 11.30am when they come ... I just have to put up with it." (Mabel, 85 years, Widnes)

> "The one that came in the evening, by the time she came round, about seven o'clock, I'd had my evening meal. It's too late to wait, you know, for her. And she just told me to get undressed ready for bed, because I had this shoulder, y'know, I couldn't lift my arm up." (Agnes, 86 years, Liverpool).

Emma, Mabel and Agnes, in other words, all felt badly served by the care they were receiving.

Reflecting further on formal carers attitudes, those I spoke to had the following to say;

> "My mum had been deteriorating for some time but, you know, they just come and ask, how are you? And after all that, they just go. I don't like making a complaint, [but] the carer complained my mum had MRSA and she had a small son at home so she wouldn't want to put her small son at risk by touching here. She had a son at home who obviously was not very well and someone like that shouldn't really have been given to my mum. So she would just come, we'd sign her paper for her, and she'd go. So once my mum had her hip done, we stopped the care package."
>
> (Mrs Derrick, 43 years, main carer to Agnes, 86years, Liverpool).

Emma, Mabel Agnes, Mrs Derrick, and others interviewed besides, all commented on problems with the attitudes of formal carers. That older people and their families must struggle to cope by themselves, despite access to formal care, shows the weaknesses that run through the present system.

The other major complaint was that formal carers spent little time with them, so that some of the tasks they had been asked to do would not be fully completed before they left. Many tried their best to perform those tasks themselves. A number of the older people I interviewed experienced falls while doing so.

> "How long did I get? That was 25 minutes, breakfast and lunch time, but you only got half hour or three quarters of an hour for tea. But they didn't do three quarters with me. They were away early because it was very dark outside. There are lots of little things left over. You wanted to be nasty but you couldn't be. I don't think it's worth it really, I don't, I wouldn't argue. I was supposed to be first on the list at 8.30am for insulin, you see, for my carer at 8.30am. You know what, she said, I looked at my sheet, and your name is last on my list. Well last on the list is near dinner time. And I said what about the dishes, oh no they're left till the next one comes in. I said, I'm not going to sit with dirty dishes in front of me all night, but that was what they started to do, and didn't do it. They never sweep, never put a carpet sweeper

> over anything, so I had to have someone in to do the cleaning, someone into to wash. All that used to be done by them and you are paying now and you weren't paying before, and you were getting everything done. Now you're paying and not getting anything done ... Well I had to get that and clear that away, and if I was in one of these dizzy moods and that, they would say, oh leave all your dishes, the next one in will wash them. But I don't think that's right, especially if you had a greasy dinner. Leaving a greasy dinner plate, knife and fork in front of you, well who wants to see that? I didn't, so I told them. So she said tell them to fill a bowl of water and stick them in the water. Well that's not caring, that's not caring for the elderly is it? And I was more capable than lots of old people for doing a bit for myself and I used to think that was terrible that."
> (Abigail, 88year, St Helens)

Abigail carers turned up late and left early, her insulin was not administered on time, and her dishes were unwashed. She was so disgusted with the sight, she got up to wash the dishes herself after the carer was gone, experienced a dizzy spell, fell and knocked herself out, waking up in hospital.

> "Even if I do want my mum to come home, my problem is with the care package. The careers are only given about 10 minutes which is not enough time to take care of an old person. I know they want to stay in their homes rather than going to care homes because they make better progress in their home and like their own things but what is the alternative?" (Betty, 59, main carer to Joan, 86years)

Betty knew that 10 minutes was unacceptable. Rather than having carers rush through their treatment, she cancelled the care package. Following the cancellation, her mother was admitted to hospital three times in a month.

When formal carers' lack education on how to address the needs of their patients have resulted, their relationships with those they provide support to starts to break down. This means that formal carers may not actually be useful sources of support for older people. Troublingly, responsibility falls on the older person themselves or their families as a result of inadequate formal care as reflected in this quote from a carer

> "I took the brunt of it quite honestly … I received a little support but the main care did not really help"
> (Vera 75, wife and carer to Allan, diseased, Widnes)

Vera had formal carers who came to take care of her husband, Allan, but confirmed that she had to provide most of his care. When she was no longer able to cope, her husband had to be readmitted to hospital.

Formal carers need to provide, and be trained in how to provide, individualized and flexible support that is specific to the older person they are caring for (Grimmer et al 2005; Homer and Gillead 1994; Wang et al 1999; Wellwood et al 1995;)., As was reported in the interviews, formal carers lack many of the basic skills that would enable them to fulfil their role properly.

4.3. Summary

The theme of information, engagement, choice and adequacy of care has been discussed in relation to statements given by the study participants. Their accounts showed that the experience of readmission was connected to the lack of information, care and support they received following a first admission to hospital. They talked about how older people and their carers are given little or no information on how to receive support at home, the place where support is both most needed and most wanted.

The interviews also highlighted the inadequacy of the forms of care that older people did receive at home. Informal carers, it was clear, were overburdened and stressed, and lacked the support that would enable then continue caring for older people. As a result older people and their families ended up making hurried, life-changing decisions about moving into sheltered accommodation, residential care or nursing homes. Avoidable hospital readmissions also became a routine feature of their lives. It is important to increase political and clinical awareness of these issues by giving older people and their carers the opportunities to have their experiences heard, to raise questions and push for change.

Chapter five: Findings and Discussions.

Service Provisions from Health and Social Care Organisations.

> "The world is not an objective thing out there but a function of personal interaction and perception. It is a highly subjective phenomenon in need of interpreting rather than measuring, beliefs rather than facts form the basis of perception" (Merriam 1988:2).

5.1. Introduction

This chapter looks at service provision by health and social care organisations, a discussion built around quotes from study participants. A particular focus will be the inadequacies that participants highlighted. The participants identified that pressures on acute beds has resulted to their early discharge from hospital when their symptoms were not fully controlled. Even after discharge home, they perceived the care provision to be prescribed rather than a negotiated care due to limited budget and resources. The present mean-tested system of social care in the UK except Scotland tend to have affected the older people in getting the right kind of care they deserve and it appears the upper class group are meeting up their need through personal care purchase . Discussions on support for independent living at home portrays delays in providing adaptations, ineffective delivered equipments and sometimes total lack of support for it. Even the use of home telecare as part of support for independent living were sometimes abandoned due to inappropriate buzzing which the participants considered disturbing. In addition to these inadequacies, a major contribution identified by the study participants' as the cause of their readmissions is the fragmentation of care and poor communication between hospital and community care. The inadequacies the various participants highlighted as it concerns them are discussed below;

5.2. Pressure on acute beds

Some of the older people who were interviewed as part of this study had to face early discharge from hospital because of pressure on acute hospital beds even though they were not well enough for continuing care at home. The imposition of reimbursement (Department of Health, 2001b), as earlier outlined in 1.5, has speeded up hospital discharge and focused the minds of managers and professionals in both health and social services. Under pressure from government, health service managers and practitioners have taken various measures to decrease the length of time older people stay in hospital. Driven by performance indicators rather than the needs of patients, these measures have contributed to the readmission rates rather than minimising them. When I asked some carers about why they felt the older people they cared for were readmitted into hospital, they identified their discharge from hospital was untimely as in these quotes;

> “I think it makes her worse; she is really traumatised because she was not properly admitted. She was sent home too early and within a week she was back again”
> (Mrs Derrick, 43years, main carer to Agnes 86 years, Liverpool).

> “She was in the X hospital for 3 weeks and then she was going to go for rehab ... My mum would pick up, but then wouldn’t eat again ... She wasn’t well enough to be transferred from the X, she was only there 3 weeks, but because there was a bed vacant they rushed her to Y hospital for rehabilitation ... I wasn’t happy for her to be moved from the X. I think she should have stayed there a bit longer to get her diet up, her weight up, because she was still losing weight while she was in hospital. And then she had about 5 falls while she was in Y, and I thought, how is this rehabilitation if she’s falling?
> (Matilda, 82 years, main carer to John, 89, Widnes).

Mrs Derrick felt her mother was discharged too early from hospital, at a point when she was not well enough to leave, something which she found traumatic, worsened her condition and hastened her return to hospital the following week. Matilda felt her husband’s weight loss had not been brought under control when he was sent for rehabilitation (Brown & Gray, 1998; Pearson et al., 2002). The rehabilitation programme did not work out well as he had to return to hospital after repeated falls – something the programme ought to have addressed.

The tendency to quickly discharge patients not well enough to be discharged meant that both medical and nursing staff were less likely to know older people and their families and often would not have the information needed to plan appropriate continuing-care for them (Dobrzanska, & Newell, 2006; Pearson et al 2004,). Early discharge also meant that older people with unstable acute conditions ultimately placed greater pressures on services. For individuals with pronounced need, the situation was made worse as a result of poor coordination across services. Responsible risk-taking, that helps to fulfil an older person's wish to remain in their own home, warrants more explicit corporate backing within the health and social care system, but can only succeed when appropriate assessments have been conducted before discharge from the hospital, where older people have access to a range of services while living at home, and where a responsive review and monitoring system is in place.

Were such a system in place and older people and their carers were aware of it, the transition from hospital to home could be supported. Rehabilitative services could aid recovery and get older people back to the point where they could live as independently as possible at home but that all depends on being fit for discharge in the first instance. Sending someone who remains unwell home undermines potential for improvement and leads to readmissions. In this regard, findings from this study are no different from other studies which identified early discharge as being associated with readmission (Brown & Gray,1998; Dobrzanska, & Newell, 2006 Pearson et al., 2002; Tieniey & Worth, 1995).

5.3. Prescribed care

Within health and social care, emphasis is now placed on the development of more personalised, preventive services across the spectrum of need, with the primary aim of keeping older people well, active and out of hospital (Department Of Health 2003). The right to request not to be admitted to a residential home after 65 years is just one of the options the government has proposed to put the individual in charge of the budget used to purchase their care, and so increase their capacity to exercise choice and control over what happens to them. The question that I will examine in this section is whether care options are actually being discussed with older people.

Present practice in the UK is that when an older person is about to be discharged from the hospital, is known to require extra support at home, he/she is referred to social services. Upon referral, social workers usually initiate a formal assessment procedure which moves from an initial assessment of an individual's mobility and personal care abilities, as well as the suitability of their current living arrangements and support network, to a more comprehensive review that draws on input from members of an interdisciplinary team of health and social care professionals, and then finally to financial assessment. Because social care is means-tested a financial assessment is required to determine what services an individual is entitled to access and whether they qualify for assistance in thin funding their care (Department of Health, 2001). In England about 15% of the elderly population use social care services provided through their local authority (CSCI 2005), with around 206,000 supported to live in residential or nursing home care (CSCI 2006).

The Department of Health (2000) has recommended that partnership and collaboration around care should be seen as the bedrock of good professional practice in this area, a prerequisite for improving the quality of care given to older people. It therefore advocates a strong partnership approach where all involved professionals work with older people and their carers/families to establish a meaningful dialogue and sense of mutual responsibility around the provision of care. What care someone is to receive is, then, a matter for negotiation. However, when asked whether this was how they thought about their relationship with health and social care services, participants in the study had the following to say;

> "They come to put my mum to bed at 7 o 'clock and no one wants to go to bed at 7. My mum likes to stay up late and watch television, but they come between 7 and 8 to put her to bed as part of a care package she doesn't like. They're not children, are they? They give them no choice, it's like being in an institution, not your own home. Why send you home, if they're going to treat you that way? I'm happy with the care my mum received in the intermediate care unit but if she could get that level of care at home it will be better"
> (Mrs Derrick, 43years, main carer to Agnes, 86 years, Liverpool).

> "I'm washed and dressed every morning ... [and] they come to put me to bed at their own time which is usually too early for me" (Agnes, 86 years, Liverpool).

Agnes does not like to go to bed early but since she returned from hospital, and without considering her preferences, her carers put her to bed at 7.00pm making the night a very long one. Agnes' daughter, Mrs Derrick, complained her mother felt institutionalised in her own home. She ended up cancelling the home care package as she felt it defeated the purpose of personalised care. Other participants made much the same points. What was clear was that people are prescribed rather consulted on their care.

For instance, Eileen, an 87year old woman who lives alone in St Helens, was diagnosed with exacerbated COPD, osteoarthritis, aortic aneurism and ataxic tremors. She was first admitted on the 17th of April 2007, before being readmitted again on the 30th due to the worsening of her COPD. Eileen has been a smoker since the age of 15, and is not willing to stop smoking. She has been prescribed with inhalers and nebulizers which should be taken four times in a day. Betty however did not adhere to her medication regimen, and had to be called to an intermediate care unit on the 8th of May, so that she could receive instruction in how to use her medication and on why it was important that she did so. Eileen was interviewed three days after her third admission, and I asked her about the differences between the care she received at home and the cared she received at the rehabilitation unit. She replied;

> "The only thing I miss is being home and being able to smoke. That's my life. I couldn't live without a cigarette. I've been smoking since I was 15, and I am 88 nearly. If this were my home now, I'd get up, go out and smoke because I always have a cigarette at night but now I can't, and I haven't had any since." (Betty, 87years, St Helens)

Eileen personal lifestyle needs had not been considered when she was admitted. An unrepentant smoker, she did not feel that the management of her health should abruptly stop her from smoking. She was ready to go back home without receiving adequate education on the medication management for her COPD, and, such were her needs, this would undoubtedly have resulted in a fourth readmission. As she had been prescribed care rather than being involved, she had started refusing treatment due to her frustration at not being allowed to smoke.

Other participants also portrayed their frustration about the one-size-fits-all approach adopted by service providers and professional;

> "The doctor said she needs a wheelchair, which is an electric wheelchair which she controls, and we took that spec down to the independent living centre in Runcorn, and it's supposed to be there to help people live an independent life, and we went down, they looked

> at the information that was given to them and they said, well we really need another doctors report off your doctor. And it was our doctor who said this in the first place, to say why he thinks this. Because my mum has angina, and gout, and arthritis, and everything else, she can't wheel herself. If she does push herself, she could have a heart attack. And her fingers are bent and twisted so it's not a good idea ... [But] they won't take [it]. The doctor's recommendation was that she needed to have this electric wheelchair, but they are too expensive. So the independent living centre decided the best they could give us on a good day would be an electric chair that I would control from the back. Right, that takes away her independence in the first place, she is supposed to be independent living, but not my mum, we are not going to give you that they said,... They finally decided to give us a regular manual wheelchair. Of course she can't manage because of her angina, because of her arthritis. That's supposed to be an independent living centre, but she has got no independence at all. If she wants to use that wheelchair, either me, my sister or my brother, has to take her out in it, she has not got independence."
> (George.38, main carer to Martha, 81 years, Castlefield, Halton)

George pointed out that while his mother was recommended for an electric wheel chair in consideration of her co-morbid conditions, she had been supplied a manual wheel chair, something which actually limited her independence. George also mentioned that he put in a request for a wet room, but the council would only promise a walk-in-shower. He did not believe that would solve their problem, even where it were to be installed. They were still waiting. Factors such as these simply increased the pressure of him when taking care of his mother. George was acutely aware of this, and talked with bitterness about social services, whose involvement he originally thought would have increased his ability to care for his mother.

> "They put us back on the list, and they have been round and they looked at it ... Because a walk-in shower is no good, really, in our situation, that is their option, I said what we really needed was a wet room. Even a wheelchair can go in there and I can wash her, in a shower cubicle. How am I going to wash her now? All they will pay for isn't what is required, but that's all they will go for. So we have to cope with something that isn't really what is going to help."

> (Shedrack, 56 main carer to Emily, 95 years, Castlefield, Halton)

These instances depict prescribed care instead of negotiated care contrary to stated policies. This experience was widely shared.

> "I said I've got a shower in it. But sometimes I've got to lift my leg over and it's a bit sore so they put a rail on there. The shower at the moment is still a problem for me even after they put the rail in. I would have preferred a walk-in shower." (Josie, 86 years, St Helens)

> "I have to fight every inch of the way. Eventually I got one of those walking sticks from the council but I didn't like it. My son came and said, I bought you this mum, it folds up you see, it folds up and I can put it in my shopping bag. I can manage it you know." (Emma, 92 years, Widnes)

Josie's needs around personal hygiene have not been taken into consideration. Providing her with rails in her bathroom predisposes her to a fall each time she goes for a bath. Similarly, Emma also complained the walking stick provided to her did not meet her mobility needs. Effective communication is one of the foundations on which agreement and shared decision-making must be based. Patients may be happy for decisions to be taken on their behalf by the professionals involved in their care, but the patient must be consulted to check that this is indeed their wish (Moret et al., 2008; Rummery and Coleman, 2003).

In 1999, the Department of Health published a report on the 'Health in Partnership' programme which synthesised findings from 12 research projects. The report contains important evidence about patient and public involvement. The report suggests that patient involvement improves satisfaction and is rewarding for professionals, while public involvement can positively influence planning and services, and increase confidence and understanding. The Department of Health (2001) has claimed that its goal is to ensure that older people are treated as individuals and that they receive appropriate and timely care which meets their needs, regardless of health and social services boundaries. Older people want their interaction with professionals to be characterised by negotiation rather than instruction, dialogue rather than dictation, something which has implications for social services planning and arranging care. Older people are getting increasingly assertive, particularly where they perceive failure in their care. Advances in information technology threaten the monopoly professionals have held in the past. Improvements in education, the dissolution of traditional class structures, and the growth of consumerism have broken down old hierarchies so that change has become necessary. No longer do older people turn up at their GPs and social services to be prescribed care without questioning. Older people are much more knowledgeable and will often challenge professionals on the decisions they make. To take account of these changes within the patient body, health and social care practitioners' need to pay much more attention to service users as individuals. The move towards more user-oriented services and the corresponding drive to roll out personalised budgets show that the UK government is beginning to grudgingly acknowledge that the patient sometimes knows best. A future where health and social care workers are needed to negotiate and commission care as much as to provide it themselves is a welcome proposal, but, as the testimony of the participants in this study shows, major changes are needed if it is to become anything like a reality.

5.4. High cost of care

The use of individual budgets through the use of means-testing is one way of empowering users which require negotiation and choices. The flexible person-centred home care promised would take individual preferences into account. The problem is that such measures can only work if health and social service staff are in a position to identify and respond to the preferences individuals express. As things currently stand, the cost of even minimal levels of home care makes the development of more sophisticated provision impossible.

Entitlement to publicly subsided personal care is means-tested in England, Wales and Northern Ireland, but not in Scotland (Kings Fund 2009; Wanless 2007). There are, however, no national rules for determining who should be eligible for publicly-subsided domiciliary care, which means that they vary from one local authority to another. The means-testing system relates charges to ability to pay. An older person receiving social care in their own home will usually be asked to pay charges so long as this does not take their net income below a certain level, a level linked with the pension credit system. The financial criterion for eligibility for means-tested support for long-term care depends on geography. According to the Audit Commission

(2000), about two-thirds of councils exempt those on the lowest incomes from charges, with the rest levying some sort on charge even on people who are in receipt of income support. The state also funds care indirectly via the benefits system, providing 'attendance allowance' and 'disability living allowance' to individuals to help them pay for care services that have not been directly funded, and to cover non-care related costs.

Unfortunately the multi-tiered nature of this system makes the funding of health and social care unnecessarily complex (Kings Fund 2009). Under the present means-tested system, eligibility rules tend to lead to a stratification of people into three groups: individuals with low wealth, who qualify for state support and receive benchmark levels of care; individuals with high means, who are able to secure high levels of services by funding their own care; and the individuals who fall in-between the other two groups, a significant proportion of whom struggle to pay for their own care, and as a result do not receive enough formal support (Wanless 2006). Individuals may decide not to buy care or to buy only what they can afford a situation which is far from ideal.

I was interested in what support those I talked to received and on what basis. Many needed mobility aids, and when asked if social services provided them, I received replies like the following;

> "No, I bought all those myself. I did have an NHS wheelchair but it was very heavy so I put that in and I got that one, and I had to pay, oh I forget how much I had to pay for it ... paid £800 for this one, £1200 for my scooter. I won't go too far, on that scooter, I go to the shopping city and do my shopping and come back ... put the bags through my knees and off I go ... I have my stick, I gave them the zimmer frame back, and I have the mobility car, you know the scooter." (David, 83 years, Halton)

> "I used to live with my son in my home and he bought a trolley leading to the back kitchen, and got a frame that fits over the toilet ... in the bathroom. The last time someone came out to me they said do away with the bath, but it cost lot of money that bath, it's a corner bath"
> (Mabel, 85 years, Widnes, England).

When social services supplied David with an effectively unusable wheelchair, he decided to buy one of his own, using his own savings, so that it would help him live a more independent life He also purchased a walking stick and mobility car for himself, returning the useless Zimmer frame given to him by the social services. Mabel's son bought the trolley and frame that he thought would help his mother without waiting for social services. These purchases were only possible because those involved could afford to pay. The situation is much more difficult for those who cannot.

I also talked to participants about the adequacy of care packages they received. The following are indicative of what I was told;

> "I'm better really having 2 carers three times a day. What I had was not enough. I wanted 24hours care. Overnight there was nobody. My son was concerned because they said it seemed to be happening overnight"
> (Mabel, 85 years, Widnes).

> "Each time I fell it affected my walking, so now they say I mustn't get up when I'm at home, I mustn't get up unless there's someone in the flat with me. But they can't have someone there all day, nobody can spare the time and my sons come as much as they can, and their wives and my sister"
> (Janine, 75years, Liverpool).

Mabel and Jennie know they need extra care at home but also know they will not get it. Mabel has been told she needs to remain seated in her home unless others are around. Yet she lives alone and has been assigned carers who can visit her just twice a day. The last time she tried to get up on her own, she had the fall that led to her last hospital readmission (the third in the series). Her care package was simply not adequate for her.

As was touched on above, some people cancelled the care packages given to them either because they did not meet their basic needs or because the cost too much. For example, Abigail, an 88year old woman lives alone in her own home in St Helens. Abigail was first admitted to hospital due to cardiac disease and had a pacemaker fitted to regulate her heart beat. A stair lift was recommended to help her get upstairs in her house. She was admitted for a second time 16 days after being discharge when she fell, struggling to climb a staircase that had not been fitted with the promised lift. She was then promised a fall alarm and two care visits a day. Initially, she received the twice daily care but was sent an exorbitant bill. Abigail was not alone in this.

> "I missed my footing you see because I was tired and I wanted to get into bed, I had had a busy day, with the shopping and the cleaning up, you know. I got a statement from the care line, to say that I owed £400. That's what made me ask you did I have to pay for people coming in. I had to borrow some money to pay the statement" (Abigail, 88years, St Helens).

> "The social service was here and they asked her did we want two women. But they took ever so much money from me, to have them two women, to come in for 5 minutes to get him out of bed into his chair, and to come at 6'oclock and put him back in his bed. I washed him, I changed him, I done all that, but they, I don't know whether it was £9 odd or £19 odd, but my daughter was furious with them, and it went out of my money"
> (Mabel, 85 years, Widnes).

> "So I thought what kind of a care package is it if you've got to prepare meals and things, you know? And it's free for a month and after that it's £8.50 for half an hour, which to me is daylight robbery if they expect people to pay that. So yes, you've got to pay for that as well, I pay £20 per month for this ... just for the life line ... I got it on the insistence of my daughter because you know if I fall over, I can't get up" (David, 83 years, Halton).

Abigail, Mabel and David all felt they are being over-charged for care at home, something which led them to cancel their care packages or continue with them at minimal levels. Faced with the costs, they had to manage things on their own. Abigail, who paid £400 for the care she received upon discharge from hospital, had no choice but to cancel the service. She explained her fear of ending up in the same condition and having to find some way of paying for more care from social services.

Both Abigail and Mabel had to live without a care package because they could not afford it. Both had to return to hospital as they could not cope with life at home. As for David, who described the cost of care as "Day light robbery", he continued to receive the minimal levels of care he could afford.

That the unaffordable extra care recommended for Minna was implicated in her readmission to hospital becomes clear from the following;

> "I went home again and the doctor said she still wants extra care. Well she put extra care on, she put care on overnight. It was going to cost an awful lot, about £60 to £70 overnight or so somebody said, and that's with the other money you've got to pay. I thought, well I couldn't do that, so I said no. Well then I had another fall, didn't I, and I was put in the enabling unit"
> (Minnal, 77years, St Helens).

Those I spoke frequently talked about how unfair and confusing the current system is, particularly for those who are not eligible for financial support. The system is overly focused on high level needs rather than prevention, and in the quality and type of services that are available varies hugely. Research shows that older people return more often to hospital when their needs are not met at home (Butt, 2004; Caldock, 1995; Godfrey, 2004; Kerr, 2003; Petch, 2003; Quinn, 2003). On the other hand, Aimonino et al (2008) contend that providing older people with full, 'hospital-at-home' care packages leads to better outcomes, mentally as well as physically.

It is not just that older people have to live with unmet needs as a result of inadequate care package and high costs; they are also faced with the embarrassment of being looked after by strangers who have little time to take concern in them as people. Josie provides an example in the quote below;

> "I tell you what; they should look into the care at home, because you don't really get it. The girls are lovely, I've no fault with any of my careers, but they weren't getting the time to do it. Do you know how long they gave her when I first went out? I was having the morning, tea time, night time. I never got anyone from morning till tea time and I said what about lunch time? And they were all lovely girls, all of them I liked,

> but they didn't have much time. No, they didn't have the time and while they were with you, they would phone and say go to so and so"
> (Josie, 88years, St Helens)

The question to ask when thinking about Josie's and other's cases, is where the dignity is in care of this sort. Older people cannot but reach the conclusion that their care does not matter to social services when it is hurried through and interrupted for the care for another. Many of those I spoke to were depressed by the way care was provided to them, particularly those who lived alone for whom carers were one of their few regular social contacts.

The Department of Health's 'Local Authority Circular' (2001) draws local councils' attention to guidance relating to "fairer charging policies for home care and other non-residential social Services" it had issued to tackle problems connected with variations in care and charging systems. It set out new rules on the exercise of social service functions, including the provision of discretionary services and the recovery of costs for them. The document advised councils that they were required to ensure that their charging policies were reasonable, and set out a broad framework to help councils determine fair charging policies and operate in line with their overall social care obligations. The circular provided clear objectives which all councils operating charging policies should achieve.

However, when it comes to care provision in practice, the relationship between costs, fees and outcomes was not explicitly set out in service contracts for older people. The development of a closer working relationship between the health and social care system would be a positive development, but has proven difficult to implement. Proposals relating to greater transparency concerning the financial responsibilities of individuals and local authorities would facilitate attempts to treat older people more equally irrespective of their care needs (Kings Fund 2009). Few of those I interviewed knew where they stood in terms of social service provision.

5.5.1 Supports for independence living.

The development of services designed to improve mobility and safety in the home is another important part of crisis prevention. Falls were responsible for precipitating readmission and exposing the tension between risk management and the proposed shift of resources towards prevention.

Long-term care services provide the kind of help that people need when they are dependent on others for assistance with some of the essential activities of daily living (OECD 2005). There are different measures in place to support older people with independent living in the community. This includes measures for more severely disabled older people who need help with personal care (e.g. toileting and bathing) and for less severely disabled people who need help with a range of activities that are necessary for general home keeping and maintaining independence at home. Roy postulates that humans interact with the environment and respond to stimuli in ways which help them cope (Roy and Andrew 1999). Social care should be about helping people maintain their independence, leaving them with control over their lives, including the services they use.

Discussion of these topics should be infused with a degree of moral authority and legal scrutiny and accountability. Access to an adequate standard of living, including adequate housing, is a basic human right as enshrined in the United Nations International Covenant on Economic, Social and Cultural Rights, to which the UK is a party. The UK government developed initiatives such as the 'Partnerships for Older People Projects' and the 'Extra Care Housing Fund' to provide additional monies to promote independence at home, personal choice and active old age (CHAI 2006).

Proactive care management encourages ambition and hope in older people by providing them with the right resources, coordinating input and evaluating how they are faring at home. It implies that investment in good rehabilitative support can make a positive difference to older people's lives and recognises that the home has special significance for older people. Home is a familiar place, where older people come into contact with others and feel in control of their lives – as was discussed in relation to this study earlier.

The health and well being of older people is intrinsically linked to housing and can be influenced by many factors including the location of the home in relation to neighbours and services, design and ease of maintenance, and the level of financial resources required to run them (Ahuri 2004). The appropriateness of housing for meeting the needs of people as they grow older thus covers a range of issues including affordability, proximity to services, amenities and social networks as well as housing design and home adaptation (Groves and Wilson 1992). I wanted to explore the support participants received in order to maintain and improve their quality of life and sustain independent living at home. The following quotes are indicative.

> "The first time I put in a request for a walk-in shower was in 88. 1988 and I am still waiting. That's 20 years ago. A Long time! Oh, we can give her a stool to put in the bath. And I tried that, I couldn't get my legs over. I can't climb in the bath, I mean I am not steady on my legs normally. It was useless, the woman that tried to help me with it couldn't, I couldn't get my legs over. She said, oh you are back on the list again. I said well I shouldn't have been taken off the list, But, I'm still waiting. I will have to ring up and see" (Martha, 81 years, Halton).

> "We had a lady coming round from the social services to help and I explained the situation and they said right, well we could get you a kettle tipper - they had already promised that, it still hadn't arrived - a Zimmer frame, a walking stick, the wheelchair, the toilet raiser, the chair raiser, the bed raisers, none of these arrived. This was after the first week, so we were in the second week now right, still nothing arrived. We got things for ourselves, we sorted ourselves out. I put house bricks under my mum's bed to raise it up, because obviously lifting her up and down from a low bed is too much, because when you are doing it all the time, it's too much. So I raised it up so it was higher." (George, 38 years, main carer to Martha, 81 years, Halton)

George's mother, Martha, was promised a Zimmer frame, wheel chair and commode and toilet seat raiser. None of these promises were fulfilled. George had tried to make life better for his mother by improvising, putting house bricks under her bed to make it higher and so easier for him to cope with lifting.

Another case was that of Janine, who suffered from arthritis in her lower limbs and whose mobility had been further reduced due to a fall. Janine had requested a stair-lift on several occasions from social services but this request had not been met. Her family were frightened that she may fall over and die so her bedroom was moved downstairs.

> "I have a nice bath but my family is a bit anxious that I might over balance and there have been 1 or 2 cases that we knew where people had over balanced and died. I've moved my bedroom from upstairs down. I have a staircase but I didn't have a stair lift. I tried but I didn't get any, so I brought my bedroom down below. It's better than a bedroom up really and my family arranged that for me" (Janine, 75 years, Liverpool).

> "A walk-in shower, they said they would give me one. At one time like, that was a few years ago like, about 2, 3 years ago they promised me that" (Suan, 90 years, Widnes).

Suanl, who has been in hospital several times due to repeated falls, explained that she had been promised a walk-in shower in the past 2-3 years but had not received it. Martha has been waiting for the past 20 years for a walk-in shower had not been any more successful. Her name had been taken off the waiting list.

Other people I spoke explained that they did not feel that their independence had been supported by those responsible for arranging adaptations.

> "Last time I had a fracture of the pelvis and was discharged home. I have a banister, the rail, I just pull myself up on this rail which I've done all the time because it costs so much for the stair lifts. Even if I am priority, it takes so long."
> (Janine, 75 years, Liverpool)

> "I hope they fix my stair lift before I go back home since at the moment I cannot lift the other leg."
> (Moss, 92 years, St Helens)

> "She has had dislocation up to two times at home and they have discharged her with no adaptation, so, when she had the third one I told them I won't take my mum back before they put in stair lift"
> (Mrs Derrick, 43 years, main carer to Agnes, 86years).

Both Janine and Mrs Derrick's mother were very frustrated with all the denials and delays they faced when trying to get the adaptations that would make life more comfortable for them in their homes. Moss had a fall and fractured her pelvis. Moss is only hoping for the best, that her stair lift would be fitted after she has hip surgery as she is frightened she might fall again.

One thing that came through during the research was the narrow view that service providers took of rehabilitation and the low priority they accorded to undertaking the work that might facilitate it. The waits older people had to endure had problematic consequences.

> "Walking over there, I fell over a couple of times and that's why they brought me that Zimmer frame. But it was after many other falls"
> (Suan, 90 years old, Widnes).

> "She had passed that stage by the time they brought a proper Zimmer frame. When they eventually gave her one it wasn't quite right. I don't know what was wrong with it, it wasn't quite to their regulations. And by the time they brought the correct Zimmer frame she didn't need it, so they delivered the cane; brought it unpacked it, packed it back up and took it away. Because she really didn't need it, it took that long. And that's no good"
> (George, 38years old, main carer to Martha, 81 years).

Suan was only given a Zimmer frame after several falls. As for George's mother, her promised Zimmer frame was supplied so late that she could no longer use it. Her situation had deteriorated so much by the time of delivery that she was already chair bound. What Martha's case showed was that even when equipment was delivered, often after along periods of waiting, there was no guarantee it could be used. This comes through in the following example as well;

> "And then we went down to Liverpool about the artificial legs. And they sent one in a van, and I'm not kidding you, I couldn't pick it up with both hands, never mind him pick it up with one leg, because at the time he only had one leg. It had a strap that went round and over his shoulder. And you couldn't do that, it was that heavy, and they had it packed with cloth to take the weight of his hip ... They had to take the knee, that's what annoyed me, the knee, taking the knee. Anyhow, I rang, got in touch with my councillor, he's an MP now, and

> he wrote off to this doctor. And he said there must be something lighter for my husband to have, to help him to get round, because his body wouldn't have shut down if we had these things earlier"
> (Mabel, 85 years, Widnes).

Mabel recalled how her husband was treated badly by social services. They had been supplied with a limb prosthesis whose weight rendered it useless. Her husband, frail from an amputation following complication of his diabetes, simply could not lift it. The fact that no workable limb was made available to her husband Jim after amputation, led to his rapid deterioration and finally death.

The data shows that rehabilitative services in the North West of England, particularly, Liverpool, Halton and St Helens are not "fit for purpose" and that the support older people receive to enable them live safely in the community after discharge from hospital is inappropriate and patchy (Allen et al 2006, Audit Commission1998b; Great Britain Royal Commission on Long Term Care 1999; Hallet 2001).There is much to do in defining a new role for long-term care, and home care services tend to be stretched and of variable quality. Primary prevention should be seen as an integral aspect of the way services are delivered to older people. The WHO promotes a common risk factor approach to the prevention and management of chronic conditions, based on recognising the cluster of such factors that contribute to chronic conditions and taking steps to deal with them as early as possible, including working on fall prevention and the prevention of complications from co-morbid conditions of older people (World Health Organisation, 2003). As physical mobility and agility declines, it is important that older people continue to be able to move around and function in their homes, as well as continue to access health, social and other services, shopping and transport facilities, and support networks. Problems can be compounded if the capacity to drive a motor vehicle is lost. Making sure that affordable housing options are available and in close proximity to such services is an issue that will need to be addressed if older people are to remain at home for as long as possible. Measures taken to prevent the loss of access to services and social networks may also reduce some of the negative effects of readmissions on health and well-being. They may even minimise the need for readmissions. Furthermore, providing access to affordable housing for older people in the United Kingdom would contribute to the creation of sustainable communities. It is important that older people are involved and have adequate information and advice concerning their housing options – whether this is moving into a bungalow, adaptation options in their homes or rehabilitative measures within the community - and that these are promptly provided.

Falls are a common and eminently avoidable cause of morbidity among older people. Research shows that approximately 30% of older people living in communities fall each year, rising to 45% in those aged 85 years and over (Tinetti et al 1988). One major consequence of falls is broken bones, particularly broken hips (hip replacement surgeries being among the most common in the UK and a significant source of expenditure (Berg et al 1997). In the UK, falls have been estimated to cost the NHS approximately £581 million a year (Schuffham et al 2003). Moreover, research has shown that older people are much more likely to have to go through a series of readmissions following falls (see Cotter et al, 2004). Given the social, economic and personal consequences of falls, the National Institute for Health and Clinical Excellence (NICE) introduced new guidelines in April 2005, recommending that all health service providers in the United Kingdom should have an integrated falls prevention service. It stated that older people experiencing falls should go through a comprehensive assessment procedure and have access to a range of services (NICE 2004). However, despite NICE's efforts, again we find that government guidelines have not been taken up at the points where older people access services. Many of the older people I interviewed for this study had experienced falls but complained that they had been largely left to cope on their own or deal with delays in the provision of equipments that would have prevented them from falling either in the first place or again.

There is good evidence to suggest that falls prevention strategies reduce falls and readmissions in older people, and there is therefore a real need to implement the strategies already set out by NICE (Chang et al 2004; Close et al 2003).

5.5.2. Supporting independence with home telecare.

Since falls are one of the most significant problems that older people must deal with, the early identification and treatment of those who have fallen is of paramount importance to reduce morbidity and mortality. Telecare is one way in which falls can be monitored, and I was keen to find out whether the people I interviewed used particular systems and what they thought of them.

The ability to live at home is a quality of life issue best thought of holistically, in terms of empowerment, recognition, status and the preservation of a sense of self worth. Falls are particularly damaging in these areas, as they restrict what older people can do for themselves. The development of new information and communication technology, however, has led to the sense that better solutions may now be at hand. Telemedicine and telecare are perhaps most promising in this regard. There is some evidence to suggest that home telecare facilitates greater continuity of care as it improves access and supports the process of disease management by practitioners (Balas et al 1997). Diagnosis via telecare has been said to be more accurate and reliable, since it is based on measurement taken in the patient's natural environment. It may also lead to cost savings, facilitate access to up-to-date patient information in a secure way, and provide strong motivation to patients to participate in their own health care (Agrell et al 2000; Chae at al 2001). The emergence of home telecare has the potential to contribute to more efficient and effective management of chronic diseases such as diabetes mellitus, hypertension and cardiac conditions (Cai et. al 2000; Gillespie 2000;).

Telemedicine is the use of electronic information and communication technologies to provide and support health care at a distance (Field, 1996). It was originally designed to address problems of access to care, particularly in rural areas, but applications have expanded to include education and administration as well as diagnosis and patient evaluation.

In the context of this study, an attempt was made to explore what participants thought about home telecare. I also asked those who were already using different forms of home telecare about its effect on their quality of life, their concerns and their preferences. What I was told demonstrated that people are still not fully receptive to the idea of home telecare. Patients, health care providers and carers remain to be convinced of its benefits. This is important because their perception of home telecare influence its take-up and diffusion. A great deal of home telecare systems goes unused because the technology is not appropriate or because using it imposes too great a burden on the user (Korpela et. el. 1993; Sonn et.al 1996). It is, therefore, worth exploring factors that would make home telecare more acceptable to patients.

When I asked older people about the use of home telecare, I received comments such as the following;

> “Home telecommunication, yes, I would love something like that, to communicate to someone outside that I need help, if it is affordable” (Josie, 88 years St Helens).

> ”You’ve got to pay for that as well. I pay £20 per month for this. Yes just for the life line. Well, I got it on the insistence of my daughter. Because you know if I fall over, I can’t get up (David, 83 years, Halton).

Josie is presently not using home telecare but feels it would be useful if and only if it were affordable. David, who is already using some form of telecare, feels the cost is too high. However, he realises it is useful as he can readily obtain help if he experiences a fall. Other participants had the following to say:

> Whenever anything happens to me, like a fall in the house or that, I press that and they send somebody down to come and help me. It’s very useful and easy to operate
> (Janine, 75 years, Liverpool).

> “Yeah that’s right, It’s just a little black thing on the top, it’s got a red button on it. If you need it, you just press it, it’s easy to operate” (Agnes, 86 years, Liverpool).

> “They are good yes, they are good. If they could identify problems with the ones they have installed and amend them. The telephone, where you can just speak and they hear your voice, yes things like that. We were going to get her a pressure mat in her bed so that when she got out of bed the light would go on and after, say 15 minutes, they would ask are you alright. And if she didn’t answer they would ring us and then of course she’d end up back in hospital so we were looking for all the things to make her safe in her own place” (Martin, 62, main carer to Margaret, deceased, St Helens).

Janine, Agnes and Martin all emphasised how easy the fall alarms they or those they cared for were to us, and saw how useful they were in terms of alerting helpers in case of falls. Martin had even promised his mother a pressure mat to further increase her safety at home. However, Martin noted that measures of that kind would not be necessary if the systems already in place were better designed and maintained.

Some participants however felt quite differently, as illustrated in the following quote;

> "I just go, just touch it, and that's it. The only thing is that sometimes, like this morning, 5 o'clock, it went off by accident and they were all here. They've got a key. Oh yes they came into the bedroom and they said are you alright, and I said yes. That was a mistake, I must have rolled over you know. But I wear it in bed and everywhere here, you know The only time I take it off is when I go for a shower ...I've got a walk-in shower" (David, 83 years, Halton).

In as much as David acknowledges the usefulness of his fall alarm, he is not happy with the frequency of false alarms. It was usually as a result of such inconveniences that users abandoned their fall alarms and other forms of home telecare. Agnes is just one of those,

> "I have got a thing I'm told to wear around my neck but it's getting in the way, you know, always getting knocked and that and I couldn't have it on all the time, so, I kept it on my trolley, you know, my shopping trolley. I wouldn't like it if it was going to get knocked all the time would I? My younger sister had it once, she had it round her neck. She had to take it off because it was doing the same as me, you know, getting knocked all the time so she had to take it off" (Agnes, 86 years, Liverpool).

Both Agnes and her sister had abandoned the use of the devices given to them. They still had them, and were paying for the service, but were not actively using them.

What this study showed is that home telecare is an area of health care that is value laden, about which professionals and older people expressed strong opinions both for and against. These positions were, I felt, less based on knowledge and experience but more on individual's general attitudes towards the ICT in the care of the very old. Those against home telecare were generally resistant towards technological change. These built-in social, moral and political perspectives on technology fell into two camps; a camp in which values were felt to form the development of technology, and another camp in which where technology was thought to form values (Nissenbaum, 2000; Winner 1986). Barnard (2001) describes dehumanisation as the loss of identity and community through objectification or the denial of human attributes. He argues that it should be possible to make use of technology at the same time as balancing the use of technology against the struggle for a humane and caring world. One way of describing the influence and importance of technology is to look at how it is used in a particular context. The "power" of the technical object is, on this reading, mediated by social interactions and cultural constraints (Sandelowski, 2000). Well functioning telemedical equipment could, from the health professional perspective, be seen as a valuable tool to facilitate remote consultations and the treatment of patients it is not possible to treat by other means (Tsuchiya, 1998). All too often, however, new ICTS are seen by health personnel, as disturbing objects symbolising all the forces that want to dehumanise health care and make it more efficient without increasing the number of staff members (Barnard 2001;Sandelowski, 2000).

Technical devices do not only receive their "power" from the context and interactions with users, they can, in some situations, also be seen as having an in-built power that makes them actors in a social process (Sandelowski, 2000). Don Ihde (2001) describes the phenomenological character of the ties between humans and machines as based on four different kinds of relation. The first type of relation he discusses are embodied relations, where technical devices extend the senses. In perfect embodied relations devices withdraw from notice to such an extent that they become almost transparent. One example might be the fall alert hanging on the users neck, where the user is not conscious of its presence most of the time. In the second type of relations, called hermeneutic relations, the technology not only transforms reality by what the instrument permits us to know of it, but the information produced is in itself an altered representation of reality. Knowledge is not obtained from the senses directly but from interpretive readings of data, such as an electrocardiogram printout, or sphygmomanometer reading. The third type of relation Ihde calls the 'alterity relation'. A home telecare that keeps generating false alarms is caught up in a love/hate relationship. It is both friendly and helpful as well as being an irrational monster that is impossible to manage and understand. The fourth relation, background human/ technology relations, covers connections among machines, rather than with them. In using this relation, Ihde refers to the fact that our environments and workplaces are increasingly controlled by technologies managing important functions, but which work away quietly in the background until something goes wrong. Ihde discusses the examples of ventilation systems, security systems, heating systems and communication systems. It seems to me that all four relationships to technology are present in care situations and can provide a useful framework for thinking about telecare and whether older people should encouraged to use it.

There is demand for telecare, as the following shows

> "I had a friend who had it and rang the emergency button and he was living alone. So, when the emergency team came, they could not get in. They called the police but before the police could come to break the door, they found him dead on the floor... If I was given it, what I would probably do would be to leave a copy of my key with my neighbour in case I have a problem" (Moss, 91 years, St Helens).

One suggestion made to me on this subject is worth considering here;

> "Really what they should have is like a pool of emergency equipment, which can be given out on that day, or the following day, to people who need it, right? They can then send someone round to assess them, as their procedure would demand, and then provide them with their own equipment and then that pool equipment can go back, to a pool for emergencies in such a case" (George, 38 year, main carer to Martha, 81 years, Halton).

Having a pool of equipment available to older people as and when it was needed would make a difference. However, in order to create such a pool, the present method of mean-tested social care provision would have to be rethought (an issue I return to later).

5.6. Investigations and treatments.

The prompt investigation and treatment of disease conditions leads to better outcomes. All too often, the symptoms associated with serious medical conditions are not recognised, and diagnosis and treatments are delayed. Even when a diagnosis has been made and treatment decided, people are still being treated for the wrong conditions. The experiences of some of the older people and their cares are highlighted .Delays in treatment, and being treated for the wrong conditions were a concern of those I spoke to;

> "When my mum was in hospital they told me it was irregular heart beat but when my mum was readmitted in casualty, the doctor in casualty told me it was heart failure. The day they discharged my mum, the cardiologist came there and told me my mum had irregular heartbeat. So, even now, I don't know if my mum has an irregular heart beat or heart failure and that's why I really want to go back. I am still confused about the diagnosis"
> (Mrs Derrick, 43years, Main carer to Agnes, 86 years, Liverpool).

Mrs Derrick does not know what her mother has been diagnosed with. Without that knowledge, it is difficult to see how she could have been properly involved in the management of the condition at home. When her mother was discharged, she was back in hospital within the week. Martin provides another case-in-point:

> "I don't know how many weeks, I can't remember, but it was weeks before she went to the hospital, Warrington hospital" (Martin, 62 years, main carer to Margaret, deceased).

Martin explained that his mother had waited several weeks following a fall at home before a decision was made by her GP to send her for an X-ray. During this period, his mother was in and out of hospital because the right diagnosis had not been made. Shelly's case provides further illustration.

> "Well they put the thing on the wrong hand. They put the plaster of paris on the wrong hand instead of the hand I had the fracture in" (Janine, 75 years old, St Helens).

Janine, 75, was admitted to hospital following a fall and a fractured ulna and radius. It was decided she should have a cast. The fracture affected the right arm, but after the administration of anesthesia, they cast the left arm. It was not until she had been sent home that she realized the procedure has been performed on the wrong arm. She had to be given another appointment to redo the procedure, a readmission of an entirely avoidable sort. Misdiagnosis and mistakes are also clear in Minna's case.

> "They only sent me to the hospital when they knew that I had the anaemia. But it was 6 months after ... The specialist turned round ... and, well he had me going up there week after week. And in 6 months, you know I used to be going up and down to the diabetic nurse, the heart nurse, asthma nurse, and to see him, the doctor, but they didn't pick it up. And it was the morning I had to go to see the diabetic nurse, I collapsed in the surgery, and she jumped up and called Dr X and he came in, and he said ,well you've got anaemia, you are very anaemic. I said, I've been telling you. I think it could have been prevented. But they didn't pick up on it" (Minna, 77years old, Halton).

Minna's anaemia was not confirmed for six months, and she had to go through a long period of recovery once the right diagnosis was made and treatment was commenced. She was initially transfused with three pints of blood, followed by iron tablets, which she still takes. Mabel had suffered similarly.

> "Well you see, when I was in the hospital I was anaemic because they gave me the wrong tablets. They put me on Warfarin and I should've never been on it. What it was doing was diluting my blood you see. So I was ill and it caused anaemia, very bad anaemia. But they took me in hospital and they put blood into me and they got the anaemia out of me" (Mabel, 85years old, Widnes).

Mabel recollected how she suffered anaemia for a long time because she had been treated with the wrong medication until the right diagnosis was made.

Daniel, aged 93years, who lives alone in St Helens, had felt unwell for a long period of time. When she finally saw her GP, he was referred to hospital. She was admitted for two days before being discharged home. He has a niece who is a retired nurse and who visits her once in two week time at home. When his niece visited his at home after discharge, he noticed a change in her general appearance and the shape of his face. Diane explained that he had been to the doctor and had been told he was fine. His niece was concerned, and decided to drive him to a hospital emergency ward. Just two weeks after his previous admission, he was admitted with a stroke. When I asked Daniel what his view on his readmission was, he told me;

> "Well I don't know much about it, but I thought it was a doctor I did speak to when he lifted my arm up. And I could feel that my arm wasn't right and I said, do you think it's a stroke? And he said, no, and we came home. And then on the Sunday, on Sunday when my niece came, she's been nursing in Liverpool you see, she noticed something was wrong. She's retired but she's been in Liverpool for years. So maybe if they had carried out more tests or checked me more properly, they would have been able to see the stroke that first time, Yes that's right but everyone makes a bit of a mistake don't they?" (Daniel, 93 years old, St Helens).

Daniel's stroke was missed on her first admission, and only discovered when her niece, a retired nurse, became worried during a visit. Daniel feels his second admission may have been avoided if he had been properly assessed and the right diagnosis made during the first admission.

As other studies have shown, health care professionals make mistakes; they arrive at the wrong diagnoses, they prescribe inappropriate medications, they do not read case notes or instructions left for them carefully enough (Avom 2001; Zhan et al 2001,). Glauber et al. (2000) in an evaluation of a study by Baker et al. (1999) found that even when provided with state of the art tools to help them make the correct decision in diagnosis and treatment, 13 of 18 emergency department physicians continued to make errors. These errors frequently involved observational lapses among members of health care teams. Glauber et al. (2000) suggested that the uniform distribution of error across physicians was indicative of a systemic problem. That these errors in treatment have major consequences for older people is demonstrated by the stories the patients tell above (Buck 1999).

Those aged sixty-five years and over are more likely to have co morbid conditions and more severe illnesses. This increases the risk and consequences of adverse drug reactions and other forms of medical and surgical error. Adverse drug events appear to be common in older outpatients who are taking multiple medications (Hanlon et al 1998; Schmader et al 1994,). Some of the people I spoke to attribute their readmissions to adverse reactions to the drugs they were prescribed;

> "It was the reaction to the penicillin. I got these horrible things all over me at one time, sores. They were like that and they were all over my

> body and they were so sore and so itchy. I seemed to go 2 steps forward, 5 steps back, everything they'd tried on me. I mean one of my friends who came to see me in hospital said you're just a giant pin cushion for them to have a go at. That's what I felt, because the world and his wife seemed to be prodding needles in me and doing things, and I wasn't getting any better" (Josie, 88years, St Helens).

> "The nurse came and she looked at it and she put this brown gooey plaster on, she peeled something off it, and she put it on and she wrapped his leg up. You wouldn't believe how big it was when she comes the next day to take it off. It was like that. The plaster had gone against the ulcer and it had made the ulcer spread. Oh we couldn't believe it, we kept looking. Anyhow. brown stuff whatever it was, had made it bigger. Oh I warned him when he got another one on his other leg, I said don't bring that brown plaster here, I said, because that's how he lost one leg, because they couldn't save it, it was like a hole" (Mabel, 85 years, Widnes).

Josie recalled how her reaction to penicillin caused painful sores that meant further hospital treatment. She felt she had not been told enough about possible side-effects of the medication she had been prescribed and so did not know that her symptoms could be related. Similar sorts of problems to those her husband faced, were also faced by Mabel.

> "He wasn't happy and he said, what have you been doing? Have you been on antibiotics? I said no, if I'm put on antibiotics I put it in my book to let you know. I said I've done nothing different, I said, all that I'm on at the moment I eat. And crab sticks, I said, but I make a packet do me 2 or 3 days, I said, and I know for a fact they do not interfere with my diabetes. So he said, oh no, no, he said, it's not fish. So I said the only other thing, I said, I've had ginger beer, half a glass and half water, I said because I couldn't take it anymore, they had to water it, I said but I had an awful lot of it. And I said so I started trying my medications, knocking off what I was on. I said and I stopped

> taking the ginger beer, I said, and I went back to my pineapple and my soda water, and it's gone" (Vera 75 years old, Widnes).

Mabel's doctor thought she might be adversely reacting to an antibiotic. Mable knew that could not be the case because she not had taken antibiotics for a long time. She did, however, take the measure of cutting down her alcohol intake after which she recovered.

As reflected in the quotes below, many of those I spoke to thought that their readmissions may have been connected to the large amount and types of medication they were taking at any one time.

> "Since the heart trouble she's on about 15 tablets and I usually put them out for her in a glass everyday. She was able to do it herself but with the way she is now I wonder if she will able to cope"
> (Abigail, 88years, St Helens).

> "She couldn't get over how much medication they were giving her for, you know, the X-ray, the operation"
> (Martin, 62 years, main carer to Margaret, deceased, St Helens).

> "I take seven in the morning. Those two, I'm due to take those two now. And then lunch time I take two. Between 8 and 10pm, I take another six" (David, 83 years, Halton).

Mrs Derrick felt her mother's polypharmacy contributed to her poor state of health, and Martin felt that the amount of medication his mother had been given had contributed to her death. David's experience – that of taking 17 different pills every day – was fairly typical for the group I spoke to.

As people get older, their use of medicines tends to increase. Four in five people over 75 take at least one prescribed medicine, with 36% take four or more (Health Survey for England 1998). Adverse reactions from medication occur throughout patient care, and a growing number of studies have examined medication errors and adverse events in patients (Honigman et al 2001b; Rothsschild et al 2001). Findings from these studies are borne out by the present study. Gandhi et al (2001a) studied a random sample of 2,248 patients. Eighteen percent of these patients reported complications brought on by drug treatment. A medical record review reported complications in only 3 percent of the sample. Drug complications in these settings are common and result in increased use of medical care to manage adverse effects. A study of adverse drug events in a large random sample (93,950 elderly and 55,333 adult patients) in Quebec in Canada, undertaken following a policy change that increased cost-sharing in the province's prescription drug benefit program, showed that these increases resulted in reduced use of essential, appropriate drugs, a higher incidence of serious adverse drug events, and increased use of emergency services resulting from the adverse reactions (Tamblyn et al 2001). Researchers observed that older patients were particularly vulnerable to medical injury. In their review of medical injury in older patients, Rothschild and Leape (2000) note that the shift from inpatient to outpatient care brought about by managed care has meant that adverse events are increasingly going unrecorded. Rather than learning from past mistakes, as should have happened, they were repeated, leading to more frequent readmissions among elderly patients for treatment for the same medically-induced problems. Reactions range in seriousness, from benign but unhelpful under-performance to life-threatening toxicity. A variety of events and factors come together to cause drug reactions in older adults. These include inability to follow multiple, complex prescription medicine routines; interactions between over-the-counter medications with prescribed drugs; error in drug dosage due to issues of optimal doses for older persons; prescriptions written by multiple physicians; and age-related changes in the body, especially the liver, that alter the way drugs are absorbed, circulated and eliminated from the body (Dudman 1990; Livingstone and Reeves 1993; Morley 1993). However, a recent study found strong evidence that co morbidity from chronic disease, rather than advancing age, increases the rate of repeat adverse drug reactions among older people. Co-morbid congestive cardiac failure, diabetes, and peripheral vascular, chronic pulmonary, rheumatological, hepatic, renal, and malignant diseases were all strong predictors of readmissions for adverse drug reactions (Zhang et al 2009).

In terms of the treatment older people receive, major challenges are involved in ensuring that medicines are prescribed and used effectively, in ways that take the ageing process and the ageing body's capacity to handle medicines into consideration. Co-morbid disease conditions affect older people more frequently, necessitating complicated medication regimes, and this affects patients' capacity and ability to manage their own treatment. I asked participants how they managed their medication after discharge from hospital and was told, among other things, the following.

> "At home I might forget sometimes now and again, but not in here because it is given to me" (Agnes, 86 years, Liverpool).

> "My mum has glaucoma and she's on eye drops. She's always done it herself. She seems quite confused now and I really doubt how she will be able to take care of her medication when she goes home" (Mrs Derrick, 43years, main carer to Agnes, 86 years, Liverpool).

Agnes talked about how she could forget to take her medications when at home. Her daughter, Mrs Derrick, also suggested that she would need supervision in future. However, before her last admission, Agnes had her own strategies for remembering to take her medication. She used to sort them out in glasses a couple of days before she needed to take them, as she explains in the statement below;

> "Yeah, well I decide. I know how much to take and it's on the bottle, I always have them in different bottles and initial glasses and I put them all out, say a couple of days before. Then I'll know they're all there. So I'll just go, take them, and put my eye drops in, generally, overnight" (Eileen 87 St Helens).

Non-compliance with medication regime is common and may be very high where the drug regimes are particularly complex. Unfortunately, because of co morbidities, older people are often faced with regimes that are complicated (Royal Pharmaceutical Society of Great Britain 1997). The failure to take prescribed medication can lead to the mismanagement of disease conditions and so readmissions to hospital, adverse drug reactions and drug wastage (Banning, 2004; Cline et. al 1999; Piramohamed, et al. 2004).

Research shows that older people take medication in both unintentional and intentional ways. The situations discussed above, which involved confusion, were situations in which individuals did not understand their medication regimen. Researchers believe that these are situations where non-compliance becomes more likely (Barat et al 2002; Bytheway , 2002; Salas et. al 2001; Westbury, 2003). As Agnes's case shows, visual impairments are also a problem here as they make it difficult to read the labels on the container. Problems around medication are aggravated when older people live alone without someone to remind or help them. It is clear that some form of home-based intervention around medication would have helped. Providing older people with medication-timed alarm clocks, positioning their medication in visible places, going through the medication routine with them at different times, placing special coloured labels on bottles and making phone call reminders are all simple measures that could be put in place with relative ease (Britten et al 2000; Fulmer et al 1999; McGraw and Drennan 2001; The Disability Discrimination Act 1995 and Progress in sight, National Standards of Social Care for Visual Impaired Adults 2002). What is more, measures of this kind are in line with existing policy documents. The Department of Health (2001), for instance, requires practitioners to carry out periodic medication reviews, including assessment of whether the patient understands their medication and is able to take it without difficulty. The 'expert patient' programme also emphasises empowering patients through information on how best to manage their conditions, something which covers use of medication.

However, some older people intentionally choose not to take their medication. Nina provides an example;

> "I'm alright I don't forget because I only take them when I go to bed, mostly to make me sleep" (Mina, 77, Widnes).

Mina, 77years old, who lives in Halton, was diagnosed with COPD and prescribed nebulizers, to be used four times a day, and an inhaler which she was to use when necessary. Her experience of breathlessness as a result of this condition is manageable during the day but not at night. She chose to take her nebulizers only once at night to ensure she slept well. This strategy, however, defeated the purpose for which she was supplied with the medication in the first place. A week after being discharged following problems, she experienced extreme breathlessness and had to be readmitted. One of the reasons why she was readmitted was so that she could be instructed in the proper use of the medication she had been given.

Like other studies, this study shows that older people may choose not to comply with their prescribed medication if their symptoms are mild (Allen 1998; Maidment et al 2002). Other reasons identified in the literature for intentional non-compliance include; avoidance of drugs that cause high dependency, perceived side effects after taking certain medications, not being encouraged to verbalise concerns about medications and personal psycho-social issues like the early onset of depression (Bissel 2003; Day, 2003; Herve et al 2004). Addressing the concerns and preferences of older people through consultation and by working as equal partners – together often termed 'concordance' – has been found to be effective in addressing intentional non-compliance (Watson , 2003; Weiss and Britten 2003).

The Department of Health's policy documents (2000) have emphasised that reforms needed to improve care for older people by obtaining and acting on their views. The plan to give patients better access to pharmacy services, and to help them to use their medication more effectively, is to be based on agreement between patients and health care workers. Improving older people and their carer's knowledge of their medication, through explanation of its functions and therapeutic effects, as well as side effects, may improve compliance. It is worth noting here that I was personally asked to give advice on medication and counselling was carried out during the interview process. Those I spoke to were particularly keen to ask me questions when we discussed how they were coping with their medication.

5.7. Care Communication

Apart from problems with medication, and its effect on readmission rates, older people and their carers also identified problems in relation to communication across health and social care services. Communication is fundamental to health care (Flach 2004, Gordon et al. 1995, Safran et al. 2001; Roter and Hall 1993; Stewart 1995). However, in certain cases, specific communication challenges are encountered. These challenges make the delivery of good care to individuals, especially vulnerable older people, more difficult. The patient-centred approach to communication is widely recognised to be a valuable strategy for building relationships with individuals and improving the quality of care provided by physicians and other health care professionals (Epstein et al. 2005, Mead and Bower 2000, Laine and Davidoff 1996; Taylor and Lurie 2004,). Patient-centred communication encompasses a moral philosophy based upon respect for individual patient's needs, wants, perspectives and experiences, and is able to provide individual older people with the opportunity to participate in their care (Epstein et al. 2005). Research shows that good communication during health care encounters improves satisfaction, compliance and adherence to treatment regimes, the success of preventive services, and clinical outcomes (Beach et al. 2005, Flach et al. 2004, Stewart 1995). Patient-centred communication can, therefore, provide a framework and a set of expectations for health care organisations who want to assess their performance and design quality improvement initiatives.

The effective communication of information underpins collaboration between health and social care practitioners, on the one hand, and older people, on the other. The UK's NSF for older people recognises that information about older people needs to be transferred across professional and organisational service boundaries in order to deliver care effectively (Department of health, 2001). However, the European working time directive has led to the fragmentation of care. More frequent handovers between service providers generate gaps in communication about a patient's past and present clinical and social conditions. Those I spoke to saw poor communication across sectors of care providers as an important factor in readmissions;

> "When my mum had pneumonia the week before they said she had a heart condition. So when I went to see the consultant it was for a cardiac problem and then when I went to see the GP, after she was discharged. He said he hadn't seen the note about my mum's cardiac problem. And you think, because they are in the same hospital, the communication would be faster but you have to keep pushing"
> (Mrs Derrick, 43 years, main carer to Agnes, 86, Liverpool).

Mrs Derrick regarded poor communication concerning her mother's diagnosis as the cause of her latest readmission. Her mother was still being assessed and treated for pneumonia because her newly diagnosed cardiac condition had not been communicated to her GP. Failure to convey accurate, complete and up-to-date information across hospital and primary care sectors is a major avoidable risk. Insufficient and inaccurate discharge information does adversely affects patient's continuity of care (Foster et al 2002; Pillai et al 2004; Sparz et al 2001). The problems include; miscommunication between doctors and nurses at key stages (Moret et al. 2008); poor transfer of information from hospital-based nurses to community-based nurses (Payne et al 2002); and poor communication of patient's diagnosis and treatment options from hospital based doctors to GPs (Balla and Jamieson 1994). These factors were all observed in the present study.

These, however, were not the only problems. In another type of case, Mabel explained that she was discharged from the hospital without all her medication. Following her return home, she suffered extreme distress and had to be readmitted within the week. Its reoccurrence the second time infuriated her daughter, and since they did not want her to go back to the hospital, they made sure their GP gave them the correct prescription;

> "And at 6 o'clock when I was due my Warfarin, she hadn't got any. So my daughter played hell. Anyhow they sent somebody down, and they came back with my Warfarin in a little cup, and our Sue said, I want all her medication back here. And you know when I did come home there was an awful lot I didn't get, I had to keep mithering my doctor for them. He'd tell you, every day I was on the phone, I haven't got this back from A, I haven't got that back from A, and I've got it all back now, thank God." (Mabel, 85 year, Widnes)

An important medication like Warfarin, which should not be stopped, was not even supplied to the patient in this instance, a failing that demonstrates poor communication and gaps in the continuity of care. Older people greatly value continuity of support and such continuity helps to maintain focus on longer-term outcomes. Currently in the UK, a hand-written interim 'To Take Out' (TTO) form incorporating the discharge prescription is given to older people when they leave hospital and a copy is posted to their GP. From what I could ascertain from those I spoke to, there was evidence of a relationship between inappropriate discharge prescriptions and readmission (Coleman et al 2005). This suggests there is a need to provide accurate and complete information about older peoples' medication and to make sure at least one month's medication is supplied on discharge to avoid medication related problems. An older person who has been discharged without the correct medication may have to wait days before they receive it. In situations of this kind, their symptoms often worsen. Research has shown that gaps in communication lead to misunderstanding, mistrust, non-adherence and other health care problems like readmissions (Cooper et al. 2003). Gaps in communication lead to medical errors, increased costs and reduce the overall quality of health care (Bernstein 2005, Flores et al. 2003; Jacobs 2004, Schillinger 2004,). This means that communication gaps have a negative impact on health outcomes and may be a root cause of some health care disparities (Berkman et al. 2004, Fiscella et al. 2002; Jacobs et al. 2005, Schillinger et al. 2002, Schneider 2002; Taylor and Lurie 2004).

Patient satisfaction increases when communication is clear, understandable and respectful (Beach et al. 2005; Morales et al. 2006; Wanzer et al. 2004).

In our interview, Davina highlighted the problems she and her mother had to content with;

> "I'm disgusted with the lack of coordination information and communication between the agency, and it was a council run one, and their staff. It was like they didn't care because they were getting paid no matter what happened ... Someone contacted me to sort out my mum's financial agreements, and I said, what? Didn't they bloody tell you that my mum was in a hospital? So again they didn't inform the council so they thought that my mum was getting this care package and this was 6 weeks after.
>
> (Davina, 44 years, main carer to Jane, 90 years, Halton).

> "I feel that the present division between the agencies and the council should be bridged, all the agencies should work together to provide adequate care for people and they should consider their individual needs"
>
> (Mrs Derrick, 43 years, main carer to Agnes, 86, Liverpool).

Davina expressed her frustration at the lack of communication between the agency that provided personal care for her mother and acute care services in the hospital she attended. It took a period of six weeks for them to realise that her mother had been admitted to hospital only three days after being discharged. The agency's records stated that care was still being provided and Davina's mother was expected to pay the bill. Confusion of this kind is routine in situations where information has to be shared across organizational and geographical boundaries (Jackson et al 1999; Mackenzie and Currie 1999).

As health care becomes increasingly complex, with more and more stakeholders involved, its ethics of care become more challenging too. Today, each participant in health care delivery is strongly affected by the ethical standards of many other participants. If we hope to build and maintain trust in the system as a whole, its various stakeholders must work together to develop shared ethical standards, clear expectations of ethical performance, and methods of ensuring accountability to these performance expectations through effective communication.

Evidence suggests that having a hospital discharge policy and key workers in the form of discharge coordinators or liaison practitioners, improved discharge planning and the co-ordination of hospital and community services. When introduced, improvement was noticeable in communication across sectors of care and both older people and their carers were more satisfied with the outcomes (Payne et al 2002; Peters et al 1997). Evidence also suggests that gaps in communication among health care professionals, often lead to medical errors and greater rates of avoidable readmission and death (Forster 2005, Gandhi 2000; Hughes et al. 2005, Poon et al. 2004; Wilson et al. 2005, Woolf 2004,). Patients who understand medication and treatment instructions are more likely to adhere to therapy and return for follow-up care (DiMatteo 1994; Jacobs et al. 2004,). What we can see is that, as self-management of complex chronic illness becomes more important to health care, effective communication becomes more important to long-term health outcomes (Ashton et al. 2003, Williams et al. 2002). The right to informed consent in care delivery depends on the effective communication of complex information (Thom 2000). Decision making between health and social care requires good communication (Charles et al. 2003). To achieve positive health outcomes, health care professionals and other stakeholders must be able to communicate with the people and populations they serve about disease prevention, treatment plans and options, risks and benefits, medication instructions, and other topics related to effective health care management.

5.8. Summary

The chapter has looked at service provision by health and social care organisations, a discussion built around quotes from study participants. The participants identified that pressures on acute beds has resulted to their early discharge from hospital. They also perceived the care provision after discharge to be prescribed form of rather than a negotiated care in which their personal needs have not been put into consideration which resulted to bouncing back to hospital. The present mean-tested system of social care in the UK except Scotland have affected the older people in getting the right kind of care they deserve so that some older people are living with unmet needs in the community.. Discussions on support for independent living at home portrays delays in their provision, ineffective delivered equipments and sometimes total lack of supply of equipments due to limited budget on social care. Some of the home telecare supplied have been abandoned due to lack of evaluation on their inappropriateness. Also the fragmentation of care and poor communication between hospital and community care has been identified. Health care communication is recognised as an essential element of public health and a core component of the health care system. Healthy People 2010, for instance, have picked out health communication as one of its focus areas, indicating that it affects all leading health indicators (Public Health Foundation 1999). Patient-centred communication is vital if health care organizations are to provide ethical, high-quality care.

Chapter Six: Findings and Discussions

Nutrition, Co-morbidity and Social Isolation

6.1 Introduction

This chapter examines issues relating to nutrition, co morbidity and social isolation among older people. Older people are a diverse group who vary in all aspects of their lives, and the variations in their physical and physiological functions are greater than in any other age group (Chapman and Sorenson 1998). There is a growing recognition that age-related physiological anorexia may predispose to protein-energy under-nutrition in older persons, particularly in the presence of co morbidity and other pathological factors associated with aging (Garriballa 2004; Machintoch et al 2000). For example, alteration in smell and taste and poor dental health decrease food intake and influence food selection (Garriballa and Sinclair 1998). In general, physical activity and lean body mass decrease with aging, while body fat increases. These factors may decrease energy requirements and intake (Garriballa and Sinclair, 1998). Lower food intake may lead to lower intake of nutrients, and, even in relatively healthy persons, mild, sub-clinical nutritional deficiencies are known to be common. In the past, the National Diet and Nutrition Survey for people aged 65 years and older in the UK has highlighted low dietary intakes and micronutrient deficiencies as problems in this group (Finch et al 1998). Moreover, there is a close but complex association between loneliness, social isolation and living alone. Some of these issues, amongst others, are some of the highlights of this chapter which are it turn supported with quotes from the study participants.

6.2 Nutrition

Good nutrition can contribute significantly to the health and well being of older individuals, and their ability to recover from illness. Ageing in human beings is accompanied by changes which may impair food acquisition, digestion, and metabolism. Anorexia and weight loss are common and important clinical problems in older people, and the causes are multi-factorial (Garriballa 2004; Machintoch et al 2000). It is important to understand that the ageing process is not usually the cause of malnutrition in healthy active elders on its own. Based on long-term observation and study, researchers have concluded that even with ageing, healthy active older people and younger adults have similar nutritional requirements (Vella 1992). Every malnourished older person has his or her unique set of life decisions, circumstances and events that come together on the continuum of wellness and illness to cause malnutrition. High percentages of older people also regularly take over-the-counter medicines for the more usual aches, pains and maladies of cold, flu, sinus, indigestion, constipation, gas and diarrhoea. A number of specific and significant risk factors that are highly associated with poor nutrition, poor health and greater use of health services in older people have been identified. The risk factors include a variety of biological, psychological and social stressors which, in any combination, can negatively affect an older person's nutritional intake and eventually his or her nutritional and physical wellbeing.

Previously well-nourished elders can become malnourished when they experience physical trauma or stress, such as surgery, infection or injury. This stress can increase their metabolism and their protein, calorie and nutrient needs to such an extent that if their nutritional intake does not meet their increased needs, they may become malnourished. Care provision for older people should thus take nutritional matters into account (Orem 1995). When I explored older people's views of receiving adequate nutrition in their homes, Janine replied;

> "And I've got a little bit of shopping but in all frankness I get better fed here than I do at home, only because I can't be bothered even if I look thin. You know, I wouldn't go hungry. I don't eat the right food, but I definitely wouldn't go hungry. That's why I'm so skinny"
> (Diane, 92 years, St Helens).

Diane reports that she eats better at the intermediate care unit than at home. Experts agree that the risk of malnutrition is high among specific groups of older people, especially those without the income to purchase decent food, those who are isolated, and those who suffer from illnesses, disease and other conditions affecting independence (Ahmed 1992, Dwyer 1991). For others, malnutrition can occur due to inadequate nutritional intake caused by any number of factors and conditions. Any circumstance that interferes with consumption of adequate calories, protein and other nutrients from a variety of foods increases the likelihood of malnutrition (Institute of medicine, 1992; Reo 1992).

In the UK, social services can provide information about delivered meal-providers in the different localities older people are living, and can also arrange for those meals to be delivered to their homes either hot or frozen. The meals-on-wheels service will usually meet the dietary, religious and cultural needs of older people. If the assessment of an older person has been done and it is decided that this is the best way of meeting his or her nutritional needs, then the meals-on-wheels service is provided in partnership with a catering service for those unable to cook meals for themselves (NHS & Community Care Act 1990). The older people I spoke to were aware of this service and keen to make use of it. It was seen as particularly welcome after a spell in hospital when older people were readjusting to life at home.

David, 83, was admitted to an intermediate care unit when he fractured his femur due to a fall. Frank was about to be discharged from the unit when I interviewed him. I asked him about his diet and preparing food. David told me;

> "I will need to ring up the people who deliver food on trolleys to deliver maybe twice a week so I can feed well when I get home, otherwise it will be very difficult" (David, 79 years, Halton).

David knew he was unlikely to get adequate nutrition without meals-on-wheels. As emerged in the course of the study, it was a much relied upon service. However, although those I spoke to relied upon it, this did not mean that the service was always up to standard;

> "My mum used to receive meals delivered to her but they bring the first meal late at 11 o'clock – assuming the first person comes by 9am to get my mum ready. Well basically these meals are delivered late and she wasn't getting a lot nutrition, that's why I am really afraid that when she lives here, she is going back into the same system and she may deteriorate and I don't want that to happen because you are back to square one" (Mrs Derrick, 43 years, main carer of Agnes, 86 years, Liverpool).

> "I used to get meals-on-wheels but the times varied, I never knew what time they were coming. Sometimes it would be 11 o'clock, sometimes 12 o'clock, sometimes not at all – so I stopped it altogether. They were alright at first, they'd come at a regular time, 12 o'clock, but then they

> just stripped it apart then, yes. So I'm better off now really without it" (Suan, 90 years, Widnes).

Both Suan and Mrs. Derrick cancelled the meals-on-wheel service because deliveries became increasingly irregular. Thus, even though they had access to the service, it was not actually meeting their requirements. Badly run food delivery services can have devastating consequences for older people reliant upon them. One particularly alarming study of such services showed that those receiving one meal service actually lost weight and lean body mass, having the opposite effect to the one it was supposed to have (Boldt 1993). Access, then, while important, is only one part of the problem; ensuring that the service actually meets needs is also part of the challenge.

Malnutrition due to disease can be further aggravated by the increased energy and nutritional needs that result from fever, chronic infection and disease-related changes in metabolism or by impaired appetite, chewing, swallowing, digestion and absorption of nutrients (Ahmed 1992, Dwyer. 1991). Malnutrition can be both a cause and an effect and its presence can further complicate the progress and outcome of any disease or condition. This is due to the serious health consequences that can result from unattended malnutrition, including decreased immunity, delayed wound healing, weight loss, decreased muscle strength, altered body responses to medications, confusion and disorientation. For older people with weight loss from chronic lack of appetite and malnutrition due to multiple and serious diseases, increased calories and nutrients from even the most aggressive nutritional interventions have not been successful in reversing their decline (Carr 1989 ;Gorbien 1990; Heber 1990;).

Swallowing problems are common in older adults and can profoundly affect food choices. In a study of homebound elders in New York, difficulty in swallowing was positively related to not eating for one or more days. Lack of assessment and effective treatment of swallowing problems has been identified as one avoidable cause of malnutrition in older people. Overall poor oral health is associated with protein-energy malnutrition, and was found to be a good predictor of involuntary weight loss, one important indicator of poor nutritional status. It is clear that oral health problems that interfere with chewing and swallowing, and thus affect food choices, will affect an older person's nutritional status. The cost of malnutrition among older people should seriously concern all of society (Carr 1989; Gorbien

1990). According to NHS figures, among hospital patients' under-nutrition and malnutrition translates directly into longer stays in hospital, slower healing, more complications, increased readmission rates and higher death rates (Gallagher and Shy 1993).

6.3 Chronic disabling conditions

The capacity to respond promptly to the changing needs of older people can help to prevent deterioration and irreversible decline. The proactive assessment, anticipation and management of risk is the key to delivering successful responses to crises. Lack of contingency planning for individuals with chronic health and mobility problems is likely to result in otherwise preventable admissions to hospital. Older adults are often treated with multiple medications for multiple chronic diseases, and as a group take more medications than any other age group. It is estimated that older adults living at home take three or more medications per day (Reeves, 1993; Varma 1994;), although those I spoke to were often taking considerably more. For older people who have chronic illnesses and are also chronically malnourished, multiple medication use might further weaken what nutritional reserves they have managed to maintain. As already revealed in the literature review, chronic disabling conditions often necessitate frequent visits to hospital. Those I spoke recognised that many of these visits were unavoidable;

> "No, no it couldn't have been avoided because it just happened, it was an extension of her stroke" (Martin, 62, carer to Margaret, deceased)

> "Oh I've been disabled for quite a while now, several years. But it all started off in 1990 when I fell down the stairs – fell down a flight of stairs, went bump, bump, bump, bump all the way down,, and crashed into the front door. I was only short the distance between the end of the stairs and the front door, crashed into the front door. I ended up in Halton hospital, and Neville, Blackpool hospital for several weeks. And my son came up for me and brought me home again. I was living in a 4 bed roomed house then. And I fractured several vertebrae and I've never been the same since" (Mina, 77, Halton).

The quotes from Martin and Mina are representative of what I was told by participants more generally. They knew that, no matter the interventions by health and social services, they were likely to return to hospital from time to time for the ongoing management of their chronic conditions.

From the standpoint of the older individual, the cost of readmission from co morbidity is high, and may lead to weak muscles and loss of strength, affecting their ability to stand, walk and lift. Those most seriously affected may suffer medical complications from decreased immunity, leaving them more vulnerable to developing pneumonia, influenza and other infections and illness that can become life-threatening (Prentice 1989; Roe 1992, Young 1988). Older people are more prone to adverse drug reactions and their wounds are more likely to heal more slowly and with more complications. This again, is a matter of social concern and every effort should be made to ensure that older people are looked after as well as they possibly can be.

6.4 Social isolation and marginalisation

Researchers define social isolation both objectively such as living alone and lacking social contacts, and subjectively, in ways that only the older adult can report on. Objectively, social isolation is a lack of contact and interaction with other people. Subjectively, it is the feeling of loneliness or lack of companionship or of close and genuine communication with others (Cattan and White, 1999; Hall and Havens 1999). Loneliness is the perception of being alone and can be experienced even when one is in contact with others. Although older people can live alone without being socially isolated or feeling lonely, living alone is nonetheless a leading indicator of the potential for social isolation. The importance of tackling social isolation and loneliness so as to improve older people's well-being and quality of life is increasingly recognised in international policy and in some national health strategies (Department of Health 1999b, 2001, WHO 2002). In the UK, the NHS NSF for Older People has provided local incentives to address loneliness and isolation (Department of Health 1999a, 2001). Health promotion services and activities intended to alleviate social isolation and loneliness among older people have long been considered important in providing support to develop, improve and maintain social contacts and mental wellbeing (Walters et al. 1999). Isolation must be dealt with if older people are to stay at home for as long as possible. This, however, requires an active lifestyle and a capacity for the individual themselves to recognise and address problems of loneliness, relationships with family members and interactions with dedicated service providers (Camarinha- matos and Afsarmanesh, 2004). The problems of older people are both medical and social in character and the lack of social support can play a role in the development of disease and disability. In older adults, loneliness negatively affects nutrient intake. The loss of a spouse can create social isolation, grief and depression. Even up to two years after the loss of a spouse, those who have been widowed have significantly worse diets than their counterparts, particularly in cases where they were used to eating together with their spouses (Walker, 1991). As was discussed above, some of the older people I spoke to left their homes following the death of their spouses and finding themselves unable to cope in a home unsuited to their needs as single people. Loneliness was often less of a problem among those who had made the decision to move. Those who remained at home, however, reported feelings of loneliness and of missing out on social interaction;

> "Just occasionally, mostly telephone. They all work you see, and when people work, they haven't got time to visit. Christmas times like that, we do get together. We play pass the parcel Christmas time. They say, are you having my mum this year, I had her last year so you have her this year?"
> (Moss, 91 years, St Helens).

> "I never ever go out in the evenings, never ever, and once it gets dark, I don't care who knocks at my front door, no way will I answer it. And I don't answer the phone after dark in case it's someone that's going to frighten me, because I like to go to bed to sleep and not worry about what's going on. So I won't answer the phone once it is dark, after that"
> (Josie, 88years, St Helens).

Moss's interaction with her family is restricted to visits during festive periods and occasional telephone calls. Josie also inhabited a world in which contact was restricted, frightened to open her front door or answer the telephone after dark. Both are examples of how loneliness and social marginalisation due to old age and frailty affects the lives of older people.

Those I spoke to were aware that support was available, support which they felt would have benefitted them. However, they did not know why they were isolated from accessing those sources of support and wondered why they were not told how to contact organisations that might have been able to help;

> "What I can't understand is, I've not been able to walk since I come out of hospital, so why wasn't I sent for therapy you know, to get my legs going. Why wasn't I sent there because I do know about people that have gone there, and it's done them good, you see. But my hands are stuck because of the arthritis and I can't move them the same, so if I'd gone there it might have done me a world of good. Whereas I'm getting worse, I'm getting worse now. The centre, I've never been in there, I don't know what it's like. I do a bit of exercise myself in here but it's not the same as going to one of them. It's not the same. Probably if I feel too ill any day, I'd dial 999 ambulances. I get stuck in sometimes"
> (Emma, 92 years, Widnes).

A study of loneliness and isolation in the UK revealed that nearly one million people aged 65 and over feel trapped in their own home (Owen, 2001). In Australia, a study of 2000 veterans found that approximately 10% could be classified as socially isolated and another 12% were at risk of social isolation (Gardner et al., 1998,). Extrapolating, the researchers concluded that, nationally, more than 34,000 veterans and war widows were socially isolated and an additional 41,000 were at risk of isolation. A study by Edelbrock et al. (2001) of social isolation/social support issues among older people in the Sydney area found very little difference between older veterans and older people in the general community. The available research findings thus suggest that there is a close but complex association between loneliness, social isolation and living alone (Andersson 1998; Wenger et al. 1996;). Social isolation has been identified in the literature as a risk factor for suicide. De Leo et al. (2000) found that living alone (for men 75+), having had a recent physical illness and having little contact with others were all related to risk of suicide. Rosenman (1998) also concluded that, for older people, loneliness and physical morbidity were risk factors for suicide and these factors also increase the possibility of older people becoming socially isolated. Those I spoke to were keenly aware of their own isolation, something that can be seen in the following quotes from Emma and Mabel;

> "My windows, I can't get anyone to clean my windows. My son comes when he can and does them when he can. I used to do them every

> week but now it's every 6 months now, and I'm lucky if I get that. I have to put with that. I love a game of bingo, can't get out to go. My son's working all day and I don't like to ask him to take me out of a night and pick me up again, so I don't, I don't go out. I love a game of bingo, can't have it, I've got nothing in life now, what am I living for? What am I living for? (crying). But now and again I get fed up looking at the walls, not going out, you know. I don't know how long this has been going on. Well if they send someone to clean my windows or change my bed, I'd be as happy as Larry. I get myself upset because I'm missing the best years of my great-grandchild's life, their children, you know, growing up. It can't be helped" (Eileen, 87, St Helens).

> "And here we are, we have no rights whatsoever, no rights whatsoever, we just have to put up with things, and do you wonder that we get depressed? You wonder that people want to commit suicide? Do you wonder at that? What have we got? Got nothing after working, I've worked all my life. It just gets you down now and again, gets me down because I've always tried to do what I could to help people and now when I could do with help no one seems to want to know me. Get fed up with it I do, like you having a little talk, you'll be surprised what that does for you, passed the day away, passes the time away, have a laugh you know" (Emily, 95, Halton).

Eileen and Emily complaints shed light on the predicament that the majority of older people living alone, and especially those with impaired mobility, find themselves in. Loneliness and social isolation makes every day look and feel the same for them, and they feel caged up in their homes. The degree of resignation Emma and Mabel express is worrying, and there is an urgent need for a more proactive way to support older people socially.

In the past, social isolation among older people has been tackled by drawing on charitable models and services have concentrated on providing basic essentials and health care aids for older people of low socio-economic status. However more recent support-group models have been found to attract older people who are already socially isolated. Programmes like the *National Benevolent Fund for the Aged* (NBFA) help people who are over 65 years and on low incomes to overcome isolation and loneliness. Free holidays are a major part of assistance NBFA provides. Another organisation, *Homeshare*, has been established in some local communities in the UK to help older people stay in their homes longer. It helps to address social isolation by bringing together older people, who need some help around the home, and younger people who need accommodation. The latter do 10 hours of agreed work in exchange for free accommodation (Squires, 2001).

Retirement village living is another option that may prove beneficial here. Buys (2001), in an evaluation of retirement village living in Queensland, Australia, found that living in close proximity with other older people in congregate accommodation influences informal contact with others and is beneficial for those who seek alternative accommodation due to isolation or loneliness. However, there is some debate about whether this type of accommodation does in fact reduce loneliness.

There is a widely-held belief that home visiting improves the well-being of housebound older people who live alone (Cattan et al. 2003). However, two systematic reviews that examined the effectiveness of preventive home-based support for older people living in their own homes reached conflicting conclusions. While van Haastregt et al. (2000) concluded that no evidence could be found to suggest that preventive home visits were effective; Elkan et al. (2001) maintained that home visiting could reduce mortality and admission to institutional care. Although these reviews considered the provision of support by health professionals, neither the alleviation of loneliness or social isolation were included as outcome measures. What is clear, however, is that poor mental health, particularly depression, is known to be a major predictor of loneliness in old age (Bowling et al. 1989; Mullins and McNicholas 1986). Depression causes loss of enjoyment in and poor quality of life and can precipitate a cycle of social withdrawal and negative thinking, which in turn increases depression. Depression is often missed at the primary care level or misidentified as loneliness, ageing or dementia (NSW Health 1999). Some migrants and refugees are thought to be especially vulnerable given the barriers to social interaction, particularly linguistic ones that they must deal with (Abbott et al 2001; Altinkaya and Omundsen 1999). The most effective programmes in these areas target specific groups and emphasise group activities, allow participants some level of control and use more than one visiting method (Cattan and White 1988). Home calling and befriending programmes, often provided by volunteers may also help to reduce depression.

Caserta and Lund (1996) suggested that the effectiveness of self-help groups in reducing grief, depression and loneliness may be enhanced by social contacts with group members outside the group, and intra-personal resources, such as self-esteem, self-efficacy and life satisfaction. Rosen and Rosen (1982) found that focus-group discussions in a senior citizens' centre in rural Georgia (USA) were effective in reducing loneliness and increasing social activity. A recent study of coping with bereavement suggested that lowered self-esteem increases loneliness over time, and that the loss of self-esteem may influence feelings of competence and personal control (van Baarsen 2002). Also McAuley et al. (2000) found that participants with greater levels of social support at the onset of the intervention were more likely to maintain reduced loneliness. Van Baarsen therefore concluded that other relevant intra- and inter-personal factors need to be taken into account when thinking of alleviating loneliness and social isolation among older people. Older people emphasise the need for reciprocity in social support, which suggests that this is more likely to occur when the volunteer visitor and the 'service recipient' belong to the same generation, have common interests, and share a common culture and social background (Cattan et al. 2003). All studies included in this review were quantitative outcome studies. Rychetnick et al. (2002) suggested that, for the transferability of evidence to be meaningful, then qualitative, observational and multi-level evaluations need to be drawn upon in addition to quantitative evidence.

6.5 Conclusion

This chapter examined issues relating to nutrition, co morbidity and social isolation among older people. It identified older people as diverse group with variations in their physical and physiological functions. The study revealed that some older people are not receiving adequate nutrition in the community which has inturn aggravate their co morbidities. The routine health screening of older people such as nutritional counselling and educational services, health promotion programmes, physical fitness programmes, home injury control services, depression and mental health screening and education, medication management, and counselling for social services and follow-up health services will help early identification and management of their co morbidity, hence minimise readmissions.

The identification of malnutrition in older people would be greatly enhanced by the development of a valid indicator, specific to older men and women. A valid marker of poor nutritional status on admission in older people would also improve research on the relationships between lifestyle, environment, functional capacity and nutritional status. Having a defined and clear measure of nutritional balance would improve interventions for preventing debilitation due to poor nutrition. The complex association between loneliness, social isolation and living alone as a cause of readmission have also been discussed.

Chapter Seven: Findings and Discussions

The nightmare of home care without social ties.

> "I do not want to end up in isolation, even in the midst of things; I never want to become accustomed to a dry, little life. And I realise that to live otherwise is up to me, Cunningham-Burley and Backett-Milburn. 1995; 55-57"

7.1. Introduction

Durkheim's (1951) theory of anomie focuses on the quantity and diversity of social ties and the extent to which the individual is socially integrated. He suggested that social relationships give people a reason for living that transcends their individual lives. Research on health and social care needs bears Durkheim's thesis out, revealing that lack of social support is associated with readmissions, increased mortality risk, poor morale, delayed recovery and poor mental health (Berkman and Syme 1979; Cohen et al 1987; Maes et al 1987; Seeman et al 1987). Social networks are the web of social relationships that surrounds an individual, and which encompass those with whom one maintains contact and has some form of social bond. The most important individual characteristics in accessing strong social networks are gender, education and household type. Through social contacts, individuals maintain their social identity; receive emotional support, material aid and services, as well as information (Walker et al 1977). Social support is also seen as an interactive process in which emotional, instrumental, or financial aid is obtained from one's social network. Government, corporate and family institutions have assisted in the creation of roles that have contributed to differentials in the development of social skills and to the support that determines the strength of social networks. However, extending life course theory by linking it to Durkheim's concepts, it appears the strength of social networks is a function of an individual's ability to socially integrate over time.

Older people have different needs and the number of interpersonal contacts they have may vary greatly, depending on the strength of ties each of them had before old age with children, siblings, friends, neighbours, and people in other groups. In this study, older people talked a great deal about the important role their family and other close contacts played in making life and care at home a possibility. Even those who lived alone talked about needing good support. The conclusion offered here is that older people without good social ties should be considered for care in other settings.

7.2 Support from immediate family

Most of the study participants talked about how their care at home depended on informal assistance from sons and daughters. For instance, when Martin was asked, as a carer, what he thought would have happened if he had not been able to live with his mother, despite the fact that she had a care package in place, he replied;

> "Oh God, she'd have been trapped there all night and nobody would have been with her, and, oh no she didn't have any fall alarm. Lucky I was with her, living with her, you know. She'd been in agony all night. She'd have probably passed away"
> (Martin, 62 years, main carer to Margaret, deceased, Widnes).

Martin's mother had a care package in place arranged by social services, but, at the time his mother had a fall, no carer was around to witness it. Luckily, Martin was there to call the ambulance. He believed she would have been discovered dead if he had not been on hand.

What others had to say about social ties was equally revealing;

> "I was quite happy and my son comes in, he's a chef, so he comes in, and sometimes he comes he's going to make some curry or mince meat, so I say, make some extra because I can freeze it, I've got a freezer. Who was it? A friend of mine said you can get fresh food, it comes round every week" (Leonard 89, St Helens).

> "I've never been out shopping or anything. I don't ever do shopping because my son and his wife always do my shopping for me because everything. So I'm really lucky, not lucky health-wise, but lucky in that way. Because I live with my son, it is easier. Yes, oh he does a lot for me, yes ... He does all the two bedrooms and the bathroom and the kitchen and stairs, hoovers them, I just hoover the living room and do the dusting. I was living alone before my son came to live with me.

> Yes, I was living alone for years, and I managed, but I was stronger then" (Moss, 91 years, St Helens).

> "Well my daughter comes every week. Yes, it's either on a Saturday or a Sunday, you know ... As for my son, they don't come as often as I'd like them to come, but they live a long way away. Oh, he rings every day but yes, he's a hell of a long way away you know, about 300 odd miles away. It's not like nipping out round the corner is it. And my daughter's three quarters of an hour away, but she comes, she'll come at a drop of a hat you know. Like I said, if I said I needed her, she'll be here" (Moss, 88 years, Halton).

> "If it's anything, climbing, my son does that for me. He changes the curtains, he changes my bed, my son does that. My daughter in law cooks me a meal every now and again. I've a microwave, I have to use that ... My son is working, he's got enough to do. Anyway they've got their own life to live. I've had my life, my life's nearly over now." (Emma 92 years, Widnes)

Josie, Moss, David and Emma all stress the direct role their children play in making their lives at home possible, by performing tasks like shopping, cooking and house-keeping. In later old age, rates of disability and needs for assistance are high. Research shows that in the UK over a third of older people living at home, who had been formally classified as having only a limited ability to carry out basic 'activities of daily living' (ADLs), were wholly or partly dependent on formal services for help, even though levels of family provided assistance were high (MRC CFAS 2001). This suggests that increases in the number of older people with ADL limitations, will lead to increases in demands for formal and informal long-term care (Comas-Herrera et al 2003; Jacobzone et al 2000). Seeman and Berkman (1987) discovered that face-to-face contacts with friends, family and acquaintances were associated with the greater availability of both instrumental and emotional support. Older people who maintain higher rates of social interaction are more likely to obtain help when needed from informal sources like family and friends (O'Brien and Wanger 1980). Living alone does not in itself indicate an absence of family contact or support. Although intergenerational co-residence has fallen, evidence points to high levels of contact and mutual support between older people and their families, even if living separately (Attias-Donfut et al 2005; Grundy 2005; Sundstrom 1994). Research also shows that older people and their relatives are involved in frequent exchanges of help, often reciprocal, with tasks and activities such as shopping, paperwork, household chores and, in the case of help provided by older people, care of grandchildren (Attias-Donfut et al 2005; Grundy 2005).

Many 'child' carers of elderly people are themselves elderly and this is likely to become increasingly usual if mortality rates continue to fall. Analysis of the 1989 British Retirement Survey showed that 7% of all women aged 55-69 were providing care to a parent. Calculations based on those actually 'at risk' of caring for a parent – those with a living parent – showed that 9% of married and 18% of unmarried women were providing co-resident care for a parent, with a further 33% and 31% respectively providing extra- resident care. Given that some women have parents who do not need care; these figures suggest a large proportion of those called upon to provide parent care were doing so. In more recent analyses for a range of European countries, Ogg and Renault (2006) found that between 6% and 13% of people aged 50-59 in the SHARE surveys, who had an elderly parent, were providing help with aspects of personal care such as bathing. Some studies also point to effects of relationships with children and other relatives on health and well-being for Britain; those who need help and live alone are more likely to receive this help from formal services than are those with a co-resident. Living with a spouse or other co-resident (usually an adult child), especially a spouse in good health, is also associated with a greater chance of dying at home – a preferred option among older people (Grundy et al 2004). It is important too, to note that there may be disadvantages to relying on families to provide personal care. Firstly, it may have negative consequences for the health and well-being of family caregivers, particularly women with other conflicting aspirations and commitments (Evandrou 1996). Secondly, it may have negative psychological consequences for those older people who attach a high value to autonomy and do not want to feel like a burden to their family (Antonucci et al 2003; Barefoot et al 2005, Lee 1985).

Apart from children, research also shows that sibling relationships are often an important element of companionship as one grows older. There is generally more closeness among older siblings than younger siblings. The shared common values and perceptions provide an element of closeness and support. Studies have found that older people with living siblings, especially sisters, have higher morale, a greater sense of emotional security, fewer depressive symptoms, and greater feelings of control over their lives (Weiss 1974).

7.3 Support from significant others

Those I spoke to talked about the support they received from extended relations like nephew, nieces and cousins;

> "My nephew comes in the morning, and he takes me shopping in the car, I can't walk very far. But he'll take me to Asda or wherever I want to go. I also have loads of visitors, loads of visitors, friends. I've got a niece I brought up from a child and she lives in Nantwich but she's come, she's been this week, she's hoovered all the bedroom, dusted you know whatever. That's what she does when she comes"
> (Janine, 75years, Liverpool).

> "Oh I don't know how I'd cope without my nephew because there's nobody else really ... And he'll peel potatoes if I need them before he goes. He'll do all sorts of things that I can't do."
> (Mina, 77 years, Halton)

Both Janine and Nina receive support from their nephews that they could not do without, demonstrating how important the roles played by close family relatives like nephew are to older people. Contact with family may have declined in modern western society but those who have maintained those ties rely upon them in older age.

7.4 Care package provisions

Formal carers are only allocated short slots of time in which to take care of the physical needs of the older people they have been assigned to, and may not be around enough to deal with many of the problems their clients face. This contrasts with the role of informal carers. There was a worry that too much responsibility was being shifted onto informal carers;

> "The care package did not work for my mum, because it means we are expected to be there, and we can't you know. We've all got lives, got our own to live. I've even had my mum living with me, ten years

> ago, when she was going in for a hip operation. And I thought her health was going to deteriorate and I was going to start looking for something
> (Tina, 55 years old, main carer to Audrey, 93, Halton).

> ”They say I mustn't get up when I'm at home, I mustn't get up unless there's someone in the flat with me, but they can't have someone there all day, nobody came spare that time. And my sons come as much as they can, and their wives, and my sister”
> (Diane, 82 years, St Helens).

> Yes, I do get proper care. While they are there, they are very good. They are very good. But, the couple of hours in-between, that's a bit stressful because I have got to watch what he is doing, and he starts bumping his head and he hates the doors being locked ... If they ring the bell, I say come in. He found out how to open the door, because he is not soft like. He has always had a very good job, so he is quite brainy but you wouldn't think so now” (Mabel, 85 years, main carer to Jim, deceased, Widnes).

Tina, Diane and Mabel are all scared of the fact that formal carers are not there all the time. In their absence, informal care provision has to take up the slack.

In a detailed examination of the underlying reasons for rising numbers of emergency admissions among elderly people in Scotland, Kendrick and Conway (2006) concluded that rising numbers of older people and social change leading to constraints on the availability of informal care played only a minor role in accounting for the increase, a major source of pressure on the Scottish health service. The main contributory factor they identified was an inappropriate emphasis on crisis management rather than co-ordinated preventive care.

Looking at the spectrum of needs across older people as a whole there remain many challenges to providing support at consistent levels. It is clear that social care alone cannot always provide the support older people need. For people who have a mix of health and social care needs, as is the case with the older people I interviewed, the effective coordination of social care with help from family, health and other paramedical services is of critical importance. Given the important role of family members as confidantes, helpers and members of social networks, family support and engagement should also contribute positively to the health and well-being of older people and must be strengthened if home care is to continue. Penning and Keating (2000), in a review of the relevant literature, have suggested that formal and informal caregivers ought to work in partnership, and without formal care displacing family help. An evaluation of the introduction of free personal care in Scotland (not introduced in England) concluded that this had led to families changing the type of support they provide, rather than withdrawing help (Bell and Bowes 2006).

It does seem that in societies which provide more generous home care, such as Denmark or Norway, older people prefer formal to informal support for personal care needs and this preference seems to have strengthened (Daatland 1990; 1996). However, Daatland and Lowenstein (2005) in their analysis of variations in intergenerational help in a number of European countries, and in Israel, concluded that easier access to welfare services has not necessarily eradicated family care but may have contributed to changing how families relate and enabled older people to maintain more independent relationships with their families (Daatland and Lowenstein 2005).

7.5 Suggestion on where to care for older people.

I sought the views of those I interviewed on where they felt older people should be taken care of. The quote below is representative of the type of suggestion made;

> "Well it depends whether they've got family or not doesn't it? They've got no family, the best place is either in, mind you that place is good, in Peel House Lane you know. They're back to you to see if you're ok, you know. And there you can visit any time of the day. You'd put them in a home or put them in hospital"
>
> (Tina, 55 years, main carer to Audrey 93 years, Halton).

Those I spoke to were of the view that older people with strong social ties could be taken care of in their homes, acknowledging that others offer much needed help. On the other hand, and despite the fact that the home is seen as the preferred place to be taken care of by older people, the most appropriate place for those without family was thought to be institutionalised care or other forms of accommodation in the community to prevent social isolation and deprivation.

7.6 Summary

Older people and their carers represented in the present study recognised that care at home is possible only with some extra support from family members/friends and not formal care services alone. This suggests that those without families should be considered for additional support which may range from additional care package to visits of health care professionals, depending on his/her condition. The comprehensive assessment of each older person's circumstances should determine whether care is possible at home or not, otherwise, readmissions to hospital will persist as a problem in the North-west of England.

The following remark by George provides an appropriate conclusion to my discussion;

> "I know this is not going to help me. It's never going to help me I know this. But if it helps someone else, and stops them from having to go through what we have gone through, it's worth it, that's what I said"
> (George, 38years, main carer to Martha, 81 years, castlefield, Halton).

George believes that while he may not directly benefit, by participating in this research, by talking about the many and varied problems older people have, research such as this has the potential to influence decision makers and lead to changes in the way health and social care services are delivered to older people. My hope is that this study contributes to that end.

More quotes supporting all the findings are in the next page.

TABLE 5; THEMES, SUBTHEMES AND QUOTES

THEMES	SUBTHEMES	QUOTES FROM INTERVIEW SCRIPTS
4. Information, Engagement, Choice and Adequacy of Care.	4.1.2. Dilemmas in getting help with care.	Yes, so I prefer a walk-in shower, I know it's impossible but that's the thing I would really love.(Mina, 77, Halton) 'I've never had a home help but I've heard of people that have and they've had extortion bill at the end of it, I can't afford it.'(Daniel, 93, St Helens). "I've asked Age Concern... they won't clean the windows. I've asked the Council … [and] Housing Trust to get someone to change the bed for me, because I can't lift the mattress up, you know … Couldn't get any one. I fought for 2 years to get someone to cut the grass at the back, and the grass was that high, it was that high. I fought for 2 years to get the grass cut and it was that high and they told me I would have to see to it myself, and I said I would have to write a letter to someone." (Emma, 92years, Widnes). "I had no contact with anybody and it, it was as though I was dropped in the middle of nowhere. And when the doctor came out he said you're not well, you look absolutely exhausted. I said I feel absolutely exhausted. I just felt as though I couldn't carry on doing anything else and also there's been no housework done since I'd done it in November. And I know it's only dust and stuff like that, but I'm looking at knowing that it's not clean and needs to be cleaned. I couldn't, I tried ringing numbers that I found for people to come and clean but they didn't come for some reason. And they just won't come out so I couldn't get anyone out to do my cleaning for me." (Josie, 88years, St Helens). "They've come on to give her this phone call, and somebody's given her this phone number. Oh no try this one, no that's wrong love, you want to try this one. And she's just hit a brick wall, nobody knows what it's for and yet he's paying £35 a week out of his lousy money. That's what I mean, it's our

		name, A and B must have a hex on it …I don't know. This is why I am ready for a break down" (Davina, 44years, main carer to Jane 90years, Halton) "I found it difficult to get in touch with the right people"(Matilda, 82years, main carer to John 89years, Widnes) Ya, Ya. But you know, that sort of thing (home telecare) is pie in the sky, it's not for someone like me, something I can't reach." (she laughs)(Josie, 88 years, St Helens) "I do push to a degree but sometimes I think maybe I haven't pushed to the extent I should and that's the way you get anything done because if you just sit back you will not get the help that you really need." (Mrs Derrick, 43years, main carer to Agnes, 86years, Liverpool) "She didn't even know she could be helped with walking, she had a bad fall and it's only because I told him to ring the doctors … got help with wheelchairs and things, she didn't even know she could do that, but there is no information given out at all." (George, 38, main carer to Martha, 81,Halton) "There must be someone in the hospital that can advise you, mustn't there, or the Rapid Access and Referral Service (RARS) team could give us a booklet thing, with some ideas of what you could claim and stuff. No. It's stupid but they have got these patient liaison officers, what do they do? You would have thought that they would have a booklet or something that they could give out. Even just to say here you are, a couple of pages stapled together with some information (Tina, 55years, Main carer to mother Audrey, 93years, Halton)
	4.1.3. Involvement in care.	"During my second admission, I mean I'd spoken to the lady who assured me that people from the hospital like her should have spoken to me before I came out. But they didn't and she said she was going to take all the details this time and hopefully you know come home with me and check everything is alright and that it won't happen again. I don't think I could take it if it happened a third time, but it's so worrying trying to work out the medicine

		side of it as well. Because after a bit you don't know if you're doing right or wrong because you've got nobody to ask properly if it's right that I'm still doing this. I am still confused with my medicines, because when I was in the hospital it was getting it done for me and they just tell me when you go home, you just carry on with it." (Josie 88years, St Helens) 'we can provide her as a family ,myself and my brother we can provide some form of care---- but not really the care that she needs,---- that's my concern really (Betty, 59, Daughter to Joan, 89, Liverpool)' They said they couldn't contact me,------ that wasn't true because they had both my house and work number and I was contactable at anytime. They just didn't contact me.---- We can provide for her as a family ,myself and my brother we can provide some form of care ---- but not really the care that she needs ---- that's my concern really." (Mrs Derrick, 43 years, main carer to Agnes, 86years, Liverpool) "No, my daughter does what she can. She has her own family so I don't like her to do so much. She is also working on the computer in her office so I don't like her to do so much". (Agnes 86, Liverpool)
	4.1.4.Preferred priorities 0f care	"My son took me out, to have a break from this place and he said "Mum, do you want to go home to see the house?", and I said no (both laughed). I couldn't face the pain of going and having to come out again. I said no, please don't take me home." (Janine, 75years, Liverpool). "You get old, you've lived all your life, you've seen wars out, you've brought your family up, you don't want to be going to hospital, you want to stay in your own home and try to live a life as best you can, well that's how I feel. I wouldn't go out of here, I want to stay here ---- Oh I wouldn't go in hospital again to receive care. The few occasions I've ever been in hospital, I'm not condemning them, they were good to me, but it wasn't like being at home. When I came home I got

		better quicker than all the while I was in hospital" (Emma, 92 years, Widnes) "Erm well, home means everything to me because I'm independent, I'm as independent as I can be" (David 83,Halton) "Oh no, no thank you. No, I don't wanna go in one of those homes. Oh no, I've a friend that went in one and it's supposed to be a good, expensive one. Well, I had two friends actually. But no, they go, you go funny when you go in them places. You start to, you know, your mind goes and it's too …no, I don't want to". (Mina, 75, Widnes) "Happiness to me, happiness. I shut my door and then I don't go out, and people come to see to me and then they ask me say, are you alright? And I went "Yes ". My home is small you know. I can do what I like and please myself." (Josie, 88year, St Helens). "You know, they like their own things around them. They have been so independent and they do not want to lose that independence". (Mrs Derrick, 43, Main carer to Agnes 86, Liverpool) "Home is my own. From my home, I am able to sensitize, which I have not been able to do all these since admission." (Daniel, 83 Halton) "I found everything too much to cope with on my own. My wife died you see. I wouldn't have moved from the house if she'd lived. I would have had to stay there you know, because she loved it too much you know,…. Because…. But…. erm my only reason was that erm, I couldn't cope with things and I always said when it started to look neglected that's the time for me to pull out" (David, 83years, Halton) "We moved on account of the area, we had a couple of break-ins in Liverpool you see. So erm ... it was that that decided the move out of Liverpool ... been here since. .. been here 7 years now." (Saun, 90 years, Widnes)

		'I love my own bed. This is nice, it's that loving, the food is good, there's nothing much I can say, other than it's not my own.'(Jane, 90, Halton) 'I've had a front garden as well but I don't go out there I only go the back garden because I like it and it's got fences as well (both laughed).(Audrey, 93, Halton)) ' 'Happiness to me, happiness. I shot my door and then I don't go out, and people come to see to me and then they ask me say, are you alright? And I went "Yes ".' 'My home is small you know. I can do what I like and please myself' (John 89, Widnes). I've got a sister in law in one of the homes and I had been to see her, not recently of course, and I thought...I thought I'd never go in one of those. Sorry but i know they do their best for them but erm...I couldn't. I'd rather die than go in one of those. Oh this is my home...I love it! I've been here 22 years now (Eileen, 87. St Helens). 'Home is mine own. From my home, I am able to sensitize, go for footballs, do part-time job, visit friends but I have not been able to do all these since on admission (Daniel 83, Halton)) . I believe home is only where personal care can take place and not hospital (Emily 95, Halton). you get old, you've lived all your life, you've seen wars out, you've brought your family up, you don't want to be going to hospital, you want to stay in your own home and try to live a life as best you can, well that's how I feel, I wouldn't go out of here, I want to stay here, (Suan 90, Widnes). R.Would you at any time want to go into a nursing home? A No, no probably pop my gut before I go in a nursing home R; What is your home to you?

		A Erm well it means everything to me because I'm independent, I'm as independent as I can be (Daniel 93, St Helens)). I moved down here when my wife died Because I didn't need a 4 bed roomed house for myself, so I've got 2, …above here One here and one here I use that one as the garage. That one has all my instruments for my mobility, I call it garage. I'm ashamed of this right now (David 83, Halton).) , I'm 92, all I want is to be able to keep my place tidy and clean and I go down the town and might meet my friends and have a talk and sit down and go and have a cup of tea and a talk, that's all I want out of life now, (Jane 90, Halton) so I would have loved some decoration of my house because my wheelchair is knocking off some of the paints, it's easy I can go around the house (Josie 88, Liverpool).
	4.2.1.Stressed families	She got stuck behind the radiator; on that wall there love, yes. Her head was behind that and all it was was grazed. That's all that did to it, and the post on the stairs. Her leg was stuck behind that …..So you can imagine...she was shouting you know, ambulance. I had a heck of a job lifting her out you know, because it was the only way I could get her, by lifting her (Martin 62, Main carer to Margaret, diseased, Widnes) She fell half way down so erm...2 falls she had on the stairs, but she didn't come all the way down I managed to stop, so after that I slept on the landing by her bedroom door, till she went in hospital in case she did it again.(Tina,55 main carer to Audrey, 95, Halton). erm...I used to go up to see if she was Ok you know, 3 or 4 times a day. And then I always used to go in before I went to bed to see if she gone asleep you know. (Betty 59, Main carer of Joan,89,Liverpool) And erm, he realised how very, very tired I was because I up in the night with him as well, it was hard...jolly hard work really, erm but I was determined he wasn't going to go into a home (Nadine,74, main carer to Victor, diseased,

		Halton) but erm 4 times I had to call the ambulance because of his breathing and he'd shout me and I'd come rushing down different times of the night, can't breath get an ambulance (Mabel 85, Widnes, England) I know that the struggle to take care of my husband has worn me down like this. Oh he wouldn't knock me. The only thing was when he was shouting me in the night .Sorry about this [Vera 75, wife to Allan, diseased, Halton) I would come at night, and like get her out of the chair with my brother, put her in the wheelchair, we would take her down, Yes, take her to the toilet, then we would put her to be, because I mean he had been up all day doing his work and then looking after my mom, and I have my family.(Betty 59,main carer to Joan, 89, Liverpool) And I was still going to work you see, my mum was expecting me to give up my work and sit in a chair talking to her, well I'm a widow I couldn't do that you know, I've had to take care of my finances (Mrs Derrick, 43, main carer to Agnes, 86, Liverpool) . I would be unhappy if she was in her own flat because I would be worried sick, also she puts her coat on to go out and out in the road so that's a risk now. (Davina, 44, Main carer to Jane, Halton) Well it's took them long enough to come and visit me hasn't he. I spend hours here on my own, because my son is working, he goes over that bridge at 6.30am every morning…he works in Frodham and then eh comes back at night time, he calls here every night to see or do any little things that want doing then goes home because he lives at Warrington. So he goes over the bridge in the morning because he works at Frodham then he goes back over the bridge at night and he calls here then he goes home to Warrington, so I can't expect him to do too much you know (Emma, 92, Widnes)

		Note; More QUOTES on result section
	4.2.2. Respite care and readmissions	"In the end it got so bad, because I was sore, my back was really sore at this stage., My mum was still really ill, and I was asking them for help and what I asked them to do was to put her into … Like because, I look after her, it's 24/7, and I manage, but because I have got myself bad as well, I couldn't look after myself, work and look after my mum, so I asked them for help, just to put her in for respite care, a nice one by the beach I said to her, just for a week, just for a week or two weeks at the most, just to help me get better … Because I am the carer, if I am ill, you could have both of us in hospital. So to let me get better, so I could, then, look after my mum. And they said, no, a blank no. No help at all, so what I had to do then, I had to lose one of my jobs … Me, I cried. I went bald, I got old. It wrecked me. My mum is not a small woman, and we asked for help at that time and we didn't get help … And by then I had no patience, I was in pain, I was extremely tired, and stressed and I thought, right, I can't cope, I can't cope, I need help." (George, 38years, main carer to Martha, 81 years, Halton) "No, no, no, no, I have not had a holiday in like 10 long years. No, there was no time to rest, no good break. I can't take the time off work because I only get statutory sick pay, which is you get nothing for the first 3 days, and then for the following 2 days you get half pay, so really what that means is you get 1 days pay for a week. Sorry, I can't survive on that, bills have got to be paid." (Shedrack, 56 year, main carer to mother in-law, Emily, 95years, Widnes)
	4.2.3. Support for family carers	"I thought, someone would have come to say, here you are, this is how you lift her out of bed, this is how you get her into the wheelchair, this is how you lift her from the wheelchair to the toilet, without hurting her. Because I mean, when there was only me on my own or my brother, she did say oh you are hurting, you are hurting, but we don't know if we were doing any more

		damage than what had happened. Because we hadn't been shown, so what we were doing was what we thought was best, but no one showed us anything, nothing at all." (Shedrack, 56years, main carer to mother in-law, Emily, 95 years) "We didn't get any help that was a long time ago; we got no help at all. And we just had to cope, just had to get on with it. And as she got better, slowly, what I did, I thought, ok then, she is getting better now and I am feeling more confident so what I'll do is when she is in bed in the morning, I'll go to work, get myself a cleaning job because I was going stir crazy in here. I had cleaned the house from one end to the other, I had cleaned all the cupboards, I had painted the bin cupboard, I had taken the airing cupboard apart and painted all that, there was nothing else for me to do really I was going stir crazy." (George, 38 years, main carer of Martha 81 years, Halton).
	4.2.4. Service from formal carers;	well I had to get that and clear that away, and if I was in one of these dizzy moods and that they would say oh leave all your dishes for the next one in will wash them, but I don't think that's right, especially it was dinner you had a greasy dinner and leaving your leaving a greasy dinner plate, knife and fork in front of you, well who wants to see that. I didn't so I told them, so she said tell them to fill a bowl of water and stick them in the water, well that's not caring...that's not caring for the elderly is it and I was more capable than lots of old people for doing a bit for myself and I used to think that was terrible that.(Diane, 92, St Helens) In the afternoon I do my dinner and alls they've done was put it down in front of me, give me a drink of tea and say you, Ok now and off they went. (Mina, 77, Halton) I was supposed to be first on the list at 8.30am for insulin, you see for my career at 8.30am, I said you know what, she said I looked at my sheet and she said your name is last on my list, well last on the list is near dinner time hour. I can do all that if I'm sitting here quietly, (Josie, 88, St Helens) A carer came and she said, oh I have to come and help you to get him

		in the hoist. We had to show her how to get him in the hoist, she hadn't got a clue" (Mabel, 85 year, Widnes, former carer to husband Jim, deceased) "I left the carer to do her medication … that kind of person … who erm ... her appearance wasn't very nice, hygienic. She had long finger nails and burst about 5 bubble packs at the same time ..." (Tina, 55years, main carer to Audrey, 93, Halton) "My mum still wants to go home and be taken care at home … but [that can only happen] if the carers can be properly educated on what to do." (Mrs Derick, 43years, main carer to Agnes, 86 years, Liverpool) "They sent a carer and they were supposed to come in every morning early to wash me and to do my hair. And I was getting out of bed and sitting here, and the time was going on and going on and then, they would roll up, just before dinner. And I've struggled, struggled to wash myself and do my hair and everything and then when they come, all they did was sit there and fill forms in. So one day I was that mad, I said to my son, I'm not having them no more, so he said, well mum you're not able. I said I'll find a way, I've promised the consultant in hospital that I'm not coming back here." (Emma, 92 years, Widnes) "They're not as punctual as they might be. They're supposed to come between 9am and 9.30am, and sometimes it's nearly 11.30am when they come … I just have to put up with it." (Mabel, 85 years, Widnes) "The one that came in the evening, by the time she came round, about seven o'clock, I'd had my evening meal. It's too late to wait, you know, for her. And she just told me to get undressed ready for bed, because I had this shoulder, y'know, I couldn't lift my arm up." (Agnes, 86 years, Liverpool).

		”*My mum had been deteriorating for some time but, you know, they just come and ask, how are you? And after all that, they just go. I don’t* like making a complaint, [but] the carer complained my mum had MRSA and she had a small son at home so she wouldn’t want to put her small son at risk by touching here. She had a son at home who obviously was not very well and someone like that shouldn’t really have been given to my mum. So she would just come, we’d sign her paper for her, and she’d go. So once my mum had her hip done, we stopped the care package.” (Mrs Derrick, 43 years, main carer to Agnes, 86years, Liverpool). “How long did I get? That was 25 minutes, breakfast and lunch time, but you only got half hour or three quarters of an hour for tea. But they didn’t do three quarters with me. They were away early because it was very dark outside. There are lots of little things left over. You wanted to be nasty but you couldn’t be. I don’t think it’s worth it really, I don’t, I wouldn’t argue. I was supposed to be first on the list at 8.30am for insulin, you see, for my carer at 8.30am. You know what, she said, I looked at my sheet, and your name is last on my list. Well last on the list is near dinner time. And I said what about the dishes, oh no they’re left till the next one comes in. I said, I’m not going to sit with dirty dishes in front of me all night, but that was what they started to do, and didn’t do it. They never sweep, never put a carpet sweeper over anything, so I had to have someone in to do the cleaning, someone into to wash. All that used to be done by them and you are paying now and you weren’t paying before, and you were getting everything done. Now you’re paying and not getting anything done … Well I had to get that and clear that away, and if I was in one of these dizzy moods and that, they would say, oh leave all your dishes, the next one in will wash them. But I don’t think that’s right, especially if you had a greasy dinner. Leaving a greasy dinner plate, knife and fork in front of you, well who wants to see that? I didn’t, so I told them. So she said tell them to fill a bowl of water and stick them in the water. Well that’s not caring, that’s not caring for the elderly is it? And I was more capable than lots of old people for doing a bit for myself and I

		used to think that was terrible that." (Abigail, 88year, St Helens) "Even if I do want my mum to come home, my problem is with the care package. The careers are only given about 10 minutes which is not enough time to take care of an old person. I know they want to stay in their homes rather than going to care homes because they make better progress in their home and like their own things but what is the alternative?" (Betty, 59, main carer to Joan) "I took the brunt of it quite honestly … I received a little support but the main care did not really help" (Vera75 , wife and carer to Allan, diseased, Widnes)
5.Service Provisions from Health and Social Care Organisations.	5.2 Pressure on acute beds	"She was in the X hospital for 3 weeks and then she was going to go for rehab ... My mum would pick up, but then wouldn't eat again … She wasn't well enough to be transferred from the X hospital, she was only there 3 weeks, but because there was a bed vacant they rushed her to Y hospital for rehabilitation … I wasn't happy for her to be moved from the x. I think she should have stayed there a bit longer to get her diet up, her weight up, because she was still losing weight while she was in hospital. And then she had about 5 falls while she was in Y, and I thought, how is this rehabilitation if she's falling? (Matilda, 82 years, main carer to John, deceased, Widnes). Yes, hospital makes my condition worse. I don't want to go back, I don't want anyone fussing over me, I just want to live my life like I want to live it. Yes not hospital. (Leonard 89, Widnes) "Well I think readmission makes her worse, she is really traumatized because,she was not properly admitted" (Mrs Derrick, 43, Main Carer to Agnes, 86, Liverpool) Oh I think you are more relaxed at home, and I think you get better at home, better quicker at home than being in hospital

		I wasn't happy for her to have been moved from the X I think she should have stayed there a bit longer to get her diet up...her weight up.... because she was still losing weight while she was still in hospital, losing weight you know, and then she had about 5 falls while she was in Y and I thought how is this rehabilitation if she's falling. (Nadine, 84, retired, main carer to Victor, Diseased, Halton).
	5.3 Prescribed care	"They come to put my mum to bed at 7 o 'clock and no one wants to go to bed at 7. My mum likes to stay up late and watch television, but they come between 7 and 8 to put her to bed as part of a care package she doesn't like. They're not children, are they? They give them no choice, it's like being in an institution, not your own home. Why send you home, if they're going to treat you that way? I'm happy with the care my mum received in the intermediate care unit but if she could get that level of care at home it will be better" (Mrs Derrick, 43years, main carer to Agnes, 86 years, Liverpool). "The only thing I miss is being home and being able to smoke. That's my life. I couldn't live without a cigarette. I've been smoking since I was 15, and I am 88 nearly. If this were my home now, I'd get up, go out and smoke because I always have a cigarette at night but now I can't, and I haven't had any since." (Eileen, 88years, St Helens) "The doctor said she needs a wheelchair, which is an electric wheelchair which she controls, and we took that spec down to the independent living centre in Runcorn, and it's supposed to be there to help people live an independent life, and we went down, they looked at the information that was given to them and they said, well we really need another doctors report off your doctor. And it was our doctor who said this in the first place, to say why he thinks this. Because my mum has angina, and gout, and arthritis, and everything else, she can't wheel herself. If she does push herself, she could have a heart attack.

		And her fingers are bent and twisted so it's not a good idea … [But] they won't take [it]. The doctor's recommendation was that she needed to have this electric wheelchair, but they are too expensive. So the independent living centre decided the best they could give us on a good day would be an electric chair that I would control from the back. Right, that takes away her independence in the first place, she is supposed to be independent living, but not my mum, we are not going to give you that they said,… They finally decided to give us a regular manual wheelchair. Of course she can't manage because of her angina, because of her arthritis. That's supposed to be an independent living centre, but she has got no independence at all. If she wants to use that wheelchair, either me, my sister or my brother, has to take her out in it, she has not got independence." (George.38, main carer to Martha, 81 years, Castlefield, Halton) "I said I've got a shower in it. But sometimes I've got to lift my leg over and it's a bit sore so they put a rail on there. The shower at the moment is still a problem for me even after they put the rail in. I would have preferred a walk-in shower." (Josie, 86 years, St Helens) "I have to fight every inch of the way. Eventually I got one of those walking sticks from the council but I didn't like it. My son came and said, I bought you this mum, it folds up you see, it folds up and I can put it in my shopping bag. I can manage it you know." (Emma, 92 years, Widnes) "No, I bought all those myself. I did have an NHS wheelchair but it was very heavy so I put that in and I got that one, and I had to pay, oh I forget how much I had to pay for it ... paid £800 for this one, £1200 for my scooter. I won't go too far, on that scooter, I go to the shopping city and do my shopping and come back … put the bags through my knees and off I go … I have my stick, I gave them the zimmer frame back, and I have the mobility car, you know the scooter." (David, 83 years, Halton) "I used to live with my son in my home and he bought a trolley leading to the back kitchen, and got a frame that fits over the toilet ... in the

		bathroom. The last time someone came out to me they said do away with the bath, but it cost lot of money that bath, it's a corner bath" (Mabel, 85 years, Widnes, England). "I'm washed and dressed every morning … [and] they come to put me to bed at their own time which is usually too early for me" (Agnes, 86 years, Liverpool). "I'm better really having 2 carers three times a day. What I had was not enough. I wanted 24hours care. Overnight there was nobody. My son was concerned because they said it seemed to be happening overnight" (Mabel, 85 years, Widnes). "They put us back on the list, and they have been round and they looked at it … Because a walk-in shower is no good, really, in our situation, that is their option, I said what we really needed was a wet room. Even a wheelchair can go in there and I can wash her, in a shower cubicle. How am I going to wash her now? All they will pay for isn't what is required, but that's all they will go for. So we have to cope with something that isn't really what is going to help." (Shedrack 56, *main carer* to Emily years, 95, Castlefield, Halton) "Each time I fell it affected my walking, so now they say I mustn't get up when I'm at home, I mustn't get up unless there's someone in the flat with me. But they can't have someone there all day, nobody can spare the time and my sons come as much as they can, and their wives and my sister" (Jannie, 75years, Liverpool). yes because my mum had deteriorated for some time now but you know---- they just come and ask how are you? And all that and they just go. I don't like making a complaint.'(Betty, 59,Main carer to Joan, Liverpool) 'Even if I do want my mum to come home my problem is with the care package the careers are giving only about 10 minutes which is not a good

		time to take care of an old person so I know they want to stay in their homes rather than going to care homes because they make better progress in their home and like their own things',(Davina 44, Main carer to Jane, Halton) 'The carer complained my mum had MRSA and she had a small son at home so she wouldn't want to put her small son at risk by touching my mum. She had a son at home who obviously was not very well and someone like that shouldn't really have been giving to my mum,-----so she would just come and we'll sign her paper for herand she goes .---so once my mum had her hip done, we stopped the care package'(Mrs Derricks) Erm well they're not as punctual as they might be, they're supposed to come between 9am and 9.30am, sometimes it's nearly 11.30am when they come. They're supposed to be here 9am or 9.30am. I just put up with .it (Abigail 88, St Helens). Q. But your mum still wants to go home and be taken care at home? A. 'Yes but if the carers can be properly educated on what to do' (Tina, 55, Main Carer to Audery 93 Halton) She fell half way down so erm...2 falls she had on the stairs, but she didn't come all the way down I managed to stop, so after that I slept on the landing by her bedroom door, till she went in hospital in case she did it again.(Shedrack, Main carer of Emily) they used to wash him and that, and they were away within a quarter of an hour. I'd probably end up giving him, his breakfast; I think the care wasn't adequate for him..No it wasn't. Not for the money he's paid in for stoppages on your wages you know (Vera 75, main carer to Allan, deseased) this is why I am really afraid that when she lives here,(Intermediate care unit) she is going back into the same system and she may deteriorate and I don't want that to happen because you are back to square one. (Davina, 44 Main Care to Jane 90 Halton)

	5.4 High cost of care	“I missed my footing you see because I was tired and I wanted to get into bed, I had had a busy day, with the shopping and the cleaning up, you know. I got a statement from the care line, to say that I owed £400. That’s what made me ask you did I have to pay for people coming in. I had to borrow some money to pay the statement” (Abigail, 88years, St Helens). ”The social service was here and they asked her did we want two women. But they took ever so much money from me, to have them two women, to come in for 5 minutes to get him out of bed into his chair, and to come at 6’oclock and put him back in his bed. I washed him, I changed him, I done all that, but they, I don’t know whether it was £9 odd or £19 odd, but my daughter was furious with them, and it went out of my money” (Mabel, 85 years, Widnes). ”So I thought what kind of a care package is it if you’ve got to prepare meals and things, you know? And it’s free for a month and after that it’s £8.50 for half an hour, which to me is daylight robbery if they expect people to pay that. So yes, you’ve got to pay for that as well, I pay £20 per month for this … just for the life line … I got it on the insistence of my daughter because you know if I fall over, I can’t get up” (David, 83 years, Halton). “I went home again and the doctor said she still wants extra care. Well she put extra care on, she put care on overnight. It was going to cost an awful lot, about £60 to £70 overnight or so somebody said, and that’s with the other money you’ve got to pay. I thought, well I couldn’t do that, so I said no. Well then I had another fall, didn’t I, and I was put in the enabling unit” (Mina, 77years, St Helens). ”I tell you what; they should look into the care at home, because you don’t really get it. The girls are lovely, I’ve no fault with any of my careers, but they weren’t getting the time to do it. Do you know how long they gave her when I first went out? I was having the morning,

		tea time, night time. I never got anyone from morning till tea time and I said what about lunch time? And they were all lovely girls, all of them I liked, but they didn't have much time. No, they didn't have the time and while they were with you, they would phone and say go to so and so" (Josie, 88years, St Helens)
	5.5.1 Support for independence living	"The first time I put in a request for a walk-in shower was in 88. 1988 and I am still waiting. That's 20 years ago. A Long time! Oh, we can give her a stool to put in the bath. And I tried that, I couldn't get my legs over. I can't climb in the bath, I mean I am not steady on my legs normally. It was useless, the woman that tried to help me with it couldn't, I couldn't get my legs over. She said, oh you are back on the list again. I said well I shouldn't have been taken off the list, But, I'm still waiting. I will have to ring up and see" (Martha, 81 years, Halton). "We had a lady coming round from the social services to help and I explained the situation and they said right, well we could get you a kettle tipper - they had already promised that, it still hadn't arrived - a Zimmer frame, a walking stick, the wheelchair, the toilet raiser, the chair raiser, the bed raisers, none of these arrived. This was after the first week, so we were in the second week now right, still nothing arrived. We got things for ourselves, we sorted ourselves out. I put house bricks under my mum's bed to raise it up, because obviously lifting her up and down from a low bed is too much, because when you are doing it all the time, it's too much. So I raised it up so it was higher." (George, 38 years, main carer to Martha, 81 years, Halton) "I have a nice bath but my family is a bit anxious that I might over balance and there have been 1 or 2 cases that we knew where people had over balanced and died. I've moved my bedroom from upstairs down. I have a staircase but I didn't have a stair lift. I tried but I didn't get any, so I brought my bedroom down below. It's better than a bedroom up really and my family arranged that for me" (Janine, 75 years, Liverpool).

		“A walk-in shower, they said they would give me one. At one time like, that was a few years ago like, about 2, 3 years ago they promised me that” (Mabel, 85 years, Widnes). “Last time I had a fracture of the pelvis and was discharged home. I have a banister, the rail, I just pull myself up on this rail which I’ve done all the time because it costs so much for the stair lifts. Even if I am priority, it takes so long.” (Suan, 90 years, Widnes) “I hope they fix my stair lift before I go back home since at the moment I cannot lift the other leg.” (Moss, 92 years, St Helens) “She has had dislocation up to two times at home and they have discharged her with no adaptation, so, when she had the third one I told them I won’t take my mum back before they put in stair lift” (Mrs Derrick, 43 years, main carer to Agnes, 86years). “Walking over there, I fell over a couple of times and that’s why they brought me that Zimmer frame. But it was after many other falls” (Suan, 90 years old, Widnes). “She had passed that stage by the time they brought a proper Zimmer frame. When they eventually gave her one it wasn’t quite right. I don’t know what was wrong with it, it wasn’t quite to their regulations. And by the time they brought the correct Zimmer frame she didn’t need it, so they delivered the cane; brought it unpacked it, packed it back up and took it away. Because she really didn’t need it, it took that long. And that’s no good” (George, 38years old, main carer to Martha, 81 years). And then we went down to Z about the artificial legs. And they sent one in a van, and I’m not kidding you, I couldn’t pick it up with both hands, never mind him pick it up with one leg, because at the time he only had one leg. It had a strap that went round and over his shoulder. And you couldn’t do that, it was that heavy, and they had it packed with cloth to take the weight of his hip … They had to take the knee,

		that's what annoyed me, the knee, taking the knee. Anyhow, *I rang,* got in touch with my councillor, he's an MP now, and he wrote off to this doctor. And he said there must be something lighter for my husband to have, to help him to get round, because his body wouldn't have shut down if we had these things earlier" (Mabel, 85 years, Widnes). I don't know, when they are going to give me a walk-in-shower It's all under the national health, I don't have to pay. Because I believe they are very expensive aren't they? (Leonard 89 St Helens) This was about oh well over a month, about 2 months ago, 3 months ago. You only asked for rails because it was slippery, you asked for a rail on it, a hand rail, and they said, they looked at it, they came back and said they can't give us a handrail because it's not a social services issue ramp, they won't condone us using that ramp so they won't give us a rail for it. And now they have come back and said they are going to look at giving us a ramp that's all we have heard (Dianne 92 St Helens) Well we were told. it would be between 3 and 5 years before someone came out, to look to see if we needed the bathroom done, she couldn't get in the bath but we have had to put a shower in that's about this high, and put a step, she can't get in there now, because she can't get up.(Janine, 75, Liverpool) Yes, I have a nice bath but erm...my family is a bit anxious that I would over balance and there have been 1 or 2 cases that we knew where people have over balanced and died. I've moved my bedroom from upstairs down. I have a stair case but I didn't have a stair lift. I tried but I didn't get any so I brought my bed room down below...so that it's better than a bedroom up really and my family had arranged that for me. (Jane 90 Halton)) A walk in shower. But they said they would give me one. At one time like, that was a few years ago like. About yes, about 2...3 years ago they promised me that....(Mina 77, Liverpool)

		I fought for 5 years to get a walk-in shower because every time I got through to the social service, they kept saying, well when we wanted to help you, you were not ready (Suan 90, Widnes) I have to fight for everything I get, now some can get things without any trouble but I've had to fight every inch of the way for everything I've got and I don't think it's fair,(Leonard, 89 St Helens) I would love a stair lift, I really would love stair lift, and I really would love walk-in shower' (Diane 92, St Helens)) She has had dislocation up to two tiimes at home and they have discharged her with no adaptation, so, when she had the third one I told them I won't take my mum back to put her at risk at home, before they made the adaptation and put stair lift.(Goerge, Halton) 'Last time I had Fracture of the pelvis and was discharged home .I have a banister, the rail, I just pull myself up on this rail which I've done all the times because it costs so much for the stair lifts and even if I am priority, it takes so long,(Moss) And I think I could do with a higher toilet like the one downstairs, I got that myself ...will have no problem with that.(Joan, Liverpool)) 'I do push to a degree but sometimes I think maybe I haven't pushed to the extent I should and that's the way you get anything done because if you just sit back you will not get the help that you really need.'(John, Widnes) 'I hope they fix my stair lift before I go back home since presently I cannot lift the other leg. I really love to be back home but made comfortable..(Eileen, 87, St Helens)
	5.5.2. Supporting	Home tele-communication, yes, I would love something like that to

	independence with home telecare	*communicate to someone outside that I need help if it is affordable* (Jossie, 88, St Helens) Whenever anything happens to me, like a fall in the house or that, press that and they send somebody down to come and help me. It's very useful and easy to operate (Janine 75 Liverpool). I wouldn't like it if it was going to get knocked all the time would I? My younger sister had it once---- she had it round her neck which she had to take it off because it was doing the same as me, ---you know,---- getting knocked all the time so she had to take it off. (Leonard). "Home telecommunication, yes, I would love something like that, to communicate to someone outside that I need help, if it is affordable" (Josie, 88 years St Helens). "You've got to pay for that as well. I pay £20 per month for this. Yes just for the life line. Well, I got it on the insistence of my daughter. Because you know if I fall over, I can't get up (David, 83 years, Halton). Whenever anything happens to me, like a fall in the house or that, I press that and they send somebody down to come and help me. It's very useful and easy to operate (Janine, 75 years, Liverpool). "Yeah that's right, It's just a little black thing on the top, it's got a red button on it. If you need it, you just press it, it's easy to operate" (Agnes, 86 years, Liverpool). "They are good yes, they are good. If they could identify problems with the ones they have installed and amend them. The telephone, where you can just speak and they hear your voice, yes things like that. We were going to get her a pressure mat in her bed so that when she got out of bed the light would go on and after, say 15 minutes, they would ask are you alright. And if she didn't answer they would ring us and then of course she'd end up back in hospital so we were looking for all

		the things to make her safe in her own place" (Martin, 62, main carer to Margaret, deceased, St Helens). "I just go, just touch it, and that's it. The only thing is that sometimes, like this morning, 5 o'clock, it went off by accident and they were all here. They've got a key. Oh yes they came into the bedroom and they said are you alright, and I said yes. That was a mistake, I must have rolled over you know. But I wear it in bed and everywhere here, you know The only time I take it off is when I go for a shower ...I've got a walk-in shower" (David, 83 years, Halton). "I have got a thing I'm told to wear around my neck but it's getting in the way, you know, always getting knocked and that and I couldn't have it on all the time, so, I kept it on my trolley, you know, my shopping trolley. I wouldn't like it if it was going to get knocked all the time would I? My younger sister had it once, she had it round her neck. She had to take it off because it was doing the same as me, you know, getting knocked all the time so she had to take it off" (Agnes, 86 years, Liverpool). "I had a friend who had it and rang the emergency button and he was living alone. So, when the emergency team came, they could not get in. They called the police but before the police could come to break the door, they found him dead on the floor... If I was given it, what I would probably do would be to leave a copy of my key with my neighbour in case I have a problem" (Moss, 88 years, St Helens). "Really what they should have is like a pool of emergency equipment, which can be given out on that day, or the following day, to people who need it, right? They can then send someone round to assess them, as their procedure would demand, and then provide them with their own equipment and then that pool equipment can go back, to a pool for emergencies in such a case" (George, 38 year, main carer to Martha, 81 years, Halton).

		Well I keep saying eventually I'll have one of those fall alarms you know, but whilst I feel well enough, I don't need them. I've got a phone and I've got a very good friend across the road. Erm...when her husband was alive, erm I used to go and visit him because he knew my brother,(Daniel) Yes, should put it on around my neck then ……and it very useful? I think old people should have it? I just, just fell over the once since I've worn it that's all you know. It's very...very handy yes oh aye, just press that button. I think everyone should have one, when you're on your own and they're like it yes just in case you fall. (Minna) . I have a fall alarm; Life line In fact they came out to me 5 o'clock this morning. Well I was in bed And I'd just rolled over and... Erm...I just said oh I'm sorry it was a mistake I'm sorry I had to get you out of bed so early in the morning They said don't worry about it, we're on all night It's very easy to set it off you know and once you set it off you can't stop it. You can't erm...cancel the call you know (David) Life line?...very useful. If I hadn't had it I could have laid there all day, because nobody was coming to see me, only my friend upstairs and she wasn't coming till late and this was in the dinner hour, (Abigail) …one woman had it on and she must have pressed it in the night when she was asleep and she woke up to see 2 fella's standing by the bed (Joan) I wanted it up there, not that the connection the box….Which is why they're to the telephone and the internet com but because it was down there because it was under the carpet and then fixed to the remote box there, I said that's not very long it would have been better up there out of her reach, so because seeing a light on she switched it off. (Betty) R Do you think that life line is helpful? A They are good yes, they are good if they could identify problems with the ones they have installed and amend them. The telephone, where you can

		just speak and they hear your voice, yes things like that,(Davina)
	5.6 Investigation and treatment	“When my mum was in hospital they told me it was irregular heart beat but when my mum was readmitted in casualty, the doctor in casualty told me it was heart failure. The day they discharged my mum, the cardiologist came there and told me my mum had irregular heartbeat. So, even now, I don’t know if my mum has an irregular heart beat or heart failure and that’s why I really want to go back. I am still confused about the diagnosis” (Mrs Derrick, 43years, Main carer to Agnes, 86 years, Liverpool). “I don’t know how many weeks, I can’t remember, but it was weeks before she went to the hospital, Z hospital” (Martin, 62 years, main carer to Margaret, deceased). “Well they put the thing on the wrong hand. They put the plaster of paris on the wrong hand instead of the hand I had the fracture in” (Janine,75, St Helens) “They only sent me to the hospital when they knew that I had the anaemia. But it was 6 months after ... The specialist turned round ... and, well he had me going up there week after week. And in 6 months, you know I used to be going up and down to the diabetic nurse, the heart nurse, asthma nurse, and to see him, the doctor, but they didn’t pick it up. And it was the morning I had to go to see the diabetic nurse, I collapsed in the surgery, and she jumped up and called Dr X and he came in, and he said ,well you’ve got anaemia, you are very anaemic. I said, I’ve been telling you. I think it could have been prevented. But they didn’t pick up on it” (Minna 77years old, Halton). “Well you see, when I was in the hospital I was anaemic because they gave me the wrong tablets. They put me on Warfarin and I should’ve never been on it. What it was doing was diluting my blood you see. So I was ill and it caused anaemia, very bad anaemia. But they took me in hospital and they put blood into me and they got the anaemia out of me” (Mabel, 85years old, Widnes).

		“Well I don’t know much about it, but I thought it was a doctor I did speak to when he lifted my arm up. And I could feel that my arm wasn’t right and I said, do you think it’s a stroke? And he said, no, and we came home. And then on the Sunday on Sunday when my niece came, she’s been nursing in Liverpool you see, she noticed something was wrong. She’s retired but she’s been in Liverpool for years. So maybe if they had carried out more tests or checked me more properly, they would have been able to see the stroke that first time , Yes that’s right but everyone makes a bit of a mistake don’t they?” (Daniel 93years old, St Helens). “It was the reaction to the penicillin. I got these horrible things all over me at one time, sores. They were like that and they were all over my body and they were so sore and so itchy. I seemed to go 2 steps forward, 5 steps back, everything they’d tried on me. I mean one of my friends who came to see me in hospital said you’re just a giant pin cushion for them to have a go at. That’s what I felt, because the world and his wife seemed to be prodding needles in me and doing things, and I wasn’t getting any better” (Josie, 88years, St Helens). “The nurse came and she looked at it and she put this brown gooey plaster on, she peeled something off it, and she put it on and she wrapped his leg up. You wouldn’t believe how big it was when she comes the next day to take it off. It was like that. The plaster had gone against the ulcer and it had made the ulcer spread. Oh we couldn’t believe it, we kept looking. Anyhow. brown stuff whatever it was, had made it bigger. Oh I warned him when he got another one on his other leg, I said don’t bring that brown plaster here, I said, because that’s how he lost one leg, because they couldn’t save it, it was like a hole” (Mabel, 85 years, Widnes). “He wasn’t happy and he said, what have you been doing? Have you been on antibiotics? I said no, if I’m put on antibiotics I put it in my

		book to let you know. I said I've done nothing different, I said, all that I'm on at the moment I eat. And crab sticks, I said, but I make a packet do me 2 or 3 days, I said, and I know for a fact they do not interfere with my diabetes. So he said, oh no, no, he said, it's not fish. So I said the only other thing, I said, I've had ginger beer, half a glass and half water, I said because I couldn't take it anymore, they had to water it, I said but I had an awful lot of it. And I said so I started trying my medications, knocking off what I was on. I said and I stopped taking the ginger beer, I said, and I went back to my pineapple and my soda water, and it's gone" (Vera, 75 years old, Widnes). "Since the heart trouble she's on about 15 tablets and I usually put them out for her in a glass everyday. She was able to do it herself but with the way she is now I wonder if she will able to cope" (Abigail, 88years, St Helens). "She couldn't get over how much medication they were giving her for, you know, the X-ray, the operation" (Martin, 62 years, main carer to Margaret, deceased, St Helens). "I take seven in the morning. Those two, I'm due to take those two now. And then lunch time I take two. Between 8 and 10pm, I take another six" (David, 83 years, Halton). "At home I might forget sometimes now and again, but not in here because it is given to me" (Agnes, 86 years, Liverpool). "Yeah, well I decide. I know how much to take and it's on the bottle, I always have them in different bottles and initial glasses and I put them all out, say a couple of days before. Then I'll know they're all there. So I'll just go, take them, and put my eye drops in, generally, overnight" (Eileen 87years, St Helensl). "I'm alright I don't forget because I only take them when I go to bed, mostly to make me sleep" (Nina. 77 years, Widnes)

		The first time I went into hospital they didn't find it, it was a terrible time. They couldn't diagnose it so they sent me home and within a period of almost one week. It was then until my niece came back and said something was different about me. Oh yes, she identified it and had to call them before I was taken back to the hospital..Well I was quite lucky really wasn't I.(Suan,90, Widnes) "My mum has glaucoma and she's on eye drops. She's always done it herself. She seems quite confused now and I really doubt how she will be able to take care of her medication when she goes home" (Mrs Derrick, 43years, main carer to Agnes, 86 years, Liverpool). when I was in the hospital, I was anaemic because they gave me the wrong tablets, they put me on Warfarin and I should've never of been on it and what it was doing was diluting my blood you see, so I was ill and it caused anaemia, very bad anaemia, but they took me in hospital and they put blood into me and they got the anaemia out of me(Mina 77 Halton) My husband waited for 20 year for his hip replacement. Actually, but he didn't benefit from waiting because by the time they came to do his hip replacement it was in such a bad state that he was in the biggest wheelchair he could get with the sides taken off because his hips were, his legs were coming out of his hip joint sideways over the sides of the chair. That's how bad his hip joints were (Vera) They only sent me to the hospital when they knew that I had the anaemia but it was 6 months after and the specialist turned round and said to me, -----and I went up to, well he had me going up there week after week and in 6 months, you know I used to be going up and down to the diabetic nurse, the heart nurse, asthma nurse, and to see him, the Dr, but they didn't pick it up. And it was the morning I had to go to see the diabetic nurse, I collapsed in the surgery, and she jumped up and called Dr and he came in to the, and he said well you have got anaemia, you are very anaemic, I said I have been telling you. I think it could have been prevented. But they didn't pick up on it.

		(Audrey, 93, Halton) Yes, they have tried her on medication, next minute they have taken, well you have said I am not taking that, that's making me bad, that is making me ill I can't take that, No but they say now and again they say well here you are we will try you on this, we will try you on that, and from here, just to the car she was nearly collapsing and I am thinking you know, what is up with her(Dianne 92 St Helens) R That second time you went to hospital, do you think it could have been avoided? A Well I don't know much about it but I thought it was a doctor I did speak to when he lifted my arm up And I could feel the...that my arm wasn't right and I said do you think its a stroke, and he said no and we came home. And then erm...on the Sunday, on Sunday when my niece came, she's been nursing in Liverpool you see. She's was retired but she's been in Liverpool for years. So maybe if they had carried out more tests or checked me more properly, they would have been able to see the stroke that first time, Yes that's right but everyone makes a bit of a mistake don't they?(Jane 90 Halton) And then we went down to Z about the artificial legs, and they sent one in a van and I'm not kidding you I couldn't pick it up with both hands, never mind him pick it up with one leg, because at the time he only had one leg. And it was a strap that went round and just over his shoulder and you couldn't do that it was that heavy, and they had it packed with cloths to take the weight of his hip. For he had no...they had to take the knee, that's what annoyed me, the knee, taking the knee. Anyhow, I rang, got in touch with my counsellor, he's an MP now, and erm..and erm, he wrote off to this doctor and he said there must be something lighter for Mr R to have, to help him to get round, because his body wouldn't of shut down if we'd of had them (Mabel, 85, main carer of Jim, deseased)
	5.7. Care	"When my mum had pneumonia the week before they said she had a

	Communication	heart condition. So when I went to see the consultant it was for a cardiac problem and then when I went to see the GP, after she was discharged. He said he hadn't seen the note about my mum's cardiac problem. And you think, because they are in the same hospital, the communication would be faster but you have to keep pushing" (Mrs Derrick, 43 years, main carer to Agnes, 86, Liverpool). "And at 6 o'clock when I was due my Warfarin, she hadn't got any. So my daughter played hell. Anyhow they sent somebody down, and they came back with my Warfarin in a little cup, and our Sue said, I want all her medication back here. And you know when I did come home there was an awful lot I didn't get, I had to keep mithering my doctor for them. He'd tell you, every day I was on the phone, I haven't got this back from Whiston, I haven't got that back from Whiston, and I've got it all back now, thank God." (Mabel, 85 year, Widnes) "I'm disgusted with the lack of coordination information and communication between the agency, and it was a council run one, and their staff. It was like they didn't care because they were getting paid no matter what happened … Someone contacted me to sort out my mum's financial agreements, and I said, what? Didn't they bloody tell you that my mum was in a hospital? So again they didn't inform the council so they thought that my mum was getting this care package and this was 6 weeks after. (Davina, 44 years, main carer to Jone , 90 years, Halton). "I feel that the present division between the agencies and the council should be bridged, all the agencies should work together to provide adequate care for people and they should consider their individual needs" (Mrs Derrick, 43 years, main carer to Agnes, 86, Liverpool)

6, Nutrition, Co-morbidity and Social Isolation	6.2 Nutrition	‘But you know I understand, I wouldn’t go hungry, yea I’m saying, but I don’t eat the right food, but I definitely wouldn’t go hungry, that’s why I’m so skinny.’ (Minna, 77, Halton) “I’m eating well in here, but this is not the answer for me. Yes. Such things should have been happening in my home.” (Janine, 75, Liverpool) “And I’ve got a little bit of shopping but in all frankness I get better fed here than I do at home, only because I can’t be bothered even if I look thin. You know, I wouldn’t go hungry. I don’t eat the right food, but I definitely wouldn’t go hungry. That’s why I’m so skinny” (Dianne, 92, St Helens)). “I will need to ring up the people who deliver food on trolleys to deliver maybe twice a week so I can feed well when I get home, otherwise it will be very difficult” (David,83years, Halton). “My mum used to receive meals delivered to her but they bring the first meal late at 11 o’clock – assuming the first person comes by 9am to get my mum ready. Well basically these meals are delivered late and she wasn’t getting a lot nutrition, that’s why I am really afraid that when she lives here, she is going back into the same system and she may deteriorate and I don’t want that to happen because you are back to square one” (Mrs Derrick, 43 years, main carer of Agnes, 86 years, Liverpool). “I used to get meals-on-wheels but the times varied, I never knew what time they were coming. Sometimes it would be 11 o’clock, sometimes 12 o’clock, sometimes not at all – so I stopped it altogether. They were alright at first, they’d come at a regular time, 12 o’clock, but then they just stripped it apart then, yes. So I’m better off now really without it” (Suan, 90 years, Widnes).
	6.3 Chronic Disabling	She had charge of her finances. Mobility wise, she was slow but since she

	Condition	was *diagnosed* with the *cardiac* problem and pneumonia she had deteriorated and we have been concerned about it' (Matilda 82, main carer of John 89, Widnes) I developed DVT in addition to the disease I have and now on Warfarine (Leonard 89 St Helens) 'She went in first with heart trouble which she never had before and she went back with pneumonia' (Betty, 59, carer to Joan 89 Liverpool,) "No, no it couldn't have been avoided because it just happened, it was an extension of her stroke" (Martin, 62, carer to Margaret, deceased) "Oh I've been disabled for quite a while now, several years. But it all started off in 1990 when I fell down the stairs – fell down a flight of stairs, went bump, bump, bump, bump all the way down,, and crashed into the front door. I was only short the distance between the end of the stairs and the front door, crashed into the front door. I ended up in Halton hospital, and Neville, Blackpool hospital for several weeks. And my son came up for me and brought me home again. I was living in a 4 bed roomed house then. And I fractured several vertebrae and I've never been the same since" (Mina, 77, Halton).
	6.4 Social Isolation and Marginalisation	"Just occasionally, mostly telephone. They all work you see, and when people work, they haven't got time to visit. Christmas times like that, we do get together. We play pass the parcel Christmas time. They say, are you having my mum this year, I had her last year so you have her this year?" (Moss, 91 years, St Helens). "I never ever go out in the evenings, never ever, and once it gets dark, I don't care who knocks at my front door, no way will I answer it. And I don't answer the phone after dark in case it's someone that's going to frighten me, because I like to go to bed to sleep and not worry about what's going on. So I

		won't answer the phone once it is dark, after that" (Josie, 88years, St Helens). I wouldn't be going out anyway even if the…I think I've passed all that now. (Audrey 93, Halton) And erm, anyhow we got this letter back to go such a such a time, and we had to find it in X and he just threw the leg at us and he said that's all we have, I don't know what you're complaining about, and well I said what's these athletes got on their legs, I see men down town I said, with thin ones, with a joist. I said how come he's not been offered them, is it money...no, no we haven't got them, we don't do them. And in the end we just walked out blazing, so he was let down by the Health Service, no two ways about it, because if he'd of got them legs or one of them, and started walking on it, he'd of been prepared for the other or the other one might not of happened, but his body just shut down because that's all he did was either sit in the chair or lie in the bed (Mabel, 85, carer to Jim, deseased) I couldn't get on it, and when I got to 64 the Government raised it to 65 so I'd just missed out again, so I never got it and all that I've got now is two halves of a pension of his which was very, very poor, because he was never one for paying a big pension out, so I'm living on buttons. And I couldn't get on it myself, my daughter's trying now, and the flaming nurse up there in Warrington, she said she had our S there for half an hour and she could get up without any effort, she could sit without any effort, she was moved...she wasn't fidgeting around, she wasn't swinging her legs, and honest to god, I wished I'd of got hold of her, she was 10 minutes if she was that with our S in that room, and she was in agony there was no arms on the chair, so I know for a fact she'd never get straight up out of it. But the lies she told on our S not getting a bloody ha'penny again, so she can't get on it now, and she's only 40 and she's like an old woman walking around the supermarket with me (Abigail,88, St Helens) they've come on to give her this phone call, and somebody's give her this phone number, oh no try this one, no that's wrong love you want to try this

		one. And she's just hit a brick wall, nobody knows what it's for and yet he's paying £35 a week out of his lousy money. That's what I mean, it's our name, J and R must be have a hex on it……I don't know, this is why I am ready for a break down (Leonard 89 St Helens) but now and again I get fed up looking at the walls, no going out you know. I don't know this was going on, how long has this been going on?. Well if they send someone to clean my windows or change my bed, I'd be as happy as Larry (Janine) I get myself upset because I'm missing the best years of my great grandchild's their children, you know, growing up, it can't be helped that it's the life she wanted so that's it (Jane Halton) I learned ballroom dancing with my sister. We went to dance school together. And later on we were doing ballroom then and then we went to sequence dancing, modern sequence. And then when ....until last year, and I can't do now because I can't even stand up now. I can't walk and I can't dance. I used to go every day of the week and twice on a Friday. Friday afternoon and Friday night. I am just stuck here because I can't get out there. I can't get to the bus stop, I have got a new bus pass that you can go on a bus anywhere, I can't get to it. Can't get to the bus stop. (David, 83, Halton) but it just gets you down now and again, gets me down because I've always tried to do what I could to help people and now when I could do with help no one seems to want to know me, get fed up with it I do, like you having a little talk, you'll be surprised what that does for you, passed the day away, passes the time away, have a laugh you know. (Dianne 97, St Helens) "What I can't understand is, I've not been able to walk since I come out of hospital, so why wasn't I sent for therapy you know, to get my legs going. Why wasn't I sent there because I do know about people that have gone there, and it's done them good, you see. But my hands are stuck because of the arthritis and I can't move them the same, so if I'd gone there it might have done me a world of good. Whereas I'm getting worse, I'm getting worse now.

		The centre, I've never been in there, I don't know what it's like. I do a bit of exercise myself in here but it's not the same as going to one of them. It's not the same. Probably if I feel too ill any day, I'd dial 999 ambulances. I get stuck in sometimes" (Emma, 92 years, Widnes). "My windows, I can't get anyone to clean my windows. My son comes when he can and does them when he can. I used to do them every week but now it's every 6 months now, and I'm lucky if I get that. I have to put with that. I love a game of bingo, can't get out to go. My son's working all day and I don't like to ask him to take me out of a night and pick me up again, so I don't, I don't go out. I love a game of bingo, can't have it, I've got nothing in life now, what am I living for? What am I living for? (crying). But now and again I get fed up looking at the walls, not going out, you know. I don't know how long this has been going on. Well if they send someone to clean my windows or change my bed, I'd be as happy as Larry. I get myself upset because I'm missing the best years of my great-grandchild's life, their children, you know, growing up. It can't be helped" (Eileen, 87 St Helens). "And here we are, we have no rights whatsoever, no rights whatsoever, we just have to put up with things, and do you wonder that we get depressed? You wonder that people want to commit suicide? Do you wonder at that? What have we got? Got nothing after working, I've worked all my life. It just gets you down now and again, gets me down because I've always tried to do what I could to help people and now when I could do with help no one seems to want to know me. Get fed up with it I do, like you having a little talk, you'll be surprised what that does for you, passed the day away, passes the time away, have a laugh you know" (Emily, 95 years, Halton).
7 Nightmare of home care without social ties	7.2 Support from immediate family.	No, my daughter does what she can. She has her own family so I don't like her to do so much. She is also working on the computer in her office so I don't like her to do so much,(Agnes, 89 Liverpool) Oh I've got 2 sons that's all yes, and they come to see me yes, yes, I've not

		long come in now really, one of them brought me...we've been out shopping, you know, they take me out shopping. And erm have a run around somewhere. I've got the good life (Leonard) "Oh God, she'd have been trapped there all night and nobody would have been with her, and, oh no she didn't have any fall alarm. Lucky I was with her, living with her, you know. She'd been in agony all night. She'd have probably passed away" (Martin, 62 years, main carer to Margaret, deceased, Widnes). "I was quite happy and my son comes in, he's a chef, so he comes in, and sometimes he comes he's going to make some curry or mince meat, so I say, make some extra because I can freeze it, I've got a freezer. Who was it? A friend of mine said you can get fresh food, it comes round every week" (Leonard, 89 years, St Helens). we can provide her as a family ,myself and my brother we can provide some form of care---- but not really the care that she needs,---- that's my concern really.(Mrs Derrick)' I've never been out shopping or anything. I don't ever do shopping because my son and his wife always do my shopping for me because everything. So I'm really lucky, not lucky health-wise, but lucky in that way. Because I live with my son, it is easier. Yes, oh he does a lot for me, yes … He does all the two bedrooms and the bathroom and the kitchen and stairs, hoovers them, I just hoover the living room and do the dusting. I was living alone before my son came to live with me. Yes, I was living alone for years, and I managed, but I was stronger then" (Moss, 88 years, St Helens). "Well my daughter comes every week. Yes, it's either on a Saturday or a Sunday, you know … As for my son, they don't come as often as I'd like them to come, but they live a long way away. Oh, he rings every day but yes, he's a hell of a long way away you know, about 300 odd miles away. It's not like nipping out round the corner is it. And

		my daughter's three quarters of an hour away, but she comes, she'll come at a drop of a hat you know. Like I said, if I said I needed her, she'll be here" (David, 83 years, Halton). "If it's anything, climbing, my son does that for me. He changes the curtains, he changes my bed, my son does that. My daughter in law cooks me a meal every now and again. I've a microwave, I have to use that … My son is working, he's got enough to do. Anyway they've got their own life to live. I've had my life, my life's nearly over now." (Emma 92 years, Widnes) Well my daughter comes every week. Yes it's either on a Saturday or a Sunday You know, Sue has to do...to work. And erm, they always -- or not. They don't come as often as I'd like them to come but they live a long way away (Dianne) Because I live with my son, it is easier. Yes oh he does a lot for me, yes. Well erm...he does all the two bedrooms and the bathroom and the kitchen and stairs...hoovers them, I just hoover the living room and do the dusting. I was living alone before my son came to live with me. Yes, I was living for years and I managed but by then I was stronger. (Emily) I had no life at all, the only life I have is my son, I think the world of him and his wife, and without them I didn't know what I would do, I don't know, I don't know at all. (Janine) , if it's anything climbing, my son does that for me, he changes the curtains, he changes my bed, my son does that,(Minna) And erm, he realised how very, very tired I was because I up in the night with him as well, it was hard...jolly hard work really, erm but I was determined he wasn't going to go into a home (Nadine,74, main carer to Victor, diseased, Halton)

		R But if you were not there, do you think those two times would have been Ok for him? A No, no. If I...I took the brunt of it quite honestly, the main thing was that I received a little support but did the main care really---Yes. I'll tell you, I also had erm...you've heard of crossroads? (Vera75 , wife and carer to Allan, diseased, Widnes)
	7.3 .Support from significant others	"My nephew comes in the morning, and he takes me shopping in the car, I can't walk very far. But he'll take me to Asda or wherever I want to go. I also have loads of visitors, loads of visitors, friends. I've got a niece I brought up from a child and she lives in Nantwich but she's come, she's been this week, she's hoovered the entire bedroom, dusted you know whatever. That's what she does when she comes" (Janine, 75years, Liverpool). "Oh I don't know how I'd cope without my nephew because there's nobody else really … And he'll peel potatoes if I need them before he goes. He'll do all sorts of things that I can't do." (Mina, 77 years, Halton) Oh I don't know how I'd cope because there's nobody else really,….. My nephew takes me shopping in the car, I can't walk very far. And then erm he'll peel potatoes if I need them before he goes, or he'll do all sorts of things that I can't do, (Moss) …….they say I mustn't get up when I'm at home, I mustn't get up unless there's someone in the flat with me, but they can't have someone there all day, nobody came spare that time and my son's come as much as they can, and their wives and my sister (Abigail). these carers erm...actually say we don't do any cookers. All the things my mum liked like crackers, so that if she didn't have the main meal for her dinner she could have the alternative that was what I was prepared to do cook a fresh meal everyday, my brother was coming and also my nephew (Martin)

		R. So, did the care package not work for your mum? A No, no, because it means we are expected to be there and we can't you know, we've all got lives, got our own to live, I've even had my mum living with me ten years ago when she was going in a for a hip operation and I thought her health was going to deteriorate and I was going to start looking for something all set up (Davina) my daughter in law, who cooks me a meal every now and again, I've a microwave I have to use that and erm…my son is working he's got enough to do, anyway they've got their own life to live, I've had my life, my life's nearly over now (Jossie) Oh yes, and she rings every day Yes, he's a hell of a long way away you know, about 300 odd miles away, it's not like nipping out round the corner is it. And my daughter's ¾ hour away, but she comes, she'll come at a drop of a hat you know. Like I said, if I said I needed her she'll be here (Jane) And I have tin peas, and that's it for the kids, get a meal down them you know, but our Sue comes to help me peel and cut them out and dish it out that sort of thing. Well I want to try carrying on doing that if I can, (John) 'At the moment I have to step into the bath to get a shower and I'm not brave enough, on my own to sit in the bath. So I have to stand, no, climb into the bath to have a shower and I haven't sat in the bath till I came here for a long, long time (Minna) my nephew comes only in the morning, and he'd take me shopping in the car, I can't walk very far. But he'd take me to Asda or wherever I wanted to go. I also have loads of visitors, loads of visitors Yes friends. I've got a niece I brought up from a child and she lives in Nantwich but she's comes...she's been this week, she's hovered all the bedroom, dusted you know whatever, erm that's what she does when she comes(David)

		Oh I don't know how I'd cope because there's nobody else really, and my friend across the road is just fantastic, she takes me to the hospital (Daniel)
	7.4 Care package provision.	"The care package did not work for my mum, because it means we are expected to be there, and we can't you know. We've all got lives, got our own to live. I've even had my mum living with me, ten years ago, when she was going in for a hip operation. And I thought her health was going to deteriorate and I was going to start looking for something (Tina,55 years old, main carer to Audrey, 95, Halton). "They say I mustn't get up when I'm at home, I mustn't get up unless there's someone in the flat with me, but they can't have someone there all day, nobody came spare that time. And my sons come as much as they can, and their wives, and my sister" (Diane, 85 years, St Helens). Yes, I do get proper care. While they are there, they are very good. They are very good. But, the couple of hours in-between, that's a bit stressful because I have got to watch what he is doing, and he starts bumping his head and he hates the doors being locked … If they ring the bell, I say come in. He found out how to open the door, because he is not soft like. He has always had a very good job, so he is quite brainy but you wouldn't think so now" (Mabel, 85 years, main carer to Jim, deceased, Widnes). They wasn't here quarter of an hour, when they come of a morning to dress her, or erm just to wash her you know...no she didn't get dressed, she just got her nightie on and erm, they used to wash her and that, and they were away within a quarter of an hour. I'd probably end up giving her, her breakfast; I think the care wasn't adequate for her. No it wasn't. Not for the money she's paid in for stoppages on your wages you know (Martin) by the time they brought a proper Zimmer frame, because they give her a Zimmer frame, eventually and it wasn't quite the right one, and I don't know

		what was wrong with it, it wasn't quite to their regulations, and then by the time they brought the correct Zimmer frame she didn't need it, so they delivered the cane, brought it unpacked it, packed it back up and took it away. Because she really didn't need it, it took that long, and that's no good (George) I went home again and the doctor said she still wants extra care, well she put extra care on, well she put care on overnight it was going to cost an awful lot, because I don't reckon about £60 to £70 overnight or somebody said so and that's with the money you've got to pay so I thought well I couldn't do that (Emily) I've asked age concern to get...they wont clean the windows, I've asked the council,… housing trust to get someone to change the bed for me, because I can't lift the mattress up you know,…. couldn't get any one, I fought for 2 years to get someone to cut the grass at the back, and the grass was that high it was, that high. I fought for 2 years to get the grass cut and it was that high and they told me I would have to see to it myself, and I said I would have to write a letter to someone,(Joan) ….the Social Service was here and they asked her did we want two women but they took ever so much money out of me to have them two women to come in for 5 minutes to get him out of bed into his chair and to come at 6'oclock and put him back in his bed. I washed him, I changed him, I done all that, but they...I don't know whether it was £9 odd or £19 odd but my daughter was furious with them, and it went out of my money (Suan) . I got a statement from the careline, to say that I owed £400 that's what made me ask you did I have to pay, for people coming in. I had to borrow some money to pay the statement. They asked me did I want, but they didn't tell me that I had to pay, I just thought it was free, from the hospital you know, but it wasn't was it? It's a lot of money you know,(John) Well you see, when I've been on care many, many years when it was free, you pay now but it was free when I first went on and every thing was done for

		you, your house cleaned top to bottom and shopping and all that, but now it is not so (Mina) And I said what about the dishes, oh no they're left till the next one comes in and I say I'm not going to sit with dirty dishes in front of me all night, but that was what they started to do, and didn't do it, well they never sweep, never put a carpet sweeper over anything, so I had to have someone in to do the cleaning, someone into to wash and all that used to be done by them and you are paying now and you weren't paying before and you were getting everything done, now your paying and not getting any done (Diane) the Social Service was here and they asked her did we want two women but they took ever so much money out of me to have them two women to come in for 5 minutes to get him out of bed into his chair and to come at 6'oclock and put him back in his bed. I washed him, I changed him, I done all that, but they...I don't know whether it was £9 odd or £19 odd but my daughter was furious with them, and it went out of my money (Audrey) so I thought what kind of a care package is it if you've got to prepare meals and things you know, and also it's free for a month and after that it's £8.50 for half hour which to me is daylight robbery if they expect people to pay that, so erm...(Matilda) Erm yes, you've got to pay for that as well, I pay £20 per month for this....Yes just for the life line Erm...well I got it on the insistence of my daughter because erm you know if I fall over I can't get up (Leonard)

Chapter Eight. Recommendations and Implications for Policy/Practice

8.1 Introduction.

Drawing on the contributions made by older people and their carers, this chapter puts forward recommendations for policy and practice. This chapter also discusses the limitations of the present study and suggests areas for further research.

8.2 Preparation for discharge after initial hospitalisation.

With regards to discharge practices, written discharge procedures should be agreed and made available to community and hospital based participants. Preparing older people for discharge after initial admission should begin as early as possible and patient and carers should be central to the planning process. A multidisciplinary approach and an effective interface between the people involved at all stages of the process and across all settings is essential. One named member of the multidisciplinary team should be responsible for discharge preparation for a named patient to avoid confusion. Also written information about lifestyle, diet, medication, symptoms of disease and where to obtain help while in the community should be made available on discharge to avoid confusion around where to get help. All preparations relating to discharge should be based on effective multidisciplinary teamwork and should involve occupational therapists, carers, doctors, district nurses and physiotherapists. A shift from targets designed for specific services and organisations, to targets that encourage different services to collaborate and join-up, should be encouraged in older peoples care.

8.3 Empowerment and involvement in care by older people.

There is a need to create more personalised metrics so that older people themselves have a greater say in defining what constitutes a good or bad outcome. Providing health education and patient-centred care planning is paramount. Developing relationships with patients will also enable the negotiation of care plans and encourage concordance around treatment requirements.

Nurse-led Clinical Managers (Community Matrons) should ensure older peoples' care is coordinated across health and social care sectors so that older people receive care and services that are appropriate to their needs. Instructing carers on good health promotion, the use of other innovative approaches and the involvement of older people in self management will reduce numbers of readmissions. Issues relating to supporting self-care include ensuring that patients and carers have the skills and knowledge they need to handle their conditions, adjust medication doses and handle flare up situations appropriately. These issues could be addressed by supplying information that is accessible and meaningful, ensuring patients have contacts in the formal care system, and by encouraging involvement in support networks for peer support and providing access to other patients with experience of similar conditions.

8.4 Support at home

Some older people have spent a life-time of contributing to their communities and therefore deserve the best in care services without excess drain on their reserve. Services must therefore be developed and tailored to their needs and their wish to remain and be taken care of in their homes and communities. We should ensure they are treated with dignity. It will be necessary to target interventions, giving older people the choice to live at home for longer by redesigning the system so that more emphasis is placed on preventative services in the community. Service provision should be based on in-depth assessments of older people's needs, mental health status and satisfaction, and providers should work with older people to design care and contingency plans, using community based resources wherever possible so as to minimise the chances of a crisis requiring a visit to hospital.

The implementation of telephone follow-ups post-discharge would be beneficial. It would help to identify problems arising soon after discharge, to give advice to patients and carers and to signpost appropriate community services.

The provision of preventive services for older people is also essential and providers should look out for 'trigger' events which are an early warning of growing instability. Such events include sudden changes to patterns of attendance at GP surgeries; people who visit accident and emergency following incidents but are not admitted to hospital on that occasion; and people who make repeated calls to social services and NHS Direct. Getting older people engaged is essential to the success of this approach, and the range of services needed extends well beyond traditional health care to include befriending, decorating, help with finances, heating, transport, as well as advice on medication, incontinence, blood pressure and fall prevention.

Handy person schemes should be created to help people with household chores and lessen anxiety in these areas. There is also a need to build up local voluntary services.

To prevent admissions to hospital, multidisciplinary rapid response teams of nurses and community workers should be created, and there should be an increase in the number intermediate care units with the right staff mix to cater for older people's needs outside the hospital setting.

Supporting informal cares is very important, as this study has shown. Respite care services should be accessible, flexible and responsive, with in-home delivery and other options offered to individual carers according to their preferences. Informal carers who juggle work with caring should be supported by their managers. Flexible working hours are essential here. Individuals in this situation also need the understanding and sympathy by their colleagues. Managers and co-workers should receive sensitivity training in this area.

8.5 Consideration for other modalities of funding care for older people in the community.

If growth in health care spending is to be kept within reasonable bounds, it is essential to develop and implement health improvement programmes that will meet the demands for health care among the older population. A single, integrated funding stream for long-term care is easier to manage and sustain than multiple, fragmented funding streams. The options include;
Free social care funding; The labour government's recent commitment to introduce free personal care for those with the highest need in England if they should still be in power was welcomed, but unfortunately, in May 2010, the general election in the UK resulted in a hung parliament, in which the conservatives which won most seats formed coalition with the Liberal democrats who have no support for free social care funding. There is also a need to explain precisely how 'highest need' and 'personal care' are to be defined for funding purposes and in setting clear eligibility criteria.

Income-related insurance contributions (or hypothecated taxation); This may be an acceptable, progressive way of raising revenue for care. It would be recalled that the conservative government presented this proposal during the last political debate of 2010 in the UK, where they proposed release of £8000.00 pounds as cap cost for care of older people in nursing or residential care, after they have made some contribution into the insurance scheme when they are not very old. However, it is hard to see how an insurance-based system would benefit adults with disabilities; individuals who are often unable to acquire assets and savings and so pay into such schemes. Any additional revenue needed could be generated from income-related co-payments. Political acceptability may be enhanced by the inclusiveness of universal schemes in which all contributors have a stake as potential beneficiaries. This is because people of all ages experience disability, episodes of ill-health or longer-term health conditions. However, any new system of funding needs to be sufficiently flexible to accommodate changing needs and circumstances over time.
Partnership; The partnership model provides people with-a-free of charge minimum guaranteed amount of care cost that is probably set at 66% of the total bench mark care package for individual older person. This may be beneficial if the state matches individual contributions pound for pound until the benchmark care package is achieved, otherwise, those older people on low income may be supported with additional contribution through the benefit system. In this case, individual contribute to the costs of their care before old age.

Whatever option is taken, a full assessment of the costs of each, alongside the projected costs of an unreformed system, are essential to arriving at an informed view on the funding of care for older people.

8.6 Improvements in communication.

Groups and organisations contributing to the care of older people should receive multi-disciplinary training. This will lead to improved co-ordination. The need for collaborative innovation requires leadership of a particular kind. The partners – local authorities, primary care trusts, acute trusts, voluntary and private sector providers – should devise new governance arrangements to establish how they would cooperate. They have to think hard about how to hold one another to account for their contributions to the care of older people. This requires skilled and intensive facilitation.

After the first admission of an older person to hospital, it is important that discharge information should be given in writing, in language and formats that are easily understood. Details should be given when the person is ready to receive them and not when he or she is too tired. It could be given more than once and in different ways to ensure complete understanding. Information should be in different languages including how to complain and where to get help in time of crises. Where possible, carers ought to be around at the time information is being given. Checks should be made that the person can hear clearly on admission otherwise a hearing aid should be provided and batteries on hearing aids should be maintained. Checks should be made throughout the period that someone is in hospital to ensure that information has been understood and digested. If necessary, large fonts should be used so that information can be read. If necessary, tapes should be given to people who are being asked to grapple with complex information. Good physical and mental health, quality of life and the ability to live independently are closely linked. Although health problems generally increase with age, disease and disability they are not inevitable consequences of growing older. Many older people remain healthy and continue to make a major contribution to society. The challenge for health and social service providers is to maximise the opportunity for each individual to enjoy a long and healthy life (Welsh Assembly Government 2008).

8.7 Eradication of marginalisation and social exclusion.

Marginalisation leads to inequality in health. Older people presently marginalised by age, social class or ethnicity need quick interventions by the government, through the relevant authorities. It is important to make sure that institutional discrimination of all sorts is eradicated. The Health Select Committee strongly recommended that the government should introduce national eligibility criteria for long term care underpinned by a standard assessment methodology (House of Common Health Report 2004-05). There is a need to implement this policy immediately. Social workers need guidance on how to arrange care for older people to make sure care packages are negotiated with them before implementation. They also need training in the negotiation skills necessary for working with a new generation of more assertive users.

Loneliness and isolation together with financial and physical insecurity remain significant factors affecting older people's quality of life. There is a real need to interview individual older people and their carers in their homes to find out what services and supports they think would prevent their feeling of loneliness and social exclusion. This would enable services to be targeted to meet their needs. Older people should also be encouraged to maintain life in the community by participating in activities they enjoy and find rewarding. Day centres, visiting schemes with free transportation, adult education schemes tailored to individual needs, leisure services, fitness centres and alumnus organisations all serve to minimise loneliness and social exclusion.

Individual circumstances must be taken into consideration in comprehensive geriatric assessments by team of health professionals prior to discharge from hospital care. Where family support is not available and care is not affordable, older people should be considered for sheltered accommodation.

8.8 Active involvement of national and local government authorities.

More detail is needed on some of the components of the proposed national care service, particularly arrangements for national assessment and eligibility, fair funding, and joined-up services. A comprehensive approach to tackling these issues requires concerted action by both central and local government, and by communities themselves. The role of national policy is critical if the system is to work. The government should embrace research evidence in making reforms to the current system. Managers should be knowledgeable of recent research. National arrangements for assessment and eligibility should be established, so that individuals have a much clearer understanding of entitlement irrespective of where they live. Local authorities must meet the challenge of tackling wide and unexplained variations in the services people are offered (DOH, 2009).

8.9. Support for intensive care at home.

Like many other studies, this research has revealed that older people prefer to receive care at home not elsewhere. It is important to look into ways of delivering intensive support to those with co-morbid conditions outside clinical settings. For those who need intensive care at home, assistive technologies and other forms of home telecare will improve and promote the care they receive. Their situation needs to be evaluated at regular intervals to determine areas of difficulty, so that changes and modifications can be made following any reassessment of their situation.

8.10 Limitations.

The North West of England is recognised for its lower life expectancy due to low health and social care provision as earlier highlighted in 1.2 under statement of problem. It is therefore not surprising that the study may still be depicting the regional deprivation in essential services when compared to other regions in England, and therefore limits its findings to the Northwest of England.

The use of qualitative method as the design for the research through use of in-depth interview has allowed the study participants to chart away in areas of the interview questions that they considered important to them, therefore living some areas of the questions unanswered, even where all rigours have been put in place as explained in interview section. Perhaps a structured interview or questionnaire would have exposed them more to all the questions with more results. This is therefore considered a limitation to the study.

Also, it was not possible to conduct a focus group discussion for the study as the individual older persons were not willing to leave their homes for a focus group in any venue. They preferred their private lives and did not want to share their life experiences with any other older person. Perhaps, a focus group would have added more knowledge to the result.

The allotment of time slots for formal carers made accessing them problematic. Only informal carers participated in the study which limits the findings to what informal or family carers have said

The use of quantitative method to test the hypothesis that older people in the North West of England are at higher risk of hospital readmission, may yield a different result, and until that are done, there is still a limitation to this findings.

It is true that the study focused only on the perception of older people and their carers to the problem of readmissions; however, issues relating to health do have immense contributions by the health care professionals themselves. This study has not involved any member of the health care professionals; like the General Practitioners, community nursing staff and other hospital staff. Also only older who have passed through the Enabling Team in St Helens and RARS Team in Halton and have experienced readmissions are included in this study. The non-inclusion of other older people who experienced readmissions but could not be assessed is also viewed as a limitation to this study.

8.11 Areas for Further Research

- Further research on the concerns of carers' and older people needs.
- Research to help develop and evaluate interventions designed to improve communication upon hospital discharge so as to reduce the risk of readmission.
- Further research on hospital and community services to diagnose the difficulties and help improve integrated service provision.
- Research to investigate if 'hospital at home' can be used for people without carers but who have access to assistive technologies and telecare.
- To improve coordination between providers of care in hospital and in the community, further exploration of the issues that surround communication between service providers may be conducted through integrated research and practice development projects.
- Research to investigate needs and concerns of patients and carers making the transition from hospital to home and, following discharge, further exploration of holistic, person-centred approaches to the provision of care and services.
- PCTs should undertake regular reviews of readmissions to help identify a framework of risk factors for older people.
- Further research is needed to determine the effect of home based care with attention to medication use and side effects of medications in consideration of polypharmacy levels and co-morbidity in this age group.
- Research to examine different financial arrangements and the extent to which these incentivise collaboration and the efficient use of resources, especially across the different funding systems for local government and the NHS.

People over sixty five frequently have complex health and social problems consisting of chronic disease and co morbid conditions, episodes of acute diseases, physiological, functional and cognitive problems. They rely on the assistance of health and social programmes and services. This research has shown that the assistance and support they need is mostly provided by their families. Given the responsibilities they have to take on with the caring role, they suffer from stress. Frail older people use a large number of health and social services, and the services available to them in the UK are fragmented. The delays of home adaptations as well as non-availability of adaptation services are detrimental to older peoples' well being.

8.12 Conclusion.

Chapter one of the thesis introduced the study by highlighting the historical transition of ageing and its health and social implications. The policy contexts of social care in the United Kingdom have also been described. The author through her clinical practice in an intermediate care unit was able identify readmission of older people into hospitals as a problem which led her to proceeds to the study of readmissions. Haven searched medical and social literature, chapter two provided an overview of the literature as well as providing an introduction to the main theoretical issues examined in this thesis. The literature review provided a framing research question and methodology adopted for this research. The information gathered from chapter two provided a background for the aims and objectives of the study as outlined in chapter three. It further provided the philosophical background that informed the phenomenological approach adopted for the study. A description of the reason for the adoption of phenomenology, drawing on the writings of great philosophers like Huserl and Schultz are detailed in chapter four. Furthermore in this same chapter are the highlights of the methods used for data collection and showing purposive sampling method as a best option. The participants for the study, comprising older people and their carers recruitment strategies have also been described. Haven adopted phenomenological approach to data analysis, older people and their carers experiences of hospital readmission were identified through the emerged themes. Chapter four opened up discussion on the first theme of the result of the study "Patients' information, engagement and choice of care" which has been discussed and illustrated with quotes from the patients and their carers. Chapter five continued the discussion on the second theme of; "service provision from health and social care" also being supported by the use of the verbatim quotes from older people and the carers. Chapter six demonstrated how older people manage a diverse range of health and social problems which affect their health and lead to readmissions to hospital. Also issues relating to the theme of "Nutrition, Co morbidity and Social Isolation" are brought to full discussion.In Chapter seven, the discussion of how older people perceived their family and other close contacts from friends made living and being care for at home a reality, without which just dependence on social care from the government would have created serious problem for them. Even those living alone expressed the view that living at home was not viable without support which therefore suggested that older people without the necessary social ties should be considered for care in other settings, residential or nursing homes, if their care needs are to be adequately met.

Community care which are both health and social care is presently mean-tested in the UK apart from Scotland, where it is free. It could be well appreciated that during the most recent political debate, the three major political parties, the Labour party, the Social democrats and the Liberal democrats, all embraced the fact that the present system is not adequately meeting older people's care need confirming the findings of this research, and have made several suggestions. I have in-turn recommended the free social care, which means borrowing a leaf from Scotland; partnership model and the income-related insurance models of funding. The establishment of national assessment and eligibility in which individual older person have a much clearer entitlement irrespective of where they live, will assist the local authorities in tackling the present wide variations in social care (Local Government Authority 2009).

The fact that readmission is still a problem in the North west of England despite all measures taken by the UK Department of Health , as outlines in 1.5, may mean that the North West of England has not received the attention it requires from government policy especially in the areas to reduce inequalities in health or to regenerate local communities (Department of Health 2009). It might imply that such policies have not been concentrated enough in the northern half of England in which case a more directed regional economic policy may be require. It might also imply an imbalance between north and south in the wider determinants of health such as education, access to cultural activities, and social capital which still requires attention.

The steadily rising number of unplanned readmissions particularly amongst older people in North West of England has remained a major source of pressure on the NHS. The notion has been that it is as a consequence of an aging population, but it is in consideration of the aging population that all the policy has been put in place in addition to integrated and co-ordinate discharge planning (Department of Health 2005). It appears a lack of integrated and co-ordinated discharge planning and continuity of care as well as a lack of holistic and proactive care focused on long term conditions has meant that the older people in the North West of England has to wait for medical crises to occur and face readmissions. The effective use of Parr++ tool will effectively manage long term conditions when older people are stratified according to their risk of readmissions. By so doing, individual older people with high complex need will be identified and followed up accordingly. This will form a key point of leverage in improving the whole system health and social care and not just in the North West of England.

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APPENDIXES

THE UNIVERSITY
of LIVERPOOL

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Appendix 1: Patient's Information Sheets.

Older people and their carers' perspectives of readmissions.

1. Invitation to the study.

You are being invited to take part in a research study. Please ask us if there is anything that is not clear in this leaflet or if you would require more information.

2. Purpose of the study?

The study aims to investigate the risk and actual causes of readmission of older people to hospital. Specifically we would like to hear from older people who have experienced readmission to hospital, and their carers, why they felt they were readmitted to hospital and their experiences of readmissions. Apart from the interviews, you will also be required to take part in a focus group discussion.

During the course of the interviews we will use an audio-recording material so as not to loose any of your important information. The focus group discussions will comprise 5-6 people altogether discussing their experiences of hospital readmissions. I t will be conducted in such a way that each member of the group is given the opportunity to express him/herself for questions raised if they wish.

3. Why have I been chosen?

You have experienced multiple hospital admissions and we are interested in hearing your view/experiences.

4. Do I have to take part?

It is entirely your decision whether or not to take part. If you agree to take part, you are still free to withdraw at any time and without giving any reason. Any information we have collected from you will be destroyed if you wish.

5. What will happen if I do take part?

You will be interviewed by Roseline Henry-Nweye, who will audio-record the interview.

6. What are the possible disadvantages of taking part?

You will be asked to be available for interview/focus group discussion regarding your views about readmissions to hospital as well as general view about other measures you might want in place. This represents a moderate time commitment which should be given consideration when deciding whether to take part or not.

7. What are the possible benefits of taking part?

You will have the opportunity to express any concerns you have regarding your readmissions to hospital. We will provide you with a summary of the findings if you wish to know it, but there are no direct benefits for taking part in this study.

8. Will my taking part in the study be kept confidential?

All information which is collected from you will be kept strictly confidential. Roseline Henry-Nweye will be responsible for making sure the recordings and any transcripts are anonymised and kept safe; locked in a filling cabinet in a locked room.

9. What will happen to the results of the study?

The results will be used in Roseline Henry-Nweye's research and will be published in one or more scientific Journal. You will not be identified in any report or publication

10. Who is organising and funding the research?

The University of Liverpool is organising the research while the research student is funding the research.

Thank you for reading about our research.

If you are harmed by taking part in this research project due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain about any aspect of the way you have been approached or treated during the course of this study, the University of Liverpool complaint mechanisms should be available to you.

Mrs Roseline Henry-Nweye
Division of Primary Care
School of Population, Community & Behavioural Sciences
Whelan Building (2nd Floor) Quadrangle

Brownlow Hill
Liverpool
L69 3GB
0151 794 5595.

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of LIVERPOOL

Revised Version 5.3; 30/05/2007
Reference: 07/Q1501/51

Appendix 2: Carer's Information Sheets.

Older people and their carers' perspectives of readmissions.

1. Invitation to the study.

You are being invited to take part in a research study. Please ask us if there is anything that is not clear in this leaflet or if you would require more information.

2. Purpose of the study?

The study aims to investigate the risk and actual causes of readmission of older people to hospital. Specifically we would like to hear from older people who have experienced readmission to hospital, and their carers, why they felt they were readmitted to hospital and their experiences of readmissions.

Apart from the interviews, you will also be required to take part in a focus group discussion. During the course of the interviews/focus group discussion, we will use an audio-recording material so as not to loose any of your important information.

The focus group discussions will comprise 5-6 people altogether discussing their experiences of hospital readmissions. I t will be conducted in such a way that each member of the group is given the opportunity to express him/herself if they wish.

3. Why have I been chosen?

The person you care for has experienced multiple hospital admissions and we are interested in hearing your view/experiences.

4. Do I have to take part?

It is entirely your decision whether or not to take part. If
you agree to take part, you are still free to withdraw at any time and without giving any reason. Any information we have collected from you will be destroyed if you wish.

5. What will happen if I do take part?

You will be interviewed by Roseline Henry-Nweye, who will audio-record the interview.

6. What are the possible disadvantages of taking part?

You will be asked to be available for interview/focus group discussion regarding your views about readmissions to hospital as well as general view about other measures you might want in place. This represents a moderate time commitment which should be given consideration when deciding whether to take part or not.

7. What are the possible benefits of taking part?

You will have the opportunity to express any concerns you have regarding your readmissions to hospital. We will provide you with a summary of the findings if you wish to know it, but there are no direct benefits for taking part in this study.

8. Will my taking part in the study be kept confidential?

All information which is collected from you will be kept strictly confidential. Roseline Henry-Nweye will be responsible for making sure the recordings and any transcripts are anonymised and kept safe; locked in a filling cabinet in a locked room.

9. What will happen to the results of the study?

The results will be used in Roseline Henry-Nweye's research and will be published in one or more scientific Journal. You will not be identified in any report or publication.

10. Who is organising and funding the research?

The University of Liverpool is organising the research while the research student is funding the research.

Thank you for reading about our research.

If you are harmed by taking part in this research project due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain about any aspect of the way you have been approached or treated during the course of this study, the University of Liverpool complaint mechanisms should be available to you.

Mrs Roseline Henry-Nweye
Division of Primary Care

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Reference: 07/Q1501/51

Appendix 3: Patients' Expression of Interest Form;

Patients Number---

Practice Number--

GP/Practioner's Name--

Older people and their carers' perspectives of readmissions

I, -- have read the patient information sheet about the above stated project and agree to a researcher contacting me regarding my participation in the project.

Name; --

Contact Number; --

Address; ---

What is the most convenient time of day for you to be contacted? (*Please tick the appropriate box*)

Any ☐

1. Morning (9 – 12noon) ☐
2. Lunchtime (12 – 14.30) ☐
3. Afternoon (14.30 – 17.00pm) ☐
4. Evening (17.00 -20.00pm) ☐
5. Names; ------------------------. Signature; -------------------.

   Date; -------

Roseline Henry-Nweye; 0151 794 5595. Mobile; 07814 506 678. Email; R.A.Henry-Nweye@liv.ac.uk

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Reference: 07/Q1501/51

Appendix 4: Carers' Expression of Interest Form;

Patients Number---

Practice Number---

GP/Practioner's Name--

Older people and their carers' perspectives of readmissions

I, -- have read the patient information sheet about the above stated project and agree to a researcher contacting me regarding my participation in the project.

Name; --

Contact Number; --

Address; --

What is the most convenient time of day for you to be contacted? (*Please tick the appropriate box*)

6. Any ☐

7. Morning (9 – 12noon) ☐

8. Lunchtime (12 – 14.30) ☐

9. Afternoon (14.30 – 17.00pm) ☐

10. Evening (17.00 -20.00pm) ☐

Names; ------------------------. Signature; -------------------. Date; -------

Roseline Henry-Nweye; 0151 794 5595. Mobile; 07814 506 678. Email; R.A.Henry-Nweye@liv.ac.uk

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Reference: 07/Q1501/51

Appendix 5: Patients Consent Form

Patients No; Practice No; GP Practitioner Name;

Older people and their carers' perspectives of readmissions.

Please Tick Box

1. I confirm that I have read and understood the full information sheet dated..............for the above study.	**YES**	**NO**
2. I have had the opportunity to consider the information, ask questions and to have these questions answered satisfactorily.		
3. I know enough about the project.		
4. I understand that my participation is voluntary.		
5. I am free to withdraw at any time, without giving any reason and that this will in no way affect my medical care or my legal right.		
6. I give consent to be contacted by the researcher to be interviewed.		
7. I give consent to be contacted for focus group discussion.		
8. I give consent for my primary carer to be contacted		

for the study.		
9. I understand the interview/focus group discussion will be taped and I can stop it at any time.		
10. I would like to receive a summary of the findings at the end of the study.		
10. I agree to take part in the above study.		

------------------------------ --------------------

Name of patient. Signature.
Date.

-------------------------- -------------------

Name of researcher. Signature.

Date.-----------------------

One copy of the consent form will be retained by the patient, one for the researcher and one to be kept with medical notes.

Roseline Henry-Nweye; 0151 794 5595. Mobile; 07814 506 678. Email; R.A.Henry-Nweye@liv.ac.uk

THE UNIVERSITY
of LIVERPOOL

Revised-Version 5.3; 18/05/2007

Reference: 07/Q1501/51

Appendix 6: Carers' Consent Form

Patients No; Practice No; GP Practitioner Name;

Older people and their carers' perspectives of readmissions.

Please Tick Box

1. I confirm that I have read and understood the full information sheet dated……………for the above study.	**YES**	**NO**
2. I have had the opportunity to consider the information, ask questions and to have these questions answered satisfactorily.		
3. I know enough about the project.		
4. I understand that my participation is voluntary.		
5. I am free to withdraw at any time, without giving any reason and that this will in no way affect my medical care or my legal right.		
6. I give consent to be contacted by the researcher to be interviewed.		
7. I give consent to be contacted for focus group discussion.		
8. I understand the interview/focus group discussion		

will be taped and I can stop it at any time.		
9. I would like to receive a summary of the findings at the end of the study.		
10. I agree to take part in the above study.		

---------------------------- ------------------------

\-

Name of patient. Signature.
Date.

------------------------- ------------------

\-

Name of researcher. Signature.
Date.

One copy of the consent form will be retained by the patient, one for the researcher and one to be kept with medical notes.

Roseline Henry-Nweye; 0151 794 5595. Mobile; 07814 506 678. Email; R.A.Henry-Nweye@liv.ac.uk

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Revised-Version 5.3; 18/05/2007

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Appendix 7: Patients' Topic Guide for In-depth Interviews/FGDs.

Older people and their carers' perspectives of readmissions

In-depth interviews will be conducted at a venue and time most convenient for the participants. From these questions, the researcher will have identified parts of the interview that will be informative according to the objectives of the study. As the interview and analysis proceeds, additional types of speech may be identified and included in the interview in order to still test the analysis. Interruptions from interviewers will be kept to a minimum, with the interviewer dialogue limited to asking questions and some probing where necessary. The interview will proceed as follows;

<u>Patients perception of receiving care in his/her home?</u>

Could you tell me about your family; wife/husband and children?
What kind of work did you used to do?

Are you living with any one and is he/she your main carer? or do you have others come in to take care of you?

What kind of relationship do you have with your carer (Ask for specific examples?)

What are your experiences of receiving care in your home? When did it start and has there been any significant change over time. (Have they been better than expectations or not).

What does your home mean to you?

Do you think receiving care elsewhere would have been better and if so why?

Patients' perception of hospital readmissions.

Could you remember an incident that led to you to be admitted in hospital and have you had a cause to be readmitted?

Did the hospital staff involve you and your carer in the discharge arrangements?

Can you give me some specific changes in your home and your life since after your admission and readmissions?

or

How do you manage with your meals/pills.?

Do you think your admission into hospital could have been prevented and if so what do you think could have been done?

How is life generally since you came back home; any contact with your family members/outings, or health staff?

Appendix 8: Carers' Topic Guide for In-depth Interviews/FGDs.

Older people and their carers' perspectives of readmissions

In-depth interviews will be conducted at a venue and time most convenient for the participants. From these questions, the researcher will have identified parts of the interview that will be informative according to the objectives of the study. As the interview and analysis proceeds, additional types of speech may be identified and included in the interview in order to still test the analysis. Interruptions from interviewers will be kept to a minimum, with the interviewer dialogue limited to asking questions and some probing where necessary. The interview will proceed as follows;

<u>Carers' perception of patients receiving care in their homes;</u>

Could you tell me a little bit about yourself about your family; partner and children?

Have you always been doing caring work?

What does the job of caring involve?

What does a particular day of caring look like?

What are your experiences of patients care at home?

Do you think receiving care elsewhere would have been better?

Has caring for your patient affected you in any way? Tease out particular examples.

Do you feel you are coping? If yes, how are you coping (what are your coping strategies) and if no, what would you like to happen?

How would you describe your relationship with your patient (s)?

Do you feel you are appreciated in your caring role? If yes, how, and if no, then how could that be different?

<u>Carers' perception of hospital readmissions?</u>

Can you remember how many times your patient (relative) have been readmitted to hospital and the reasons why?

Could you tell me at what stage the hospital staff involved you in the discharge arrangements and were your needs considered?

What changes have affected your patient since she left hospital and do you think those changes required any intervention?

In your opinion and experiences, why do you think older people are generally admitted to hospital, and could you give me some examples?

How do you manage your patients' meals/pills or medicines?

Do you think your patients' admission to hospital would have been prevented and what do you think would have been done?

How is life generally since your patient came back home; any contact with family members/outings/respite care/holidays or hospital staffs?

Halton and St Helens NHS
Primary Care Trust

Damian Nolan
Clinical Facilitator Intermediate Care
Rapid Access Rehabilitation Service
2nd Floor Abbeystead
Runcorn
WA7 2ED

0151 471 7645

28 May 2008

Dear

Invitation to participate in a research study

I am writing to you with information about a research study that is being undertaken by Mrs Roseline Henry-Nweye as part of a doctorate at Liverpool University. The research has been approved by the ethics committee at the University and agreed by Halton and St Helens PCT

The research is looking at the experiences of people who have been in hospital and then readmitted at a later date. The research is also interested in the experiences of their families and carers. Further information is enclosed.

If you would be interested in taking part in the research please complete the enclosed 'expression of interest' form and return it in the pre-paid envelope.

No information about you or any care you received during your time with the Rapid Access and Rehab Service has been passed to Mrs Henry-Nweye.

Please do not hesitate to contact me should you require any further information.

Kind regards

Damian Nolan

St.Helens Council

Barry Harrison, Team Manager
Reablement and Rapid
Response Team
Park House
55 Higher Parr Street
Fingerpost
St.Helens

WA9 1BP

Contact: Barry Harrison
Tel: 01744 621724
Fax: 01744
barryharrison@sthelens.gov.uk
Our ref:
Your ref:

Re: Invitation to participate in a research study

I am writing to you with information about a research study which is being undertaken by Mrs Roseline Henry-Nweye as part of a doctorate at Liverpool University. The research has been approved by the ethics committee at the University and agreed by Halton and St Helens PCT.

The research is looking at the experience of people who have been in hospital or intermediate care services and are then readmitted at a later date. The research is also interested in the experiences of their families and carers. An information sheet is attached. In the information sheet it talks specifically about people who have been in hospital but Mrs Henry-Nweye is also interested in the experience of people who have received intermediate care services on a number of occasions, for example, the St Helens Reablement and Rapid Response Team.

If you would be interested in taking part in the research please complete the enclosed 'expression of interest' form and return it to Mrs Roseline Henry-Nweye in the pre-paid envelope.

No information about you or the care you have received during your time with the Reablement and Rapid Response Team has been passed directly to Mrs Henry-Nweye.

Please do not hesitate to contact me should you require any further information

Yours sincerely,

B Harrison

Barry Harrison
Team Manager

Halton & St Helens NHS
Primary Care Trust

Honorary Research Contract

between

Halton and St Helens

And

Mrs Roseline Henry-Nweye
University of Liverpool
Division of Primary Care
Whelan Building
Quadrangle Brownlow Hill
Liverpool L69 3GB

Fixed term contract from 09.11.07 to 09.11.10

Signatures

Researcher……….Roseline Henry-Nweye…… Date.14·11·07.

Signed………………………………………………………

Research & Development Officer ……….Kirsty Pine…… Date.9-11-07

Singed.KPine………………………………………………

Effective Date
09.11.07

THE UNIVERSITY
of LIVERPOOL

I M Carter, BSc, PhD, CEng, MIEE, MCMI
Director of Research

Research and Business Services

The Foresight Centre
3 Brownlow Street
Liverpool L69 3GL

Telephone: 0151 794 8723
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Email: i.carter@liv.ac.uk

Ref: SP000240

UOL000223

02/04/07

Dr Andrew Sixsmith
Population Community and Behavioural Science

Dear Dr Sixsmith

I am pleased to confirm that, the University will act as Sponsor under the DoH Research Governance Framework for Health and Social Care for your study entitled "Older people and their carer's perspectives of causes and risk factors of hospital readmissions in Liverpool". In accepting this role the University expects you, as Chief Investigator, to conduct the project in full compliance with the requirements of the Framework so that it is able to meet its obligations as Sponsor.

Having consulted the insurance broker, I also confirm that the University professional indemnity and clinical trials insurances will apply to the project as appropriate. The University does provide cover for non-negligent harm and this must be made clear to prospective participants in the work.

I trust that this statement will enable you to proceed with your project. Please let me know if I can be of any further assistance in this matter.

Yours sincerely,

Cc Head, Population Community and Behavioural Sciences
Ms S Fletcher, Research Administrator, Faculty of Medicine Office

NHS
National Research Ethics Service
Sefton Research Ethics Committee
1 Arthouse Square
61 - 69 Seel Street
Liverpool
L1 4AZ

Telephone: 0151 296 7539
Facsimile: 0151 296 7536

07 June 2007

Mrs Roseline Awhoma Henry-Nweye
PhD. Student
University of Liverpool, Division of Primary Care,
School of Population,Community & Behavioural Sciences
Whelan Building, Quadrangle, Brownlow Hill
University of Liverpool, Liverpool
L69 3GB

Dear Mrs Henry-Nweye

Full title of study:	**Older people and their carers perpectives of causes and risk factors of hospital readmissions.**
REC reference number:	**07/Q1501/51**

Thank you for responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Application	5.3	30 March 2007
Investigator CV		
Protocol	5.3	28 March 2007
Covering Letter		30 March 2007
Interview Schedules/Topic Guides		28 March 2007
Letter of invitation to participant		28 March 2007
Participant Information Sheet		28 March 2007

Participant Consent Form		28 March 2007
Response to Request for Further Information		21 May 2007
Statement of indemnity arrangements		23 March 2007
Summary CV for supervisor		28 March 2007

R&D approval

All researchers and research collaborators who will be participating in the research at NHS sites should apply for R&D approval from the relevant care organisation, if they have not yet done so. R&D approval is required, whether or not the study is exempt from SSA. You should advise researchers and local collaborators accordingly.

Guidance on applying for R&D approval is available from http://www.rdforum.nhs.uk/rdform.htm.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Feedback on the application process

Now that you have completed the application process you are invited to give your view of the service you received from the National Research Ethics Service. If you wish to make your views known please use the feedback form available on the NRES website at:

https://www.nresform.org.uk/AppForm/Modules/Feedback/EthicalReview.aspx

We value your views and comments and will use them to inform the operational process and further improve our service.

07/Q1501/51	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

Peter Owen

Dr Peter Owen
Chair

Email: sue.culshaw@liverpoolpct.nhs.uk

Enclosures: *Standard approval conditions*

Copy to: University of Liverpool
R&D office for NHS care organisation at lead site

Sefton Research Ethics Committee

Attendance at Committee meeting on 25 April 2007

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Adegoke Adejumo	Consultant Anaesthetist	Yes	
Dr Douglas Anglesea	Retired Senior Lecturer in Microbiology	No	
Dr Martin Bamber	Consultant Anaesthetist	No	
Mr John Bridson	Clinical Ethicist	No	
Dr John Brindley	GP	Yes	
Mr D Eccleston	Senior Chief Biomedical Chemist/Manager of Cellular Pathology & Immunology	No	
Ms Gillian Grundy	Rheumatology Specialist Nurse	No	
Ms Patricia Harvey	Hospital Chaplain	Yes	
Mrs Christine Haywood	Manager	No	
Dr Ben Johnson	Consultant Psychiatrist	Yes	
Mrs Margaret Norval	Chief Pharmacist	Yes	
Dr Peter Owen	Chairman	Yes	
Mrs Elizabeth Sinker	Joint Chair	Yes	
Mr Mike Williamson	Consultant Urologist	Yes	
Mr John Wood	Corporate Affairs Manager	No	

Also in attendance:

Name	*Position (or reason for attending)*
Miss Sue Culshaw	REC Co-ordinator