

Self management support amongst older adults: the availability, impact and potential of locally based services and resources

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Contents

Contents	3
Acknowledgements	7
Abstract.....	8
1. Introduction and background to the study	9
1.1 Long term conditions (LTCs) – increase in prevalence; cost to healthcare/society; care transition	9
1.2 Definitions of self care / self management	10
1.3 Influences on older people's attitudes to self care and self management.....	11
1.4 Other sources of support: GPs / other health professionals; support for medicine taking; social capital / support	12
1.5 Purpose and objectives of the current project.....	12
1.6 Structure of the report.....	13
2 Aims and study design	14
2.1 Purpose of the current project.....	14
2.2 Overall study design.....	14
2.3 Aims of mapping phase.....	14
2.4 Aims of questionnaire phase.....	15
2.5 Aims of qualitative interview phase.....	15
2.6 Selection of case study areas.....	17
3. Mapping of case study areas characteristics and services	18
3.1 Aims of mapping phase.....	18
3.2 Method	18
3.3 Results	21
3.3.1 Demographic profile of case study areas (Table three)	21
3.3.2 Deprivation and employment profiles of the case study areas (Table four)	22
3.3.3 Housing tenure (Table five).....	25
3.3.4 Health status of the case study area populations (Table six)	27
3.3.5 Organisation of health, social and support services.....	30
3.3.6 Classification of support services	35
3.4 Discussion.....	39
3.4.1 Why have we taken a case study approach?.....	39
3.4.2 Rationale for selecting case study areas.....	39
3.5 Chapter summary	40
a. North East case study area.....	40
b. London case study area	41
c. North West case study area.....	42
d. South West case study area	42
4. Questionnaire survey	44
4.1 Aims of questionnaire survey.....	44
4.2 Method.....	44
4.2.1 Survey design	44
4.2.2 Questionnaire development.....	44
4.2.3 Questionnaire piloting using cognitive interviewing	46
4.2.4 Sampling method	46
4.2.4 Questionnaire administration.....	47
4.2.5 Coding the questionnaire responses.....	48
4.2.6 Quality control.....	48

4.2.7	<i>Data protection</i>	48
4.2.8	<i>Data analysis</i>	49
4.3	Results	50
4.3.1	<i>Response rates to questionnaire</i>	50
4.3.2	<i>Non respondent analysis</i>	51
4.3.3	<i>Characteristics of questionnaire survey respondents</i>	52
4.3.4	<i>Prevalence of LTCs and demographic characteristics of the survey respondents</i>	53
4.3.5	<i>Prevalence of LTCs and willingness to self manage</i>	61
4.3.6	<i>Service and support use amongst those reporting LTCs</i>	65
4.4	Chapter summary	79
5.	Qualitative study – older people and carers	80
5.1	Aims	80
5.1.1	<i>Aims of interviews with older people</i>	80
5.1.2	<i>Aims of interviews with carers</i>	80
5.2	Method	81
5.2.1	<i>Older people with LTCs and their carers</i>	81
5.2.2	<i>Data analysis</i>	82
5.3	Results	84
5.3.1	<i>Description of LTCs</i>	90
5.3.2	<i>Impact of LTCs</i>	90
5.3.3	<i>General attitudes towards responsibility for health</i>	95
5.3.4	<i>General experiences of care</i>	98
5.3.5	<i>Self care and self management activities</i>	100
5.3.6	<i>Factors influencing the decision to self manage</i>	105
5.3.7	<i>Barriers and facilitators to self care and self management</i>	106
5.3.8	<i>Current experiences of support</i>	112
5.3.9	<i>Willingness to seek support</i>	113
5.3.10	<i>Ease of obtaining support and services</i>	114
5.3.11	<i>Acceptability and usefulness of advice and support</i>	117
5.3.12	<i>Awareness of local support providers</i>	119
5.3.13	<i>Carers' awareness of support options</i>	120
5.3.14	<i>Beliefs about future support needs</i>	121
5.3.15	<i>Wider social networks</i>	121
5.4	Chapter summary	124
6.	Qualitative study – service providers and commissioners	127
6.1	<i>Aims of interviews with service providers and commissioners</i>	127
6.2	Method	127
6.2.1	<i>Data analysis</i>	128
6.3	Results	129
6.3.1	<i>Meaning of self management and self care</i>	131
6.3.2	<i>Beliefs about the usefulness and effectiveness of self management</i>	132
6.3.3	<i>Perceptions of service users' expectations</i>	139
6.3.4	<i>Background and rationale of self management support and services across the case study areas</i>	141
6.3.5	<i>Process of identifying need for services</i>	153
6.3.6	<i>Challenges to providing services</i>	157
6.3.7	<i>Challenges to promoting services</i>	160
6.3.8	<i>Role of service in relation to other support options</i>	164
6.4	Chapter summary	169
7.	Discussion	171
7.1	<i>Questionnaire survey</i>	171

7.1 .1. Prevalence of LTCs, demographic factors, health outcomes, social capital and willingness to self manage.....	171
7.1.2. Service and support use amongst older people with LTCs	172
7.2 Qualitative study: interviews with older people and carers	173
7.2.1 Influences on participants' beliefs about support needs	173
7.2.2 Impact of LTCs on participants and their everyday lives.....	174
7.2.3 Factors influencing participants' decision to self manage.....	175
7.2.4 Potential providers of support for self management	176
7.2.5 What should good support for self management look like?.....	178
7.3 Qualitative study: service providers and commissioners	179
7.3.1 Beliefs about self management	179
7.3.2 Beliefs about useful self management support and advice for older people	180
7.3.3 Beliefs about older people's willingness to get involved in self management	182
7.4 Methodological discussion	182
7.4.1 Mapping work.....	182
7.4.2 Questionnaire survey.....	183
7.4.3 Qualitative interview studies.....	184
Recruitment and sampling	184
Interview process	185
8. Conclusions and recommendations	186
8.1 Self care versus self management.....	186
8.1.1 Recommendations	187
8.2 Influences of the characteristics of older people on their expectations of health and of care and support	188
8.2.1 Recommendations	189
8.3 Applicability of existing self care / self management support to older people with LTCs.....	190
8.3.1 Recommendations	190
8.4 Role of the GP in providing self care and self management support	191
8.5 The interface between GP and allied primary health care services and other forms of LA and PCT funded care	192
8.6 The development of PCTs and LAs as integrated service commissioners	192
8.7 Self care and medicines taking in later life.....	193
8.7.1 Recommendations	193
References	195
Appendix one Report of questionnaire development	198
Background	198
Characteristics of interviewees	200
Changes to questionnaire draft one to produce draft two.....	201
Changes to questionnaire draft two to produce draft three	201
Changes to questionnaire draft three to produce draft four	202
Changes to questionnaire draft four to produce final questionnaire	202
Appendix two: Questionnaire administration	216
2a. Questionnaire survey covering letter.....	216
Appendix three: Topic guide for qualitative study of older people	234
Background	234
Accessing support in general and for self management	234
Meaning and experience of self care / looking after yourself	235

Appendix four: Topic guide for qualitative study of carers237

<i>Introductions and reiteration of the study's background and purpose.....</i>	<i>237</i>
<i>Background</i>	<i>237</i>
<i>Role as a carer</i>	<i>237</i>
<i>Accessing support for their caring role and for their general health</i>	<i>238</i>
<i>Accessing support for their caree</i>	<i>238</i>
<i>Self management / self care support</i>	<i>239</i>

Appendix five: Topic guide for qualitative study of service providers and commissioners.....240

<i>Background</i>	<i>240</i>
<i>Description of the support / service they provider</i>	<i>240</i>
<i>Self management / self care support</i>	<i>240</i>
<i>Experiences of providing the support service</i>	<i>241</i>
<i>Role of service in relation to other support options</i>	<i>241</i>
<i>Background</i>	<i>242</i>
<i>Description of the support / service they commission and the commissioning process</i>	<i>242</i>
<i>Self management / self care support</i>	<i>242</i>
<i>Beliefs about services to support self management / self care</i>	<i>243</i>

Appendix six: Qualitative study documentation244

<i>i. Information sheet</i>	<i>244</i>
<i>ii. Consent form</i>	<i>248</i>

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Abstract

Background

Supporting the self management of Long Term Conditions (LTCs) is becoming a key issue for older people as the proportion of older people in the population increases and as any added years are not necessarily healthy ones. For older people, local resources and support services may be of particular importance.

Aim

To investigate the self management experiences and expectations of older people, and to compare these against the availability of support from locally based services within four areas of England.

Method

Within each area we carried out the following work

- a) Mapped the socio-demographic, health status and service organisation;
- b) Questionnaire survey to a random sample of 625 older people to explore LTC prevalence, general health, patient activation, demographics and service use;
- c) Qualitative studies of service providers and commissioners to explore their experiences of providing support and of older people and carers to explore their experiences of obtaining support.

Results

The questionnaire survey response rate was 40%. The prevalence of LTCs was 65% with arthritis being the most prevalent condition (53%). Those with multiple LTCs had decreased confidence in self management and therefore sought help from a wider range of sources. Influences on people's support needs included: expectations of health in later life; beliefs about responsibility for health and beliefs about self care versus self management. When there was mutual trust GPs were most effective at providing patients with self management support. Pharmacists were also valued due to the large number of medications taken by many of those with LTCs; improving medicines management was considered to be particularly important for older people. Participants were reluctant to obtain support from social services and were often unaware of the voluntary sector support available. Across all interview groups (service providers, commissioners, older people and carers) there was no consensus regarding the value of the Expert Patients Programme.

Conclusions

Older people's perceptions and everyday practices should be taken into account when developing new policy initiatives and services to increase their relevance. We found that deprivation was associated with serious difficulties in promoting, providing and accessing self management support. At the same time, in areas with high levels of social and ethnic diversity there was often a wide range of small scale services available. Better coordination between services is needed, which underlines the importance of joint health and social care commissioning and cross sector working. General Practice may be particularly relevant in developing this coordination as they are considered by older people to be key to their care and self management.

1. Introduction and background to the study

1.1 Long term conditions (LTCs) – increase in prevalence; cost to healthcare/society; care transition

Supporting self care, and in particular the self management of LTCs, have become major issues in health policy in recent years (Department of Health 2006a; Department of Health 2006b). The original NHS Plan (Department of Health 2000) and subsequent National Service Frameworks (NSFs) have placed considerable emphasis on the individual, and their families or carers, taking greater personal responsibility for health. This approach was reinforced by the Wanless Reports (Wanless 2002; Wanless 2004) where increased investment in health services was seen to be optimal only in the circumstances of a 'fully engaged scenario'. As Wanless put it: 'Individuals are ultimately responsible for their own health'..... and it is the aggregate actions of individuals, which will ultimately be responsible for whether or not such an optimistic scenario as 'fully engaged' unfolds' (Wanless 2004).

It is clear that an ageing society (that is, a society with a secular trend towards an older age population structure) provides a particular context for developments in health care and self management. The objective of promoting independent living among older people and increasing well being and quality of life all point in the same direction (Department of Health 2001; Department of Work and Pensions 2005). It is arguable that high quality health and social services cannot hope to match the needs and expectations of an ageing society without the simultaneous development of self care and self management capacities within the population. Alongside health policy, initiatives directed at older people have thus become major features of governmental activity. A National Service Framework for Older People was launched in 2001 (Department of Health 2001), and follow up reports by Ian Philp (Philp 2004; Philp 2006), National Director for Older People from 2000 to 2008, emphasised the question of managing LTCs in later life and the challenges these pose to service providers in supporting individuals and their families. Other programmes such as Sure Start to Later Life (2006) underlined the need to see the older person in a wider context (Social Exclusion Unit: Department of Communities 2006). Such issues as personally held budgets for managing care were set against the need for improving 'social relations' (here meaning leisure, learning and volunteering), the home (loneliness and accident prevention) and the local area (the 'social capital' of safety in relation to crime and good local transport). The aim of this approach was to provide more personalised services and 'produce economic returns', i.e. savings on the public purse (p9). The paper continued: 'Put another way, as our society ages, the costs of the failure of services to meet these challenges will be too big to ignore' (ibid).

The size of the problem underlies and underlines this argument. For the first time in British history those aged 60 and over now constitute over 20 per cent of the population, and, as is well known, the older age groups within later life populations are growing rapidly (Government Actuaries Department 2006). The enormous achievements of

reducing early deaths and of postponing rapid decline in old age have combined to increase average life expectancy, both at birth and in later years. At the same time, added years do not always mean added healthy living. As the ONS has reported: 'the expected number of years spent in poor health in Great Britain rose from 6.4 to 8.8 for men between 1981 and 2002, and from 10.1 to 10.6 for women' (Office for National Statistics 2007). The prevalence of limiting long term conditions (LTCs) rises with age. By the age of 75 and over some 40 per cent of men and women report suffering from such conditions (Office for National Statistics 2007). The presence of considerable numbers of older people living with LTCs poses challenging problems, not only for themselves and their families, but for the formal agencies as well.

At the same time, it is clear that the older population is highly diverse and the age group '60 and over' in a country such as Britain comprises a wide range of individuals, backgrounds and cultural dispositions. Older people constitute a varied population in terms of their health status, as well as their origins. Collectively, however, they are the main users of health and social services. In primary care, according to the NHS Improvement Plan, about 80 per cent of GP consultations are for patients with LTCs (Department of Health 2004). By the beginning of the 21st century those aged 65 and over were responsible for 40 per cent of the NHS budget and some 50 per cent of social services expenditure (Department of Health 2001). In secondary care the figures are even higher; 'almost two thirds of acute and hospital beds are used by people over 65' (ibid). In its review of services for the elderly, the National Service Framework (Department of Health 2001) identified four areas of action for the NHS and local authorities to promote a healthy active life: prevention or delay of onset; reduction of the impact of illness and disability; identification of barriers to healthy living; and partnership to develop more healthy communities. These are major challenges and, as far as health is concerned, involve radical change in the orientation and structure of services.

Under the pressures of demographic transition (an ageing society) and epidemiologic transition (decline in infections and rise in chronic disorders) all advanced societies - together with many developing ones - face the necessity of fashioning new forms of health care along the lines set out above. The combination of investment in formal services with promoting shared decision-making, choice and self management in LTCs has been called 'care transition' (Bury & Taylor 2008; Taylor & Bury 2007). This term signals a radical shift in thinking about health and health care and extends earlier actions to encourage a more 'consumerist' attitude to care on the part of patients, to one of a revived version of 'co-production' where health is managed by individuals, carers, voluntary bodies and formal services in new forms of partnership. Self management of LTCs, the focus of the project reported on here, has an important place on this new terrain.

1.2 Definitions of self care / self management

We should note that in this report we give preference to the term 'self management' in order to refer to those actions individuals and others take to mitigate the effects of a long term condition (or LTCs) and to maintain the best possible quality of life. 'Self care' refers to a wider set of behaviours which both the healthy and the not so healthy take to

prevent the onset of illness or disability, and, again to maintain quality of life. The distinction is not a hard and fast one – our focus on LTCs, and on some of the interventions designed to tackle them, has led us to give some prominence to self management issues.

1.3 Influences on older people's attitudes to self care and self management

In speaking of individuals and self management we need to be aware of the settings in which people live, and the impact these can have on behaviour. The four goals of the NSF for Older People (Department of Health 2001), and other initiatives such as Sure Start to Later Life (Social Exclusion Unit: Department of Communities 2006), outlined above, are linked to the successful provision of support for older people in managing their health. This means in practice developing integrated health and social care, partnerships with the voluntary sector and the mobilisation of community resources such as the local pharmacy. At the same time, it is widely recognised that such goals are not easily met. Kennedy *et al* (Kennedy, Rogers, & Bower 2007) argue that a 'whole systems approach' to self care and management requires changes at all levels of the health and social care services. It also means changes in expectations and behaviour amongst older people which are not always in line with policy goals.

Previous research by the Picker Institute (Ellins & Coulter 2005) found that knowledge, confidence and skills for self management decrease with age. In part this is to be explained by the rise in poor health as later life proceeds. Older people rate their health as lower than those in younger age groups, and are more likely to be living with more than one LTC. Moreover, older people are more likely to want to receive health information, support and advice from face-to-face encounters, especially with their general practitioner, rather than from outlets such as the Internet. Unsurprisingly, it was found in the Picker survey, that reliance on technology for health information was far lower among those aged 75 and over than those at younger ages.

Reviews of the research literature (Coulter & Ellins 2006; Newbould, Taylor, & Bury 2006) have shown that there has been a rapid increase in policy guided activities and interventions related to self management in LTCs in recent years. Some research in the area has taken the shape of trial based studies and other evaluations of outcomes. In England the Expert Patients Programme (EPP - based on a six week course of goal setting and skills training) has been shown to be a cost effective intervention in raising levels of confidence (Kennedy & Reeves 2007) although the effect sizes of the outcomes of the intervention were not large. A qualitative evaluation by the same team indicated that whilst many participants on the EPP were positive about their experience, few could specify how it had made a difference to their LTC (EPP evaluation team 2005).

Despite the growth in international research, important questions remain unanswered. There are few studies which explore lay people's attitudes towards active involvement in self managing their condition, or the implications of self management for their everyday lives. In addition, much of the research into strategies to support self management consists of formal evaluations, in which differences with real-world settings may be substantial. Moreover, the majority of studies are of interventions that comprise self

selected participants, who are likely to be already motivated and able to take on a more active role. Consequently, relatively little is known about self management in everyday settings, or the effects (both positive and negative) of personal, social and health system factors. The research reported here aims to begin filling these gaps in our knowledge.

1.4 Other sources of support: GPs / other health professionals; support for medicine taking; social capital / support

For older people it seems clear that resources and services in local areas are of particular importance (Joseph Rowntree Foundation 2004). The lack of integration of initiatives such as the EPP into local primary care services may be limiting their usefulness for this age group, at least among the 'oldest old'. It has also been found that help and guidance from health professionals, in order that patients can monitor and manage their health, is often lacking (Coulter & Ellins 2006). Those factors that act as barriers to developing such support need to be better understood. This is especially important given the value older people place on key relationships such as that with their GPs. Whether alternative sources of support (for example, with community pharmacists in the important area of medicines use) are becoming more acceptable also needs to be understood.

It needs to be recognised finally, that local NHS and social care providers are not the only source of community support for older people with LTCs. Social capital theories draw attention to the importance of social networks (family, friends and neighbours) as well as the membership and/or involvement in local organisations and activities (Halpern 2006). Organisations such as Age Concern and Help the Aged operate in many areas on the boundaries of informal and formal support. Neighbourhood influences on health can include economic conditions, service provision, housing and safety (Cattell 2001). The importance of these factors, their configuration in specific areas, and their salience for particular individuals, might well influence the way in which people manage health problems and whether appropriate support is available to them (Shaw & Dorling 2004). Research has shown how levels of social capital may be linked to beliefs and actions surrounding self management, and their outcomes. Intervention studies have pointed to the role of social support in chronic illness self management (van Dam 2005). There is still much to be explored in the relationship between self management, local contexts and service provision.

1.5 Purpose and objectives of the current project

Against the backcloth of the above considerations the project reported here was designed to investigate the self management experiences and expectations of older people, and to examine the relationship between these and the availability of support from locally based services and community resources.

The key objectives of the research were to:

1. Document older people's attitudes towards self-management, their existing self-management practices and desired levels of personal involvement in the care of their LTCs;

2. Measure awareness, use and experiences of community based self-management support, and identify and describe areas of unmet need;
3. Explore how the practice and experience of self-management is influenced by local support services and resources: including NHS providers and facilities, other agencies and organisations, and informal networks and resources within the community;
4. Assess the nature of integration and cooperation among local service providers, and examine whether and how patients get an appropriate and acceptable mix of support to manage their LTCs;
5. Analyse variations in the support available to people with LTCs, and identify factors that act as facilitators or barriers to supported self-management;
6. Consider how support can be effectively targeted and delivered to under-served groups, with particular reference to older and socially disadvantaged persons.

1.6 Structure of the report

The report begins with a summary of the relevant research based literature and policy in this area, which provides a detailed background to the study rationale (Chapter one), the aims of the study are then described and discussed (Chapter two). In chapter three we describe the case study mapping work and in chapter four the questionnaire survey of older people. For our analyses of the questionnaire survey, we have described the characteristics of the survey respondents overall, and those with LTCs. We have also explored the factors likely to influence support use amongst those with LTCs.

In the next two chapters, we report the aims, methods and findings from our qualitative studies of older people and carers (Chapter five) and service providers and commissioners within each case study area (Chapter six). In chapter seven, we have discussed the methodology used within the study and our findings from all of the study elements. Finally, within chapter eight we have discussed the implications of our findings for policy, practice and further research. We have also provided the reader with detailed appendices for the study, detailing all methods and approaches used for data collection.

2. Aims and study design

2.1 Purpose of the current project

The project was designed to investigate the self management experiences and expectations of older people, and to examine the relationship between these and the availability of support from locally based services and community resources in four case study areas in England.

2.2 Overall study design

The research was conducted in four case study areas that were selected to represent diversity in terms of deprivation level, ethnicity, age distribution, rural or urban location and prevalence of LTCs. The case study areas were coterminous with pre-2007 PCT boundaries. We selected case study areas in the

- North West
- North East
- South West
- and London

There were three elements to the study:

1. Mapping of case study area demographic and health status characteristics, organisation of care and the availability of local support services for older people in general and for those with LTCs;
2. Postal questionnaire survey to a random sample of the over 60s in each case study area;
3. Qualitative interviews with service providers and commissioners, older people and their carers within each case study area.

2.3 Aims of mapping phase

- To describe the case study areas in terms of their demographic and health status characteristics;
- To map the availability, scope and type of locally available support for people with LTCs;
- To provide a sampling frame for a more detailed investigation of local self management support services.

2.4 Aims of questionnaire phase

- To investigate the prevalence and type of LTCs in the sample of respondents;
- To investigate the extent to which older people are willing to engage in self care and self management;
- To investigate older people's attitudes and beliefs towards the self management of LTCs;
- To investigate whether older people's attitudes and beliefs vary according to the type and complexity of LTCs that they are living and coping with;
- To investigate the use of services which support self care;
- To investigate whether, and how, the use of, and perceived needs for, support services vary according to age, gender, ethnicity, social capital, number and type of LTCs, quality of life, willingness to engage in self care activities, and case study area.

2.5 Aims of qualitative interview phase

Interviews with older people

- To explore older people's attitudes towards, and preferences for, an active role in self management of LTCs;
- To investigate older people's awareness of, and need for, information and support services focused on LTCs;
- To identify the factors that impede or facilitate self care and self management and obtaining appropriate support such as:
 - The extent to which attitudes are shaped by perceived benefits or shortcomings of taking a more active role in healthcare;
 - The extent to which older people integrate self management into their everyday lives and the barriers they face;
 - Older people's experiences of receiving services across organisational boundaries;
 - Difficulties faced by older people in identifying and gaining access to the help they require;
 - Involvement with existing support and social networks in the local community.

Interviews with carers

- To explore attitudes towards, and preferences for, an active role in self management in those who care for another person;
- To explore how carers cope with caring for their own and for others LTCs;
- To identify factors that impede or facilitate self management and obtaining appropriate support for them and/or the cared for person;
- To explore differences between self management by an individual and care given by carers.

Interviews with commissioners and service providers

- To explore the organisations' perspectives on the principle and promotion of self management and greater responsibility for health;
- To explore interviewees' experiences of planning and delivering self management support;
- To explore the challenges that interviewees face in identifying local support needs and providing appropriate services;
- To explore interviewees' attitudes towards, and practice of, working in partnership with other local service providers;
- To explore the extent to which a coordinated approach is pursued and if not, the barriers to pursuing a coordinated approach with other agencies;
- To explore the organisations' future plans for the area in terms of service provision and service development.

2.6 Selection of case study areas

We examined a range of different data sources to identify a short list of potential case study areas representing a range of deprivation levels, ethnicities, age distributions, rural or urban locations and LTC prevalence. Case study areas were chosen using data from the 2001 census (Office for National Statistics 2009a), Office for National Statistics 'Neighbourhood Statistics' website (Office for National Statistics 2009b), and other locally available data on the shortlist of case study areas.

The case study areas were selected for the following reasons:

Table one: Prevalence and number of LTCs by gender

AREA	RATIONALE
North West	Affluent ; urban; relatively low percentage of older people medium prevalence of LTCs
North East	Deprived; rural; low ethnic diversity high prevalence of LTCs
South West	Affluent; rural; high population of older people high prevalence of LTCs
London	Deprived; urban; high ethnic diversity young population

3. Mapping of case study areas characteristics and services

3.1 Aims of mapping phase

- To describe the case study areas in terms of their demographic factors, deprivation, health status and organisation of care;
- To map the availability, scope and type of locally available support for people with LTCs;
- To provide a sampling frame for a more detailed investigation of local self management support services.

3.2 Method

To understand the context within each case study area, we collected data on the socio-demographic and health status of the local population. For example, age and gender profiles, ethnicity, deprivation indices, home ownership data and prevalence of LTCs. We also collected information on benefit claims and the percentage of unpaid carers.

We developed a snapshot of the organisation of health and social care within each case study area to gain a greater understanding of how self care and self management services might relate to the provision of health and social services within each case study area. For example, we collected data on the number of general practices, dentists, pharmacies and hospitals, and on the availability of care homes, or retirement accommodation schemes.

More detailed data was collected on the general health of older people within each area and on the local services to support self management. This data was collected to increase our understanding of the support services available within each case study area, and to enable us to compare the services that were reported to be available, with what participants reported using in the questionnaire survey.

Finally, we used the data collected to provide a sampling frame for the service provider and commissioners interviews (section five). We collected the following information on services: contact details; service type; details of service offered; funding source; referral/access to service; links with other agencies. We have not included the full details of the services identified within each area within this report to preserve the confidentiality of the case study areas (Although this information is available on request). The identified services were then categorised according to whether they were disease specific, generically focused, lay or professionally led or providing support for carers.

We used multiple data sources for the service mapping stages which are described in table two. Where necessary we also used telephone calls to obtain more information.

Different sources of data were used for different case study areas as not all sources held the same or same detail of, information for each area.

Table two: Data sources for service and case study area mapping

Demographics and health status	
Community health profiles	www.communityhealthprofiles.info/index.php (Association of Public Health Observatories 2009) The profiles provide an overview of population health in local authority areas across England, using data that is drawn primarily from local and national government sources.
English indices of deprivation	www.communities.gov.uk/publications/communities/englishindices These indices provide data on the deprivation level within each case study area.
Public health observatories	Each public health observatory website provides regional public health information North West Public Health Observatory www.nwph.net (North West Public Health Observatory 2009) North East Public Health Observatory www.nepho.org.uk (North East Public Health Observatory 2009) South West Public Health Observatory www.swpho.org.uk (South West Public Health Observatory 2009) South East Public Health Observatory www.sepho.org.uk (South East Public Health Observatory 2009)
Organisation of health and social services	
Case study area PCT websites	These websites provide information on services, service providers, commissioning staff, and access to policy documents and PCT reports
NHS Choices website	www.nhs.uk/Pages/homepage.aspx (NHS Choices 2009) Provides a directory of NHS services across the UK
Case study area local council websites	Provides information on health and social care services and carer support. We have not included details of these websites to preserve the confidentiality of our case study areas.
Care Quality Commission	www.cqc.org.uk/ (Care Quality Commission 2009) Independent commission set up by the government to improve health and social care. The website contains a directory of health and social care services

Provision of self care and self management support	
Expert patient programme	www.expertpatients.co.uk This site provides information on the Expert Patient Programme, a national self management programme
Medical research charities	Many of the medical research charities run local support groups for people with the relevant conditions Diabetes UK – www.diabetes.org.uk Arthritis Care – www.arthritiscare.org.uk/inyourarea Asthma UK- www.asthma.org.uk British Lung Foundation – www.lunguk.org British Heart Foundation – www.bhf.org.uk Stroke Association – www.stroke.org.uk
Older people's charities	Age Concern and Help the Aged - www.ageconcern.org.uk www.helptheaged.org.uk These sites provide information on the support and services offered by these charities in areas across the country
National Council for Voluntary organisations	www.ncvo-vol.org.uk - Contains details of all voluntary organisations within the UK
Carers support	
Carers' charities	Crossroads – National charity offering support services to carers- www.crossroads.org.uk Carers' information – Information, support and advice for carers - www.carersinformation.org.uk Carers.gov – Government site providing support for carers - www.carers.gov.uk Care UK – Information, support and advice for carers - www.carersuk.org/home

3.3 Results

3.3.1 Demographic profile of case study areas (Table three)

Throughout this report, the case study areas will be presented in the following order: North East; London: North West and South West.

North East

The North East case study area has a population of 93,993, of which 40% are aged between 30 and 65 years old and 18% aged 65 years and older. In this area, the percentage of women aged 75 years and older is twice that of men. The gender distribution is 48% male and 52% female. The percentage of white British within this area is 98.7% compared to 87% in England as a whole. Therefore, the area has a very low ethnic diversity score of 0.02. This score means, that there is a two percent chance that two people chosen at random in this area would belong to different ethnic groups.

London

The London case study area has a population of 210,009, of which 48% are aged between 18 and 44 years and just 9.5% are aged 65 years or older. The gender distribution in the area is 48% male and 52% female. The area is very ethnically diverse, as just 60% of the population are white, 24% are black (11% black African, and 9% black Caribbean), 10% are South Asian and 1% are Chinese.

North West

The North West case study area has a population of 151,204, of which 56% are aged between 18 and 44 years, and 23% of the population are aged 65 years and older. The gender distribution in the case study area is 48% male and 52% female. The percentage of white residents within the area is 98.3%. Therefore again, this is a relatively ethnically homogenous area.

South West

The South West case study area has a population of 92,360, of which 51% are aged 45 years and older and 23% are aged 65 years and older. The gender distribution within the area is 48% male and 52% female. As with the North East, the area has a low ethnic diversity score of 0.02. This is evidenced by the high percentage of white British in the area, almost 10% higher than the England average.

Comparison of case study area demographics

The London case study area had the largest population, followed by the North West, North East and then the South West. The oldest population was in the South West, followed by the North West and the North East, with the youngest population being in the London area. The most ethnically diverse area was the London case study area and the other case study areas were ethnically very homogenous.

All demographic data was obtained from the Office for National Statistics Neighbourhood Statistics website. (Office for National Statistics 2009b)

Table three: Comparison of age ranges of case study areas

Age range	% of North East case study population	% of London Case study population	% of North West case study population	% of South West case study population
0 – 4	7	8	5	5
5 – 15	14	15	13	13
16 – 17	3	3	2	3
18 – 29	18	21	13	9
30 – 44	20	28	22	19
45 - pensionable age	20	17	21	28
Pensionable age – 74	12	5	15	11
75 – 84	5	3	6	9
85+	1	1	2	3

3.3.2 Deprivation and employment profiles of the case study areas (Table four)

North East

The Index of Multiple Deprivation (IMD) 2004 reports a measure of deprivation based on the following factors; unemployment, incapacity and childcare benefits; educational achievement; hospital admission; access to services; crime rates; housing condition; and air quality (Department of Communities 2004). A lower IMD score indicates a more socially deprived area. The rank of average scores of these factors was 8 for the North East Case Study area. This indicates that this area is the 8th most deprived area in England. The area is so deprived that 68% of the population live in the most deprived super output areas in England.

Twenty nine percent of the working age population are claiming key benefits, compared with 14% in England as a whole, and 31% are long term unemployed compared to 30% in England. Amongst the over 60s, 19% of the population live in income deprived households. The area has a higher economically inactive rate compared to the England average.

According to the Audit Commission website, of those who are working 25% work in manufacturing industries; 7% in construction; 19% in distribution and hotels and restaurants; 25% in public administration, education and health and 72% in the service sector. The traditional industry within the area was coal mining (Audit Commission 2009).

London

The IMD score for the London case study area is 2. Therefore, this area is one of the most deprived in England and so all of the wards within this area are within the top 10% of the most deprived in England. The London case study area has a relatively high number of people of working age claiming a key benefit at 23%, compared with 14% of England as a whole.

One fifth of the working aged population is economically inactive compared to one quarter in London as a whole. The London case study area has a higher long term unemployment rate compared to the England average.

The area has a long history of suffering relative economic disadvantage compared to nearby areas. However, recently its economy has grown quickly, particularly within the service sector. Within the area, real estate, renting and business activities are the largest employers, followed by retail and health and social work (Audit Commission 2009).

North West

The IMD score for the North West Case study area was 178. Therefore, this area is the 178th most deprived area in England. This is evidenced by the percentage of the population who claim a key benefit being 6.9% compared to 14% of the English population. The percentage of long term unemployed is also lower than the England average.

South West

The IMD score for the South West Case study area was 207. This indicates that it is a relatively affluent area in England. The case study area has a relatively low number of people of working age claiming a key benefit, as 11% of its residents make a claim, compared with 14% of England as a whole. The percentage of long term unemployment is lower than the England average.

Deprivation data and employment data were obtained from the Audit Commission website (Audit Commission 2009) and data on unemployment and benefits were obtained from the Office for National Statistics Neighbourhood Statistics website (Office for National Statistics 2009b).

Comparison of case study areas

The London case study area was overall the most deprived area, followed by the North East. Both the North West and South West case study areas were relatively affluent in comparison to the other areas. Despite the age range of the population the highest percentage of economically active residents was in the South West case study area. In all of the other case study areas the percentage of economically active residents was lower than the England average of 61%. The highest percentage of economically inactive residents was in the North East case study area at 28% and the lowest in the North West case study area at 10% compared to the England average of 15%.

Table four: Employment status across the case study areas

Aged 16-74 years	% of North East Case study population	% of London Case study population	% of North West Case study population	% of South West case study population	% England
Economically active (seeking work)	48	44	47	60	61
Economically active (seeking work): unemployed	4	7	2	2	3
Economically inactive (not seeking work) (excluding retired and student)	28	21	10	12	15
Long term unemployed	31	32	27	26	30

3.3.3 Housing tenure (Table five)

North East

The majority of residents in the North East area (38%) are property owners with a mortgage, which is similar to the percentage in England as a whole at 39%. Although, a slightly lower proportion own their homes outright compared with the rest of England. A notably higher percentage of the case study area residents rent their houses from the Council compared with the England average; although figures for renting from Housing Associations and privately are lower than average.

London

The majority of residents in the London case study area rent their properties from the council (30% compared to 13% in England overall). The area also contains the lowest number of homes owned outright across the case study areas (10% compared to 29% in England overall).

North West

The majority of residents in this area are property owners with a mortgage. The proportion of owners with a mortgage is much higher than the figure for England as a whole (46% and 39% respectively). A notably lower percentage of case study area residents rent their houses from the council compared to the England average of 13%.

South West

The majority of residents (41.1%) in this case study area own their property outright, a higher proportion than the England average. The percentage of the population who own their property with a mortgage (30.6%) is lower than the England average of 38.9%. A very low percentage of the population rent their home from the Council compared to the England average. All data on housing tenure was obtained from the Office of National Statistics Neighbourhood Statistics website (Office for National Statistics 2009b).

Comparison of case study areas

Across the case study areas, the lowest percentage of households owning their property outright was in the North East at 10%, and the highest percentage was in the South West at 41% compared to the England average of 29%. The North West had the highest percentage of properties that were owned with a mortgage at 31%, compared to the London area which had the lowest percentage at 21%, and 39% in England overall. The highest percentage of houses rented from the council was in the London case study area, at 30% compared to the England average of 13%. The lowest percentage of houses rented from the council was in the South West case study area at 1%.

Table five: Housing tenure across the case study areas

	% of household s in North East Case study area	% of household s in London case study area	% of household s in North West case study area	% of household s in South West case study area	% of household s in England
Owens outright	25	10	29	41	29
Owens with mortgage	38	21	46	31	39
Shared ownership	0.2	2	1	1	1
Rents from Council	26	30	6	1	13
Rents from Housing Associatio n	4	19	8	4	6
Rents privately	4	15	1	9	9

3.3.4 Health status of the case study area populations (Table six)

General health and healthy living

North East

Life expectancy within this area is below the England average, with males living until 74 years compared with 77 years in England, and females living until 78 years, compared with 81 years in England. In terms of healthy lifestyles, many more people smoke and binge drink compared to the England average. In addition, fewer people eat healthily and are physically active compared to the rest of England. The rates of obesity are higher in the region, as are the death rates attributable to heart disease and stroke. Finally, the percentage of people who report feeling "in poor health", is almost double that of the England average.

London

Life expectancy for men within this area is below the England average, with males living 75 years compared with 77 years in England. Life expectancy for females is equivalent to the England average. In terms of healthy lifestyle, fewer people smoke and binge drink than the England average and more people are physically active than the England average. The percentage of people who are obese is lower than the England average. However, mortality due to stroke and heart disease, and the percentage of people feeling in poor health is higher than the England average.

North West

Life expectancy for male residents is 78 years and for females is 82 years. This is slightly higher than the England average of 77 years for men and 81 years for women. In terms of healthy lifestyle behaviours, the case study area residents are similar to the population of England as a whole in terms of smoking, binge drinking, healthy eating and physical activity levels. The mortality rate attributable to heart disease and stroke is less than the England average, as is the proportion of people reporting mental health problems.

South West

The life expectancy of people in this case study area is higher than the England average: males live until 79 years of age, compared with the England average of 77 years; females have a life expectancy of 83 years, compared with the England average of 81 years. In terms of healthy lifestyle behaviours, the case study area residents are less likely to smoke, binge drink, to be obese, to be in poor health and to claim incapacity benefit than the England average, and they are more likely than the England average to eat healthily and to be physically active.

Health status data was obtained from the Community Health Profiles for each of the case study areas (Association of Public Health Observatories 2009).

Comparison of case study areas

In terms of healthy lifestyle behaviours, the least healthy area was the North East. Within this area the percentage of the population who reported smoking, binge-drinking, who were obese and who felt that they were in poor health was highest, and higher than the England average. Rates of physical activity were also lowest within this area. The

healthiest case study area was in the South West. Within this area, residents were less likely to smoke, binge drink, be obese, to feel in poor health and to die from heart disease or stroke. They were also more likely to eat healthily.

Table six: Health status across the case study areas

	North East case study area	London case study area	North West case study area	South West case study area	England average
% population who smoke	37	25	23	18	26
% population who binge drink	24	14	23	11	18
% population who eat healthily <i>5+ portions fruit & veg daily</i>	14	27	23	29	24
% population who are physically active	9	13	14	12	12
% population who are obese	25	18	21	19	22
Mortality attributable to heart disease & stroke <i>Rate per 100,000</i>	130	121	76	66	91
% total population not in good health	17	11	8	8	8
% of total population on incapacity benefit	13	8	11	11	4

Prevalence and nature of LTCs

North East

he percentage of the case study area population with LTCs was 22% which is 4% higher than the England average of 18%. Within this area, over half of all households contain at least one person who has a LTC.

London

The percentage of the case study area population with LTCs is 18% which is equivalent to the England average. The percentage of households within this area which contain at least one person with a LTC is 34%.

North West

The percentage of the case study area population with LTCs is 17% compared to the England average of 18%. The percentage of households within this area which contain at least one person with a LTC is 32%.

South West

The percentage of the South West case study area with LTCs is 19% compared with the England average of 18%. The percentage of households within this area which contain at least one person with a LTC is 34% which is equivalent to the England average. The prevalence of LTCs in the South West case study population is higher than the England average, in particularly the prevalence of hypertension, asthma and cancer, possibly reflecting the older age group in the area.

All data on the prevalence and nature of LTCs was obtained from the Office for National Statistics Neighbourhood Statistics website (Office for National Statistics 2009b).

Comparison of case study areas

The highest percentage of LTCs was reported in the North East case study area (22%), whereas the lowest was reported in the North West area (17%). The percentage of households containing at least one person with a LTC was highest in the North East case study area where over half of the households contained someone with a LTC compared to the England average of 34%.

3.3.5 Organisation of health, social and support services

Health services (Table seven)

The London case study area had the highest number of general practices at 51, and the North East case study area had the lowest number of general practices at 13. The highest average list size was in the North East area, followed by the London area. The South West and North West areas had similar average list sizes.

Walk in centres were available in London and in the North East. Finally, there was some variability in the number of pharmacies within the case study areas. The London case study area had the largest number at 64 and the South West had the lowest at 5. The large number of pharmacies within the London case study area may have been due to the high population density within this area.

Data on health services within each case study area was obtained from the NHS choices websites (NHS Choices 2009).

Table seven: Comparison of health services provision across the case study areas

	North East	London	North West	South West
GPs	152	160	124	102
PCT average list size	1852	1643	1363	1398
General practices	13	51	17	23
Walk in centres	1	1	0	0
Dentists	10	33	26	9
Pharmacies	20	64	24	5
Hospitals	3	3	3	3

Housing services (Table eight)

The South West case study area had the highest percentage of people living in residential care which may reflect the older age profile of the area. The lowest number of residential and nursing homes were in the London case study area, whereas the North East and North West areas had almost equal numbers of residential and nursing homes.

The highest percentage of over 60s who were home owners lived in the South West at 77% followed by the North West at 73%. This may reflect the reputation of this area as a place to retire to. The lowest percentage of older people who were home owners was in the London area at 22%. These figures may reflect the lower percentage of older people living in this area and the relative deprivation experienced by the older people living within this case study area.

Housing data was obtained from the Office for National Statistics Neighbourhood Statistics website (Office for National Statistics 2009b).

Table eight: Comparison of housing services across the case study areas

	North East	London	North West	South West
% of people living in residential and nursing care	0.8	0.2	0.8	2.7
Number of nursing homes	12	3	17	16
Number of residential homes	25	16	24	50
% of over 60s who are home owners	54	22	73	77

Self management service and support options within the case study areas

Below, we have described the service and support options identified during the mapping work within each case study area. We have described each support option in terms of whether they were focused on promoting general health and self management for individuals with a range of LTCs, or whether they were focused on providing self management support for individuals with a particular LTC (generic versus condition specific support). Within these two categories we have also classified services and support into whether they were professionally or lay led. Data on the available services was identified from a range of sources, including PCT websites and medical research charity websites. Within section five of this report we have described some of the available services in more detail using the qualitative data from our interviews with service providers and commissioners. In this section, we therefore present a broad overview of all of the services that we identified

Generic self management (Table nine)

In terms of generic self management, the Expert Patient Programme (EPP) was available in three out of the four case study areas. The EPP was not available within the North West case study area as the PCT had decided to develop their own version of a generic self management programme.

Age Concern was active across all of the case study areas and provided support on a wide range of levels, for example, health promotion, exercise, falls prevention, benefits advice, and help to navigate the health and social care system and social support.

General health information and support was available in three out of four case study areas. In the London area, this was in the form of a health information shop, at which local residents could drop in for advice. In the North East area, this was in the form of a healthy living centre, which provided health information along with a broad range of support groups. In the North West case study area, there was a disability rights centre which provided similar type of advice and support.

Finally, the voluntary sector had a powerful role to play in providing support to older people within each of the case study areas. For example, within the London area, there was a healthy living partnership which provided support, advice and healthy living classes specifically for older people, and there was a local voluntary sector organisation which provided support to the ethnic minority communities within the area.

Two of the case study areas (South West and North West) had older people's forums at which older people could share their views about their local areas, including the development of health services within the areas. Some of the sources of support that we were able to identify are described in Table nine.

Table nine: Comparison of generic self management available across the case study areas

Run by	North East	London	North West	South West
Expert patient programme	Generic self management course	Generic self management course	No – PCT running own self management course	Generic self management course
Older people's charities	Age Concern Health information and promotion Good companions scheme Information about benefits	Age Concern Age Well UK – Senior health mentors; Specialist advice and support; Healthy lifestyle checks	Age Concern Day centres, falls prevention, exercise and social support, mental health advocacy service, direct payments support, good companions, health mentoring, support brokers	Age Concern Advice and information, day centres, lunch clubs and personal care, information and welfare line
Health services	Healthy living centre – providing a range of health improvement and community regeneration services	Health information shop - Drop in information centre		
Voluntary sector		Self management courses run for the Bangladeshi population- Also Exercise classes and health guides Healthy living partnership for the over 50s – partnership of seven charities	Older people's network- run by older people to enable the sharing of views about issues that are important to them	Older people's Forum – sharing of views on local and national issues. Forums aim to influence the planning, development and delivery of local services Way finders – information and signposting

Condition specific support (Table ten)

Across the case study areas, condition specific support was available such as the DAFNE and DESMOND courses for Type I and Type II diabetes self management which were run at the local acute hospitals. Medical research charities were also active in each of the areas, in particularly Arthritis Care, and the British Lung Foundation's Breathe Easy courses for those with respiratory problems.

The majority of support available from medical research charities was peer led support groups rather than formal self management courses, although Arthritis Care within the London case study area had been asked to tender by the PCT to provide both generic self management courses and support for those with chronic pain. The majority of the support groups that were available were run by volunteers with some support from the medical research charities.

Table ten: Comparison of condition specific support across the case study areas

Run by	North East	London	North West	South West
Health services	DESMOND and DAFNE courses run at local acute hospital	X-Pert Chronic disease self management DESMOND and DAFNE courses	DESMOND and DAFNE courses run at local acute hospital	DESMOND and DAFNE courses run at local acute hospital
Medical research charities	Arthritis care monthly meetings Breathe easy group	Arthritis care – Challenging your condition course Parkinson's disease society support group Alzheimer's society support group	Arthritis Care monthly meetings Breathe easy group	Parkinson's disease support group MS support group Backcare – advice and support for back problems
Voluntary sector	Speech after stroke club Deaf support group	Stroke survivors project	Disability rights centre Heart support group Family and carer support for sufferers of stroke	ME support group

These tables provide a snapshot of the available support services within the case study areas. We were just able to take a snapshot of the availability of services within each area during the mapping process, and we supplemented the mapping by identifying additional services via the responses to our questionnaire survey and during our interviews with commissioners, service providers, older people and carers.

3.3.6 Classification of support services

We classified the types of support that were available into lay led and professionally led, and condition specific (focused on providing support to people with particular conditions) versus generic (focused on providing support to those with a range of LTCs)

Lay led condition specific support (Table eleven)

We classified the following types of services as being lay led condition specific support;

- a. EPP style programmes focused on the management of particular LTCs, e.g. Challenging Arthritis
- b. Lay led support groups often run by medical research charities
- c. Information / advocacy for people with specific conditions
- d. Prevention support – such as stroke and falls prevention

Lay led generic support (Table eleven)

We classified the following types of services as being lay led generic support;

- a. Support to navigate health and social services
- b. Local peer support general healthy living groups
- c. Advocacy groups for older people's rights
- d. Social support groups
- e. Information / advocacy for a range of LTCs

Within table eleven, we have described and categorised the lay led services that we identified within each case study area according to the classifications detailed above. No shading = London case study area; light grey = South West case study area; dark grey = North West case study area; mid grey = North East case study area

Table eleven: Lay led condition specific and generic support for older people with LTCs across the case study areas

Lay led condition specific support					Lay led generic support				
<i>Prevention</i>	<i>EPP style programmes</i>	<i>Lay led support groups</i>	<i>Information / advocacy support</i>	<i>Generic self management programmes</i>	<i>Navigating health and social services</i>	<i>Exercise</i>	<i>Lay led general health support</i>	<i>Advocacy for older people's rights</i>	<i>Social support</i>
Stroke prevention service	Challenging arthritis	Parkinson's Disease support group		Expert patient programme	Age Concern – Senior Health Mentors	Healthy moves	Local peer support health groups	Older people's forum	
		Alzheimer's society support group		Generic self management for Bangladeshi population	Health Shop			Disability rights service	
		Parkinson's disease society		Looking after me – course for carers	Health guides			Older People's network	
		ME support group		Expert patient programme	Way finders				
				Expert patient programme	Age Concern Mentoring Support				
		Heart Support group		Expert patient programme	Age Concern Senior Health Mentors				
		Breathe Easy							
		Speech after stroke							

Condition specific support (Table twelve)

Professionally led condition specific support

We classified the following types of services as being professionally led disease specific support.

- a. Prevention / behaviour change interventions
- b. Disease specific self management e.g. DAFNE / DESMOND
- c. General practice based LTC clinics e.g. asthma clinics
- d. Intermediate care services for people with specific conditions
- e. Condition specific medication review
- f. Condition specific support groups

Professionally led generic support

We classified the following types of services as being professionally led generic support.

- a. Health promotion
- b. Medications support and review
- c. Intermediate care
- d. Information support
- e. Support to navigate health and social services
- f. Social support

Within table twelve we have described and categorised the professionally led services that we identified within each case study area according to the classifications detailed above.

No shading = London case study area; light grey = South West case study area; dark grey = North West case study area; mid grey = North East case study area

Table twelve: Comparison of professionally led support across the case study areas

Professionally led condition specific support							Professionally led generic support					
<i>Prevention / behaviour change</i>	<i>Condition specific self management</i>	<i>GP based clinics</i>	<i>Intermediate care services</i>	<i>Condition specific medication review</i>	<i>Condition specific navigation of services</i>	<i>Condition specific support groups</i>	<i>Health promotion</i>	<i>Medications support and review</i>	<i>Intermediate care</i>	<i>Information support</i>	<i>Navigating health services</i>	<i>Social and self care support</i>
Stop falls network	Structured education for type one diabetes	Diabetes Asthma Blood pressure Coronary Breathing	Community mental health team for older people	Alzheimer's medication services	Age Concern mental health advocacy	Stroke associatio n – family and carer support	Age concern – ageing well project	Pharmacist first scheme	Staying put and hospital discharge service	Age concern information line	Age Concern Support Brokers	Age concern day services / centres
Stop smoking services	Structured education for type two diabetes	Diabetes Asthma	Day hospital for older people with mental health problems				GP well person clinics, and over 75 clinics	Pharmacist free prescription delivery	Older people's domiciliary service	Age Concern direct payments support	Age Concern Supporting You	Salvation army lunch club and over 60s club
Age concern fall prevention programme	Community heart failure service	Diabetes Asthma					General practice health lifestyle advisor	Pharmacist free prescription delivery	Continuing care team	County Council Welfare rights		Adult and community services day centre
NHS Stop Smoking service	Stroke and TIA follow up service	Asthma COPD					Age Concern – Get Active	Dispensary service		Healthy living resource centre		Age Concern Day Centres

3.4 Discussion

3.4.1 Why have we taken a case study approach?

Firstly, it may be useful to describe our rationale for undertaking a case study approach to this study. We took a case study approach to explore the issues around providing support for self management to older people in four different contexts. We did this as there is evidence to suggest that the prevalence of LTCs is likely to vary across different English regions, (Becker & Choudhury 2005) and as a consequence of this varying prevalence, it is likely that the perceived need for support services for those with LTCs is also likely to vary across different areas. The characteristics of the rest of the population within an area may also impact on the perceived need for services. For example, if there is a higher proportion of younger people within an area (as there was in our London case study area), then local PCT and social services departments may feel less able to prioritise the commissioning and delivery of services for older people.

Each of our case study areas had different population and geographical characteristics which may influence peoples' experiences of accessing services and support options. For example, experiences of accessing services are likely to be very different for people living in an area of high population density where services are closely located, compared to the experiences of those in rural areas, where the population density is low and services are spread over a wider geographical area.

Each of the case study areas also had different levels of social deprivation, which has been shown many times to impact on people's access to and use of services. Previous research has suggested that more socially deprived areas may have poorer access to services, poorer service provision and that residents of such areas may be less confident in self managing.

Related to deprivation is the concept of social capital which includes people's access to social networks and support. Therefore, those with a high level of social capital may be more likely to be engaged with the local community and able to obtain information about services. They may also therefore be more likely to be aware of and able to access a wide range of services. The level of perceived social capital and strength of the social networks within a particular area may impact on people's confidence and ability to self manage and access information and support for self management. Social capital is likely to vary according to the area that an individual lives in and so this provided further rationale for our case study approach. Within section six we describe our case studies in more detail and reflect on how their varying characteristics may have impacted upon the provision of services to support self care and self management.

3.4.2 Rationale for selecting case study areas

The case study areas were selected to represent diversity in terms of age profile, ethnicity, deprivation and area type. We achieved diversity in terms of age profile as our areas ranged from London which had a predominantly younger population compared to

the other areas, to the South West which had a much older population. We originally selected both the North West and London case study areas to represent diversity in terms of ethnicity, but in reality just the London area was ethnically diverse. We achieved diversity in terms of deprivation level, as we selected two relatively affluent areas (South West and North West case study areas) and two relatively deprived areas (North East and London case study areas).

As is to be expected, those living in the more socially deprived areas (North East and London) appeared to have the poorest health status. However, despite being a relatively affluent area, the South West had the second highest prevalence of LTCs. This may have been due to the population within this area being older than in the other case study areas.

In terms of service provision, on the surface, similar organisations appeared to be active within each area. For example, the Expert Patient Programme (EPP) was available in three out of the four case study areas, and Age Concern was very active in all four areas. Three out of the four areas also had forums for older people to express their views and opinions and lobby for future service provision.

However, what on the surface appears to be a similar pattern of service provision and availability within each of the case study areas, demonstrated the importance of exploring how the experiences of accessing services may differ due to the varying characteristics of our case study areas and the varying characteristics and needs of the older people living in each of the case study areas. Within section five, we describe and discuss the commissioning and service provision processes within each case study area in greater detail, and within section six, we reflect on how the characteristics of the case study areas may have affected the availability of support for self management.

3.5 Chapter summary

Chapter three describes and characterises each of the case study areas in terms of their demographic profiles, deprivation levels, health status and provision of services to support people living with long term conditions.

a. North East case study area

The North East case study area is one of the most socially deprived in England, and has almost double the number of over 65s compared to the London case study area. This area is ethnically very homogenous with the percentage of White British within the area being 98.7% compared to 87% in England as a whole. Although there was a relatively large number of those aged 65 and over in the case study area, life expectancy was lower than the England average. Therefore, in this area, due to the high prevalence of LTCs and the relatively high percentage of over 65s, there is a great need to provide services to support self management within this age group (Office for National Statistics 2009a; Office for National Statistics 2009b).

This area was a former mining area, and the health of many of its residents appeared to be influenced by the changes that had occurred following the closure of the mines. For example, the difficulties for some of obtaining employment following the pit closures had led to an increased number on incapacity benefit, often for many years. In such circumstances the meaningfulness of self management messages to this group appeared to be limited. Some interviewees also spoke of their perceptions of the breakdown of their communities following the pit closures. Interviewees spoke of people moving out of the area, the closure of many of the working men's clubs which had been focal points for the community, and the increase in what they felt was anti-social behaviour. All of these factors may have affected the feasibility of promoting self management within the area. For example, with the closure of their working men's clubs there were fewer opportunities for people to get together and to exchange information about local support. Some of our interviewees also spoke about their concerns about attending support groups and social groups at night because of a fear of anti-social behaviour.

As a result, a key difficulty within this area was accessing support for self management. The case study area is a rural area with relatively poor public transport, and so for many of our interviewees accessing services was particularly difficult.

This area forms part of a county wide PCT and unitary local authority, and the commissioners interviewed spoke about the diversity of people's needs within the PCT area and the difficulties of providing services to meet these differing needs. For example, it was felt that those in the nearest city were thought to be more demanding of services than those who were living in the case study area. Given that our case study area was some distance from the nearest major town, older people had to either travel some distance to obtain health care services, or that they were often referred to hospitals in neighbouring areas where access was often problematic.

b. London case study area

The London case study area was an urban area with a very diverse population in terms of age, social deprivation and ethnicity. This area had a very large overall population and the lowest percentage of older people of all of our case study areas (Office for National Statistics 2009a; Office for National Statistics 2009b). There was a broad range of services available, due to many organisations trying to satisfy the needs of the diverse communities and individuals living within the area. Some of our interviewees felt that this intense targeting of services often meant that those with more generic support needs missed out in terms of accessing support. That is, if an individual did not fall into a given category of support offered to a given client group support would be unavailable.

Some of the commissioners and service providers interviewed also spoke about older people missing out in service provision due to the high proportion of younger people resident within the case study area. The need and demand for services for younger families and children were often high in service providers' and commissioners' priorities.

Several of our interviewees also spoke of their feelings that the area had changed within recent years, notably in a sense of loss of community cohesion within the area due to the rapidly changing nature of the population. Some spoke about perpetually closed and locked doors within their block of flats and the difficulties of asking people for advice and

information. Inevitably, part of the explanation for this situation appeared to be a fear of crime.

c. North West case study area

This area had a relatively large population compared to the North East and South West case study areas. It had a relatively high percentage of older people aged 65 and over. As with the North East case study area this area is relatively homogeneous in terms of ethnic group, being 98.3% white. This is also a relatively affluent area as seen by its IMD score of 178 (Office for National Statistics 2009a; Office for National Statistics 2009b).

Both males and females within this area have a slightly higher life expectancy than the England average, and in terms of healthy lifestyle behaviours such as smoking and alcohol consumption, the area is very similar to the England population as a whole.

Looking at the routinely collected statistics on this area, it appears to be the least extreme in terms of its socio-demographic and health status characteristics. However, the area is projecting a significant rise in those aged 85 and older which means that its current service levels may become difficult to sustain, and that there will be a need for a greater emphasis on self care and self management within this area. Perhaps for this reason, this area could be argued, at least at the time that the study was being undertaken, to be the most proactive in terms of developing systems to promote and support self management within this age group. This is evidenced by self management being embedded within all LTC patient pathways for general practices, and by the pilot work that the PCT was doing on stratifying the population in terms of their LTC needs.

Commissioners also spoke about the need to try to spend money now on those who were not currently in the greatest need to reduce demands on services later. As a result, the case study area PCT was focused around providing wellness and prevention services.

d. South West case study area

This case study area had the highest percentage of older people aged 65 years and older. This is predominantly a rural / seaside area and it is therefore an area to which people often choose to retire. It is not an ethnically diverse area, with a very low ethnic diversity score of 0.02 (Office for National Statistics 2009a; Office for National Statistics 2009b).

This was the most affluent of all of the case study areas with an IMD score of 207. The health status of residents appears to be relatively positive with life expectancy for both men and women being higher than the England average, and those living in the area being less likely to smoke or to consider themselves to be in poor health.

Although much more affluent than the North East case study area, this area experienced many of the same problems because of its rural location, poor public transport and services being spread widely across the case study area. This made it difficult for those with lower levels of mobility and no access to a car to make use of some services.

On the whole, those who we were able to approach for interview within this case study area appeared to be in relatively better health and perhaps because of this were more willing and able to self manage their LTCs than those who were in poorer health in the North East and London case study areas.

Next chapter

Chapter four describes the development, administration and findings of a postal questionnaire survey exploring beliefs, attitudes and experiences relevant to long term conditions, self-management and use of support services.

4. Questionnaire survey

4.1 Aims of questionnaire survey

- To investigate the prevalence and type of LTCs experienced within the sample of respondents;
- To investigate the extent to which older people are willing to engage in self care and self management;
- To investigate older people's attitudes and beliefs towards the self management of LTCs, and to investigate whether these vary according to the type and complexity of health problems that an individual is coping with;
- To investigate respondents' use of services which support self care;
- To investigate whether, and how, the use of, and perceived needs for, support services vary according to age, gender, ethnicity, social capital, number and type of LTCs, quality of life, willingness to engage in self care activities, and case study area.

4.2 Method

4.2.1 Survey design

We undertook a postal questionnaire survey to a random sample of 125 patients registered with five purposively selected general practices within each case study area. We did not select participants on the basis of being diagnosed with LTCs, as we wanted to measure the reported prevalence of LTCs, and to compare the characteristics of those with and without LTCs across the sample and within each case study area.

4.2.2 Questionnaire development

We explored the following factors within the questionnaire survey.

1. *General health* – This question was taken from the Health Survey for England and allowed us to explore the general health of the population and to compare it with previous surveys of older people (Becker & Choudhury 2005; Department of Health 2009).
2. *Reported prevalence of LTCs*– We explored the prevalence and nature of LTCs, to allow us to examine the relationships between having a LTC and other factors such as service use, and to enable the identification of patients with LTCs to take part in the interview studies. The reported prevalence of LTCs was assessed using a question from the Health Survey for England (Becker & Choudhury 2005; Department of Health 2009).

3. *Quality of life*- Quality of life was important to measure because having a LTC has been shown to influence quality of life, and perceiving that you have a poor quality of life may impact negatively on your ability to self manage.
4. *Patient activation* – We measured older people’s willingness to self manage using the nine-item version of the Patient Activation Measure (PAM)(Hibbard et al. 2004;Hibbard et al. 2005). This is a validated tool for assessing people’s knowledge, confidence and skills for self-management, which the Picker Institute has previously adapted for use in UK populations (Ellins & Coulter 2005). A patient who is activated is considered to have the knowledge and skills to self manage, collaborate with providers, maintain function and prevent further declines in their health, and to believe that all of these are important roles for patients. The PAM allowed us to examine variations in capacity and willingness for self-management across the case study areas and between demographic sub-groups. The PAM allowed us to segment individuals into one of four progressively higher activation levels;
 - a. Level one - Individuals do not feel confident enough to play an active role in their own health and so they are predisposed to be passive recipients of care
 - b. Level two - Individuals are considered to lack confidence and an understanding of their own health or recommended health regimes
 - c. Level three - Individuals have the key facts and are beginning to take action, but may lack confidence and the skills to support their behaviours
 - d. Level four – Individuals have adopted new behaviours but may not be able to maintain them in the face of stress or health crises
5. *Demographic factors*- Collecting valid and reliable data on participants’ age, gender, ethnicity and social class, is essential when exploring the epidemiology of LTCs, as many of these factors have been found to be associated with the prevalence of LTCs. We used the demographic questions that were developed for the 2001 census.
6. *Social Capital* - A short measure of social capital was also included in the questionnaire, taken from the Health Survey for England (Becker & Choudhury 2005;Department of Health 2009). The items measured aspects of social networks and support and social participation. We measured social capital as we hypothesized that those with a high level of social capital may be likely to be more engaged with the local community and more likely to be aware of and access a wide range of services.
7. *Interest in further research* – We included a section at the end of the questionnaire which allowed participants to express an interest in further research. Participants were asked whether they would be willing to participate in an interview, and if so to provide their contact details. There was also a section where the contact details of their carer, if applicable and if they had previously agreed, could be given.

4.2.3 Questionnaire piloting using cognitive interviewing

The questionnaire was developed using 'cognitive interviewing'. This approach involves participants, similar to those likely to be included in the study, being asked to complete the questionnaire in the presence of a researcher (Willis 2005). Cognitive interviewing is an iterative process, with changes being made to the questionnaire following each set of interviews and the new draft of the questionnaire then being tested.

During cognitive interviewing, participants were asked to read each questionnaire item aloud prior to completing it, and to verbalise their thoughts about the question in general and their response to the question. Respondents were also asked to highlight any areas of the questionnaire which were unclear, inappropriate or repetitive. The participants' thoughts about the questionnaire were recorded by the researcher both on audiotape and in note form. This approach enabled the researcher to determine whether the questionnaire is being interpreted in the way that they intended. It also helps to identify any changes that need to be made to the questionnaire to increase its ease of completion and intelligibility.

Interviews were undertaken in two Age Concern day centres in London. A total of 16 individuals participated in this stage of the research. The first two stages were undertaken in November 2007 and the final stage was undertaken in January 2008. Participants were given a copy of the study information sheet, consent form and questionnaire and sat with a researcher to complete the questionnaire (Willis 2005). All participants were given a £20 gift voucher to compensate for their time. The interviews were conducted by two members of the research team (SP and SC).

Several changes were made after each stage of the interviewing process. For example, open ended questions were removed or altered, and instructions on how to answer questions were placed in bold font to make them distinct from actual survey items. Further details of the questionnaire development process are described in Appendix One.

4.2.4 Sampling method

The questionnaire sample was drawn from GP registered lists via relevant NHAIS (National Health Application and Infrastructure Services, now known as NHS Connecting for Health Systems and Service Delivery) databases after approval from the Caldicott Guardians in each case study area PCT.

A maximum variety purposive sample of five GP practices was selected within each case study area. Practices were selected to represent variations within each case study area in deprivation, age, ethnicity, prevalence of LTCs and practice list size. Data from the quality and outcomes framework database, local community health profiles (Association of Public Health Observatories 2009) and the census 2001 (Office for National Statistics 2009a) was used to inform the selection of practices. Within each practice, a systematic random sample of 125 patients aged over 60 years was drawn. This built a degree of implicit stratification into the sample, and ensured that the samples reflected the age distributions of patients aged 60 or over within each practice. No other discriminating

factors (for example LTCs) were used, as we wanted to be able to estimate the prevalence of LTCs within each case study area and across the sample as a whole.

The sampling procedure involved determining the total eligible population within each practice, N (e.g. number of registered patients aged 60 or over), then dividing this by the desired sample size n to give an interval k . A random integer j was then generated between 0 and k and every k th unit starting at unit j was selected from the age-sorted sample frame.

Target sample sizes were calculated based on power calculations and analysis requirements such that sampling error for top-line estimates would be approximately 2.5% at the 95% confidence level and that the sample would have sufficient power to detect differences between key sub-groups. Based on this, a sample of 125 patients within each of the 20 practices was drawn, giving an overall sample size of 2500. Given an assumption of a 50% response rate, this would provide a target figure of around 60 responses per practice. This equated to a total of around 300 responses per PCT and therefore a target of 1200 responses overall.

The NHAIS data also contains highly accurate postcode data, and so it was feasible to link the sample to the Index of Multiple Deprivation (IMD) data (Department of Communities 2004) to enable analysis by affluence/deprivation.

4.2.4 Questionnaire administration

A sample of 625 older adults aged 60 and over, within each of the four case study areas (2500 in total) were sent a questionnaire. A survey subcontractor (Greens Digital) distributed the questionnaires to participants. Responses were collected by the contractor, reminders sent, and data entered onto a SPSS database, pre-designed by the research team. This database was then forwarded to the research team. Greens Digital was selected as the survey subcontractor as they conform to the ISO20252 standard for social research and undertook research in line with the Picker Institute Europe's confidentiality agreement.

The following measures were taken to maximise response rates to the questionnaire:

1. We selected data from GP registered records as it provides accurate and up to date sampling information;
2. The questionnaire was rigorously tested on a relevant population;
3. The cognitive interviewing stage ensured that the questionnaire was easy and interesting to complete
4. Freepost envelopes were provided for returning the questionnaire.
5. The questionnaire and covering letters were designed to be interesting and relevant to the population of interest; the logo of our partner organisation, Age Concern England, on covering letters and related information, lent a sense of familiarity to the study, and supporting information illustrated the importance of the survey for improving patient care and support.
6. It was made clear to respondents that the information they provided would be anonymous and confidential.
7. We used a system of two reminder letters, the latter including a second copy of the questionnaire to maximise response rates (Appendix two)

8. Help was available, when needed, free of charge: a FREEPHONE helpline and a *Language line* for translation were available if respondents had any queries or concerns.

Mailings were sent out at two weekly intervals. Mailings in the North West, North East and London case study areas were sent out at the same time, but the first mailing in the South West Case study area was sent later due to delays in obtaining research governance approval and honorary research contracts with the South West Case study area PCT.

4.2.5 Coding the questionnaire responses

The research team set up an SPSS coding database for the questionnaire survey responses. The usability of the database was piloted using the initial survey responses. Data was then entered by the questionnaire survey subcontractor. All validated outcome measures were coded using the coding system developed by the originators of the scales and the research team developed an appropriate coding system for the remaining questions.

4.2.6 Quality control

Data cleaning rules were developed for the database (and are available on request). For example, if the response to question two was non applicable, then there would be a need to check that all of the related questions were coded as non applicable. The data was cleaned using these rules and by running frequency analyses on all of the variables to check for outliers and mistyped data. Errors were corrected by checking the original returned questionnaire. The raw data was checked for errors by selecting 10% of returned questionnaire and checking responses against data entered on the SPSS database.

4.2.7 Data protection

The research complied with the Data Protection Act 1998, and permission to access patients' names and addresses for the survey was obtained from the Caldicott Guardians from the case study area PCTs. Details of how patient confidentiality was to be preserved was described in the questionnaire covering letters and information sheets (Appendix Two). For example, the covering letters that accompanied the mailed questionnaires informed patients that their name and address would never be linked to their responses. Furthermore, patients' responses were never presented in such a way that allowed individuals to be identified. Completed questionnaires were stored in a locked filing cabinet, and a CD containing patients' name and address details was stored in a locked safe at the Picker Institute Europe during the course of the survey and destroyed when the survey was completed.

4.2.8 Data analysis

Data analysis was conducted using SPSS. Our analyses focused on the following areas

1. Comparison of the characteristics of respondents and non respondents to the questionnaire survey, according to age, gender and postcode deprivation;
2. Investigation of the prevalence, type and impact of LTCs experienced by the survey respondents, by age, gender, ethnicity, working status, willingness to self care, beliefs about medicines and social capital;
3. Investigation of the survey respondents willingness to self care, and the extent to which this varies according to the type and complexity of their LTCs
4. Investigation of respondents use of services which support self care
5. Investigation of whether and how the use of and perceived needs for support services vary according to age, gender, ethnicity, working status, willingness to self care, and social capital amongst those with LTCs

A number of statistical methods were used to interrogate the survey data including chi-square tests, analyses of variance (ANOVAs), t-tests (and non-parametric equivalents), correlations and regression analyses. Tests were chosen on the basis of the level of data collected.

4.3 Results

4.3.1 Response rates to questionnaire

The overall response rate to the questionnaire was 40% (857/2146). The response rates by case study area are detailed in the table below. We did not have details of the opt outs by case study area and so the full denominator has been used to calculate the response rate by case study areas.

Table thirteen: Response rates overall and by case study area

	Response rates
Overall response rate	40% (857/2146)
North West Case study area	38% (241/625)*
North East Case study area	32% (199/625)*
South West Case study area	42% (260/625)*
London case study area	25% (154/625)*

*Full denominator as records were not kept of the opt outs by area

4.3.2 Non respondent analysis

Aim- To compare the characteristics of respondents and non respondents to the questionnaire survey, according to age, gender and postcode deprivation.

The overall response rate to the questionnaire was 40% (857/2146). 14% (354/2500) opted out of the survey by calling our FREEPHONE number or returning their questionnaire unanswered and 52% (1314/2500) did not respond to the survey.

Respondents were younger than non respondents and those who opted out of the survey (71 years versus 72 years versus 74 years). Respondents were more likely to be female than non respondents (56% versus 54%). Respondents had a lower mean index of deprivation than non respondents (28.9 versus 32.9). This is evidenced by the higher response rates that we obtained in our more affluent case study areas (North West and South West).

Table fourteen: Comparison of socio-demographic characteristics of respondents and non respondents and opt outs

	Respondents N=830	Non respondents N=1314	Opted out N=354
Mean age	71 (range 60-101) SD=8.4	72 (60-101) SD=8.7	74 (60-101) SD=8.7
% in age bands			
60-69	50 (411/824)	45 (596/1314)	35 (123/354)
70-79	32 (262/824)	34 (452/1314)	35 (125/354)
80 and over	18 (151/824)	20 (266/1314)	30 (106/354)
% Female	56 (467/836)	54 (714/1314)	64 (227/354)
Mean index of multiple deprivation	28.9 SD=17.2 N=828	32.9 SD=17.8 N=1308	28.5 SD=18.4 N=350

Base = All of those surveyed

4.3.3 Characteristics of questionnaire survey respondents

a. Demographic characteristics of respondents (Table fifteen)

Those in the youngest age group were most likely to respond to the questionnaire survey. Fifty percent of those responding to the questionnaire survey were in the 60-69 year age group, compared to 32% who were in the 70-79 year age group and 18% who were in the 80 and over year age group. This is fairly comparable to the percentages of people in these age groups across the England population as a whole (45% - 60-69 years; 35% 70-79 years and 20% 80 years and older). The mean age of the survey respondents was 71 years, and more women replied to the survey than men (56% versus 44% compared to the England wide percentages of 52% versus 48%). Finally, the majority of the survey respondents were white.

Table fifteen: Demographic characteristics of the survey respondents

	Respondents
Mean age	71 (60-103) SD=8.5 N=826
% Female	56 (467/836)
% White	93 (769/829)

Base = All respondents

4.3.4 Prevalence of LTCs and demographic characteristics of the survey respondents

Aim – To investigate the prevalence, type and impact of LTCs experienced by the survey respondents, by age, gender, ethnicity, willingness to self care and social capital.

Prevalence and nature of LTCs (Table sixteen)

We used the question 'Do you have any long standing illness, disability or infirmity' as our main method of assessing the prevalence of LTCs. The overall prevalence of LTCs amongst the survey respondents using this method was 65% (537/830).

When examining the prevalence of LTCs by type, the denominator for these questions is 509 rather than 537, as not all of those who reported having LTCs completed the questionnaire items about the types of LTCs that they were experiencing.

Table sixteen: Prevalence of LTC by type

Type of LTC	% with LTC (number) N=509
High blood pressure	51 (260)
Pain	27 (137)
Arthritis /Rheumatism	53 (270)
Depression/anxiety	14 (71)
Diabetes	17 (87)
Asthma / Bronchitis	23 (117)
Cancer	11 (56)
Angina / heart problems	28 (143)
Bowel	16 (81)
Digestive / stomach problems	19 (97)
Stroke	7 (36)
High cholesterol	31 (158)
Hearing	25 (92)
Bladder	18 (92)
Any other condition	23 (117)

Base = All of those reporting LTCs

The most prevalence LTC within our sample of responders was Arthritis / rheumatism (53%) followed by high blood pressure (51%) and high cholesterol (31%). The least prevalent LTC was stroke (7%).

Prevalence of multiple LTCs (Table seventeen)

The majority of our respondents with LTCs had three or more, which confirms the findings of other research which found that multiple morbidity, is very common within those aged 60 years and older.

Table seventeen: Prevalence of multiple LTCs

	% with LTCs N=509
% with one condition	11 (58)
% with two conditions	18 (94)
% with three or more conditions	70 (356)

Base = All of those reporting LTCs

Prevalence of LTCs and age (Table eighteen)

The prevalence of LTCs increased with age, from 58% of the 60 to 69 year olds to 72% of the 70 to 79 year olds and finally to 70% of those aged 80 years and older. Amongst the survey respondents, the 60-69 year age group was the largest group with LTCs, making up 45% of the total sample of respondents with LTCs, followed by the 70-79 year age group (36% of the total sample of respondents with LTCs) and finally the 80 plus age group (19% of the total sample of respondents with LTCs).

The 60-69 year age group formed the largest group with LTCs, perhaps as they also formed the largest group of respondents to the questionnaire survey.

Table eighteen: Prevalence of LTCs and age group

	% with LTCs within the age group	% of whole sample with LTCs
60-69	58 (233/403)	45 (233/516)
70-79	72 (185/257)	36 (185/516)
80 and over	70 (98/140)	19 (98/516)
Total	65 (516/800)	100 (516/516)

Number of LTCs and age group (Table nineteen)

The highest percentage of those with three or more LTCs were in the 80 and over age group (86%), although 60% of those aged 60-69 years reporting LTCs had three or more LTCs. The highest percentage of those with one LTC was in the 60-69 year age group at 17%.

Table nineteen: Number of LTCs and age group

	60-69	70-79	80 and over	Total
% with one LTC	17 (40/230)	8 (15/181)	3 (3/98)	11 (58/509)
% with two LTCs	22 (51/230)	18 (32/181)	11 (11/98)	18 (94/509)
% with three or more LTCs	60 (139/230)	73 (133/181)	86 (84/98)	70 (356/509)

Base = All of those reporting LTCs

Gender, ethnicity and social class (Tables twenty, twenty one and twenty two)

A higher percentage of male respondents to the questionnaire reported having LTCs compared to female respondents. However, women were more likely than men to report having three or more LTCs.

Table twenty: Prevalence and number of LTCs by gender

	Males	Females
% with LTCs	67 (239/359)	63 (284/451)
% with one LTC	11 (27/236)	11 (32/280)
% with two LTCs	22 (54/236)	14 (40/280)
% with three or more LTCs	66 (155/236)	74 (207/280)

Base = All of those reporting LTCs

There were no differences in the prevalence of LTCs in the white respondents to the questionnaire survey compared to the prevalence of LTCs in the respondents from other ethnic groups. Those with LTCs were more likely to report having living in a less deprived area as evidenced by their higher mean IMD scores than those who did not report having LTCs. Those with three or more LTCs were more likely to live in an area with a higher IMD score.

Table twenty one: Prevalence of LTCs and ethnicity

	Ethnicity	
	White	All other ethnic groups
% with LTCs	65 (483/747)	65 (37/57)
% with one LTC	20 (132/663)	11 (5/46)
% with two LTCs	22 (148/663)	17 (8/46)
% with three or more LTCs	58 (383/663)	72 (33/46)

Base = All of those reporting three or more LTCs

Table twenty two: Prevalence of LTCs and Index of Multiple Deprivation Score

	% with LTCs	% without LTCs	Diff	% with one LTC	% with two LTCs	% with three LTCs	Diff
Mean IMD score	28.5 SD=17.7 N=520	23.2 SD=15.6 N=290	t=-4.2 p<0.01	21.2 SD=15.7 N=59	23.9 SD=15.9 N=93	31.0 SD=17.9 N=360	F=12.2 p<0.01

Base = All of those reporting LTCs

LTCs and health outcomes (Table twenty three)

Those experiencing LTCs were significantly less likely to believe that their general health was good or very good, than those who did not report having LTCs. They were also less likely to believe that their quality of life was excellent, very good, or good compared to those who did not report having a LTC. Amongst those with LTCs, 37% believed that their conditions limited them a little or not at all.

As the number of LTCs increased from one to three or more, the percentage of individuals who believed that their general health was very good or good decreased from 85% to 33%; the percentage believing that their quality of life was excellent, very good or good decreased from 95% to 53% and the percentage believing that their LTCs limited them a little, or not at all decreased from 74% to 29%.

Table twenty three: Prevalence of LTCs and health outcomes

% Believing that	% with LTCs	% without LTCs	Diff	% with one LTC	% with two LTCs	% with three or more LTCs
their health is very good or good	41 (215/530)	90 (264/293)	Chi=23 df = 4 P<0.01	85 (121/142)	75 (117/156)	33 (142/425)
their quality of life is excellent, very good or good	59 (304/519)	95 (272/287)	Chi = 16 df= 6 P<0.01	95 (132/139)	82 (129/157)	53 (219/412)
their LTC limits them a little or not at all	37 (195/530)	N/A	N/A	74 (61/82)	61 (64/105)	29 (112/391)

Base = All of those reporting LTCs

Prevalence of LTCs and social capital (Table twenty four)

The mean social capital score amongst those with LTCs was lower than the mean social capital score amongst those without LTCs. However, those with LTCs were more likely to have lived in their local area for longer than those without LTCs. This may be because those reporting LTCs were more likely to be older than those not reporting LTCs. We also may have expected that those who had lived in an area for longer would have stronger social networks.

Respondents with LTCs were significantly less likely than those without LTCs to enjoy living in their local area, to believe that their area is a safe place to live and to believe that their area has good healthcare services. There were no significant differences between those with and without LTCs in terms of how often they had contact with friends and neighbours. Although those with LTCs were less likely to speak to relatives on the phone, speak to neighbours face to face and meet up with friends and relatives than those without LTCs.

These findings suggest that having a number of LTCs may limit people's social networks and may also increase their negative perceptions of their local areas. Therefore, those with LTCs were likely to be older, to have lived in an area for longer and perhaps also to have a reduced social network because of their LTCs.

Table twenty four: Prevalence of LTCs and social capital

	Responders with LTCs	Responders without LTCs	Difference
Mean social capital score	27 SD = 4.0 N=533	27 SD= 3.4 N=293	t= 2.15 p<0.01
Mean number of years lived in local area	34 SD=23 N=519	30 SD=20.3 N=290	t= -3.0 p<0.01
% agreeing or strongly agreeing that			
This area is a place that I enjoy living in	88 (459/522)	94 (272/289)	Chi = 8.9 p<0.05
This area is a place where neighbours look after one another	72 (370/512)	76 (211/279)	Chi = 5.7 p=NS
This area has good local transport	71 (364/514)	70 (199/284)	Chi = 0.9 p=NS
This area is a safe place to live	78 (406/518)	87 (247/284)	Chi = 10.3 p<0.05
This area has good leisure facilities for people like myself	63 (297/474)	67 (176/261)	Chi = 6.9 p=NS
This area has good local healthcare services	85 (430/505)	90 (250/277)	Chi = 4.1 p=NS
% who once or twice a week or more			
Speak to friends or relatives on the phone	47 (241/517)	49 (140/286)	Chi=4.0 p=NS
Speak to neighbours face to face	41 (212/515)	43 (122/287)	Chi = 1.6 p=NS
Meet up with friends or relatives	29 (149/514)	34 (97/285)	Chi = 2.4 p=NS

Case study area (Table twenty five)

In all case study areas, the majority of respondents reported having three or more long term conditions. Respondents in the London area were most likely to report having three or more LTCs at 81%, followed by the North East at 77%, the South West at 60% and the North West at 56%.

Table twenty five: Prevalence and number of LTCs by case study area

	All respondent s	North East	North West	London	South West
% with LTCs	65 (537/830)	79 (150/190)	56 (133/239)	69 (102/147)	60 (152/254)
% with one LTC	12 (62/537)	7 (10/150)	14 (19/133)	6 (6/102)	18 (27/152)
% with two LTCs	18 (95/537)	15 (23/150)	22 (29/133)	15 (15/102)	18 (28/152)
% with three or more LTCs	70 (372/537)	77(115/150)	62 (83/133)	80 (81/102)	61 (93/152)

Base = All respondents reporting LTCS

4.3.5 Prevalence of LTCs and willingness to self manage

Aim – To explore whether the survey respondents' willingness to self manage varies according to the type and complexity of their LTCs.

Prevalence of LTCs and willingness to self manage (Table twenty six, twenty seven and twenty eight)

Those reporting LTCs had a lower patient activation score than those who did not report LTCs. Therefore, those reporting LTCs appeared to be less activated and willing to self manage than those without LTCs.

The Patient Activation Measure (PAM) enables people to be allocated into one of four activation levels according to the willingness to self manage (Hibbard, Stockard, Mahoney, & Tusler 2004; Hibbard, Mahoney, Stockard, & Tusler 2005). The activation levels are as follows;

- a. Level one - Individuals do not feel confident enough to play an active role in their own health and so they are predisposed to be passive recipients of care
- b. Level two - Individuals are considered to lack confidence and an understanding of their own health or recommended health regimes
- c. Level three - Individuals have the key facts and are beginning to take action, but may lack confidence and the skills to support their behaviours
- d. Level four – Individuals have adopted new behaviours but may not be able to maintain them in the face of stress or health crises

Those both with and without LTCs were most likely to report being at activation level three, i.e. they felt that they had the key facts for self management and were beginning to take action, but that they lacked the confidence and skills to support their behaviours. Those with LTCs were more likely than those without LTCs to report being in the lower activation levels, i.e. levels one and two and therefore to take a more passive approach to their healthcare. Just 18% of those with LTCs were likely to report that they were in the highest activation level compared to 30% of those without LTCs.

Therefore having a LTC or LTCs appears to impact negatively on people's confidence in self management. Although the majority of our respondents, both with and without LTCs reported being in the third activation level, they still appeared to need support to increase their confidence and skills in self management.

Table twenty six: Prevalence of LTCs and Patient Activation level

	Respondents with LTCs N=530	Respondents without LTCs N=287	Difference
Mean patient activation score	56 SD=14.3 N=509	64 SD=15.8 N=273	t=7.3 P<0.01
% Believing that the patients role is important	20 (89/447)	11 (24/225)	Chi = 27.3 df=3 P<0.01
% Believing that they have the confidence and knowledge to take action	21 (93/447)	12 (26/225)	
% Believing that they are taking action	42 (186/447)	47 (106/225)	
% Reporting that they are staying the course under stress	18 (79/447)	31 (69/225)	

Base = All respondents split into those reporting and not reporting having LTCs

When the individual items of the Patient Activation Measure are explored, we can see that for both those with and without LTCs that the areas in which they felt least confident were in terms of;

- a. Knowing how to prevent further problems with their health condition
- b. Confidence in figuring out solutions when new situations or problems arise with their health condition

Therefore, our respondents appeared to be fairly confident in managing their LTCs provided that how their conditions affected them did not change, i.e. their symptoms stayed the same. However, they were less confident in dealing with any new symptoms or problems as they arose.

Table twenty seven: Prevalence of LTCs and individual Patient Activation Measure items

% agreeing or strongly agreeing that	Responders with LTCs N=530	Responders without LTCs N=287	Difference
I am the person responsible for managing my health condition	80 (426/530)	82 (234/287)	Chi=21 df=3 p<0.01
Taking an active role in my healthcare is the most important factor in determining my health and my ability to function	88 (464/530)	90 (258/287)	Chi=16 df=3 p<0.01
I am confident that I can tell when I need to obtain medical care and when I can handle a problem myself	85 (450/530)	90 (257/287)	Chi=11 df=3 p<0.05
I am confident that I can follow through on medical treatments I need to do at home	89 (473/530)	90 (257/287)	Chi=12 df=3 p<0.01
I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health condition	84 (443/530)	83 (237/287)	Chi=20 df=3 p<0.01
I have been able to maintain the lifestyle changes for my health that I have made	77 (409/530)	71 (203/287)	Chi=27 df=3 p<0.01
I know how to prevent further problems with my health condition	62 (326/530)	64 (183/287)	Chi=49 df=3 p<0.01
I am confident I can figure out solutions when new situations or problems arise with my health condition	52 (274/530)	60 (172/287)	Chi=42 df=3 p<0.01
I am confident that I can maintain lifestyle changes like diet and exercise even during times of stress	72 (381/530)	76 (218/287)	Chi=22 df=3 P<0.01

Base = All respondents

Table twenty eight: Number of LTCs and patient activation level

	Those with one LTC	Those with two LTCs	Those with three or more LTCs
Mean patient activation score	60 SD=11 N=53	59 SD=13 N=76	54 SD=12 N=312
% Believing that the patient's role is important	5 (4/88)	10 (9/88)	85 (75/88)
% Believing that they have the confidence and knowledge to take action	12 (11/93)	14 (13/93)	74 (69/93)
% Believing that they are taking action	14 (25/183)	13 (33/183)	68 (125/183)
% Reporting that they are staying the course under stress	17 (13/77)	27 (21/77)	56 (43/77)

Base = All respondents reporting LTCs

As the number of LTCs experienced by our participants increased from one, to three or more, they appeared to be more likely to be in the lower activation levels, and therefore were less willing and confident in self management. Therefore, those with three or more LTCs were most likely to be in the lowest activation level and to be predisposed to be a passive recipient of care. As the number of LTCs was likely to increase with age, those who were older were therefore also more likely to be more predisposed to be a passive recipient of care and may therefore need a greater level of support to self manage and to sustain self management behaviours.

4.3.6 Service and support use amongst those reporting LTCs

Aims

1. To investigate respondents' use of services to support self management
2. To investigate whether and how the use of and perceived needs for support services vary according to age, gender, ethnicity, working status, number and type of LTCs, willingness to engage in self care, beliefs about medicines and social capital.

Overall service and support use amongst the questionnaire survey respondents (Table twenty nine)

Questionnaire respondents were most likely to use the following services, GPs, practice nurses, hospital outpatients and social workers. This pattern of consulting may be related to the age range of those responding to the questionnaire. As the majority of our respondents were in the 60-69 year age group and were on the whole healthier than older respondents, they may have been less likely to need and use services such as home helps, meals on wheels and district nursing which are more likely to be used by older groups.

Table twenty nine - Overall service and support use

	Percentage using N=726
GP	83
Practice nurse	53
District nurse	6
Outpatients	45
Inpatients	8
Casualty	6
Physiotherapy	11
Home help	5
Meals on wheels	1
Lunch club / day centre	2
Social worker	37
Occupational therapist	3
Speech therapist	0.1
Social worker	37
Occupational therapist	3
Speech therapist	0.1
Other	5

Base = All respondents

Service and support use amongst those with and without LTCs (Table thirty)

Amongst those both with and without LTCs, the most frequently used services were the GP, practice nurse, hospital outpatients and the pharmacists. However those with LTCs were more likely to use each of the services and support options listed within the questionnaire than those without LTCs. Those both with and without LTCs were most likely to be using purely health services, just 16% of those with LTCs were using health as well as social services. However, only 8% of those without LTCs were using health and social services. Those with LTCs were more likely to be using three or more services than those without (33% compared to 9%)

Table thirty: Service and support use amongst those with and without LTCs

	With LTCs N=492 % (number)	Without LTCs N=211 % (number)	Difference
GP	88 (433)	72 (151)	Chi=28 df=2 p<0.01
Practice nurse	58 (286)	40 (85)	Chi=19 df=1 p<0.01
District nurse	8 (40)	0.5 (1)	Chi=16 df=1 p<0.01
Hospital outpatient	54 (268)	25 (53)	Chi =51 df=1 p<0.01
Hospital inpatient	11 (55)	2 (5)	Chi = 15 df= 1 p<0.01
Hospital casualty	7 (34)	3 (6)	Chi=4.6 df=1 p<0.05
Physiotherapist	13 (62)	6 (12)	Chi=7.5 df=1 p<0.01
Home help	7 (32)	1 (3)	Chi=18 df=1 p<0.01
Meals on wheels	1 (6)	1 (2)	Could not calculate*
Lunch club / day centre	3 (13)	1 (2)	Could not calculate*
Social worker	3 (16)	2 (4)	Could not calculate*
Pharmacist	40 (198)	30 (64)	Chi=6.2 df=1 p<0.05
Occupational therapist	4 (18)	0.5 (1)	Could not calculate*
Speech therapist	0.2 (1)	0 (0)	Could not calculate*
Other	5 (26)	6 (12)	Chi = 0.05 df=1 p=NS
Use of health and or social services			

Health services only	84 (413)	92 (194)	Chi =11.3 df=2 p<0.01
Health and social services	16 (79)	8 (16)	
Number of services used not including GP			
0-2 services	67 (330)	92 (193)	Chi =46 df=1 p<0.01
3 or more services	33 (162)	9 (18)	

Base = All respondents

*Could not undertake significance test as the figures in at least one cell were too low

Total number of LTCs and service use (Table thirty one)

Those with three or more LTCs were more likely to be using three or more services than those who had two or fewer LTCs. Those with three or more LTCs were also more likely to be using both health and social services than those who had two or less LTCs. This suggests that prevalence of more LTCs is likely to increase the number of services used and that those with LTCs are likely to become more reliant on social services.

Table thirty one: Total number of LTCs and service use

	One LTC	Two LTCs	Three or more LTCs
% using 0-2 services	13 (42/326)	21 (69/326)	66 (215/326)
% using three or more services	4 (6/161)	12 (19/161)	84 (136/161)
% using health services	11 (43/409)	19 (79/409)	70 (287/409)
% using health and social services	6 (5/78)	12 (9/78)	82 (64/78)

Base = All respondents reporting LTCs

Service and support use and age (Table thirty two)

Across the age groups there were no differences in service use apart from in the following areas: a) 60-69 year olds were most likely to report seeing physiotherapists. b) 70-79 year olds were most likely to report consulting GPs, practice nurses and hospital outpatients. Those aged 80 years and older were most likely to report consulting the district or community nurse, hospital inpatients, accident and emergency, paid home helps, meals on wheels, lunch club, social worker, occupational therapists and pharmacists. Therefore it appears that those who are older are more likely to rely on a wider range of services.

In terms of the type of service consulted, the percentage purely consulting health services decreased from 91% of the 60-69 year olds to 69% of the 80 plus year olds. Therefore, those in the oldest age group were most likely to be consulting both health and social services, and they were also most likely to be consulting a larger number of, services. Therefore, increasing age and an increasing number of LTCs were likely to increase the number and type of services consulted.

Table thirty two: Age group and service use amongst those with LTCs

	60-69 N=213	70-79 N=173	80 and over N=89
General practitioner	87 (185)	91 (158)	83 (74)
Practice nurse	54 (115)	65 (113)	55 (49)
District nurse or community nurse	4 (9)	7 (12)	20 (18)
Hospital outpatient	49 (105)	62 (107)	52 (46)
Hospital inpatient	9 (20)	12 (20)	13 (12)
Accident and emergency	6 (12)	6 (11)	11 (10)
Paid home help	2 (5)	5 (8)	20 (18)
Meals on wheels	0 (0)	1 (2)	3 (3)
Lunch club/ day centre	0.5 (1)	2 (3)	9 (8)
Social worker	2 (4)	3 (5)	8 (7)
Physiotherapist	12 (25)	12 (21)	16 (14)
Occupational therapist	2 (5)	3 (6)	7 (6)
Speech therapist	0 (0)	0.6 (1)	0 (0)
Pharmacist	36 (77)	43 (74)	46 (41)

	60-69 N=213	70-79 N=173	80 and over N=89	Difference
Health services	91 (194)	84 (145)	69 (61)	Chi=24 df=2 p<0.01
Health and social services	9 (19)	16 (28)	31 (28)	
Number of services used not including GP				
0-2 services	76 (162)	64 (110)	51 (45)	Chi = 20 df=2 P<0.01
3 or more services	24 (51)	36 (63)	49 (44)	

Base = All of those reporting LTCs

Service and support use and gender (Table thirty three)

There were no differences between males and females in their service use, apart from in the following areas: Males were more likely than females to report seeing hospital outpatients and females were more likely than males to report seeing the district nurse or the physiotherapist. Females were more likely than males to consult both health and social services, but there was no difference between males and females in the percentage purely consulting health services. Females were more likely than males to be consulting three or more services.

Table thirty three: Service use and gender

	Males N=225	Females N=257
General practitioner	87 (196)	89 (229)
Practice nurse	60 (135)	57 (146)
District nurse or community nurse	7 (15)	10 (25)
Hospital outpatient	60 (134)	50 (128)
Hospital inpatient	11 (24)	11 (29)
Accident and emergency	8 (17)	6 (16)
Paid home help	2 (4)	11 (28)
Meals on wheels	0 (0)	2 (5)
Lunch club/ day centre	1 (3)	4 (10)
Social worker	3 (6)	4 (10)
Physiotherapist	9 (21)	15 (39)
Occupational therapist	3 (6)	4 (11)
Speech therapist	0.4 (1)	0 (0)
Pharmacist	41 (93)	40 (103)

	Males N=225	Females N=257	Difference
Use of health and / or social services			
Health services	50 (201/405)	50 (204/405)	Chi=8.9 df=1 p<0.01
Health and social services	31 (24/77)	69 (53/77)	
Number of services used not including GP			
0-2 services	48 (154/322)	52 (168/322)	Chi=0.5 df=1 p=NS
3 or more services	44 (71/160)	55 (89/160)	

Base = All respondents reporting LTC

Service and support use and ethnicity and deprivation (Table thirty four)

There were no significant differences between white and non white ethnic groups in whether they used health, or health and social services, and in the number of services that they used. There were no significant differences in the mean IMD scores of those using health and health and social services and of those using 0-2 or 3 or more services.

Table thirty four: Service use, ethnicity and deprivation

	Health services	Health and social services	Difference	0-2 services	3 or more services	Difference
Ethnicity						
White	94 (377/402)	92 (71/77)	Chi=0.26 df=1 P=NS	93 (298/319)	94 (150/160)	Chi =0.02 df=1 P=NS
All other ethnic groups	6 (25/402)	8 (6/77)		7 (21/319)	6 (10/160)	

	Health services	Health and social services	Difference	0-2 services	3 or more services	Difference
Mean IMD score	29.2 SD=17.9 N=398	26.6 SD=16.1 N=78	t=1.2 p=NS	28.4 SD=17.9 N=314	29.5 SD=17.3 N=162	t=-0.67 p=NS

Base = All of those reporting LTCs

Service and support use and health outcomes (Table thirty five)

Participants who were using both health and social services were less likely to believe that their health was good or very good compared to those who were just using health services. Participants were also less likely to believe that their general health was good or very good if they were using three or more services.

Similar patterns were found when the characteristics of those reporting excellent, very good or good quality of life were considered, with those using health and social services, and those consulting three or more services being less likely to believe that their quality of life was excellent, very good or good. Those who believed that they were limited a lot by their LTC were also more likely to use health and social services and three or more services than those who did not feel that they were limited a lot by their LTC.

Table thirty five: Service use and health outcomes

% believing that	Health services	Health and social services	Difference	0-2 services	3 or more services	Difference
general health is good or very good	40 (164/410)	28 (21/75)	Chi=16 df=4 p<0.01	42 (137/328)	31 (48/157)	Chi = 20 df=4 p<0.01
quality of life is excellent, very good or good	60 (238/401)	42 (32/76)	Chi=18 df=6 p<0.01	61 (195/320)	48 (75/157)	Chi=17 df=6 p<0.05
they are limited a little or not at all by their LTCs	37 (152/409)	22 (17/77)	Chi = 11 df=3 p<0.05	39 (129/327)	25 (40/159)	Chi=13.9 Df=3 p<0.05

Base = All of those reporting LTCs

Service and support use and patient activation (Table thirty six)

Respondents who were just consulting health services had higher patient activation measure scores than those who were consulting both health and social services. Those who were consulting just health services were 12% more likely than those who were consulting health and social services to be in the third activation stage. Whereas those who were consulting both health and social services were more likely to be in the first activation level, i.e. to believe that the patients' role is important in health care but to not feel confident enough to take an active role in their healthcare.

When the number of services being used by participants was considered, there were no differences in overall patient activation score between those using 0-2 services and

those using three or more services. However, those using 3 or more services were more likely to be in the first activation level and less likely to be in the highest activation level than those using 0-2 services.

Table thirty six: Patient activation and service use

	Health services	Health and social services	Difference	0-2 services	3 or more services	Difference
Patient activation score	56 SD=14 N=396	52 SD=15 N=72	t= 2.4 p<0.05	55 SD=15 N=121	55 SD=15 N=152	t=0.47 p=NS
Believing that						
Patient's role is important	18 (64/347)	30 (20/66)	Chi = 5.9 df=3 p=NS	18 (48/270)	25 (36/143)	Chi = 5.4 df=3 p=NS
Have the confidence and knowledge to take action	21 (73/347)	23 (15/66)		21 (57/270)	22 (31/143)	
Taking action	42 (146/347)	30 (20/66)		40 (109/270)	40 (57/143)	
Staying the course under stress	25 (36/143)	22 (31/143)		40 (57/143)	13 (19/143)	

Base = All of those reporting LTCs

Service and support use and social capital (Tables thirty seven and thirty eight)

There were no differences in mean social capital between those using just health services and those using health and social services. However, those using health and social services were less likely to believe that their area had good local transport, and more likely to speak to friends or neighbours on the phone, and more likely to meet up with friends or relatives than those who were just consulting health services. However, none of these differences were significant at the 5% level, which may have been due to the low number of respondents who reported using both health and social services.

Table thirty seven: Social capital and health or social services use

	Health services	Health and social services	Difference
Mean social capital	26 SD=4 N=342	27 SD=4 N=56	t=-0.13 p=NS
% agreeing or strongly agreeing that			
This area is a place that I enjoy living in	88 (360/409)	90 (71/79)	Chi =3.0 df = 3 p=NS
This area is a place where neighbours looks after one another	72 (287/401)	75 (58/77)	Chi=2.4 df=3 p=NS
This area has good local transport	72 (295/407)	62 (46/74)	Chi=3.3 df=3 p=NS
This area is a safe place to live	78 (315/406)	82 (64/78)	Chi =1.8 df =3 p=NS
This area has good leisure facilities for people like myself	62 (228/369)	61 (40/66)	Chi = 1.3 df=3 p=NS
This area has good local healthcare facilities	86 (333/389)	83 (62/75)	Chi=1.95 df=3 p=NS

% who once or twice a week or more			
Speak to friends and neighbours on the phone	47 (184/403)	59 (43/73)	Chi =5.2 df =3 p= NS
Speak to neighbours face to face	41 (164/400)	43 (32/75)	Chi = 1.7 df =3 p = NS
Meet up with friends or relatives	29 (114/399)	34 (25/74)	Chi=3.6 df = 3 p = NS

Base = All of those reporting LTCs

Those using three or more services were more likely than those using 0-2 services to believe that their area had good local transport, and to believe that their area had good leisure facilities.

Table thirty eight: Number of services used and social capital

	0-2 services	Three or more services	Difference
Mean social capital	26 SD=4 N=268	27 SD=4 N=130	T= -0.7 p =NS
% agreeing or strongly agreeing that			
This area is a place that I enjoy living in	88 (286/326)	90 (145/162)	Chi = 6.0 df =3 p=NS
This area is a place where neighbours look after one another	71 (227/318)	74 (118/160)	Chi=7.5 df=3 p=NS
This area has good local transport	69 (225/325)	74 (116/156)	Chi = 5.2 df =3 p=NS
This area is a safe place to live	77 (250/323)	80 (129/161)	Chi=2 df=3 p=NS
This area has good leisure facilities for people like myself	60 (176/293)	65 (92/142)	Chi=6 df =3 p=NS
This area has good local healthcare facilities	85 (265/310)	84 (130/154)	Chi =2 df =3 p=NS

% who once or twice a week or more			
Speak to friends and neighbours on the phone	48 (153/317)	47 (74/159)	Chi = 2.9 df = 3 p=NS
Speak to neighbours face to face	43 (134/316)	39 (62/159)	Chi = 0.9 df=3 p=NS
Meet up with friends or relatives	28 (88/315)	32 (51/158)	Chi = 3.5 df=3 p=NS

Base = All respondents reporting LTCs

Case study area and service use (Table thirty nine)

There were no differences between the North East and the London case study areas in the percentage of people using either 0-2 or 3 or more services, but in the North West area fewer people were using three or more services, and in the South West more people were using three or more services. There were no major differences in each of the case study areas in terms of the percentage of responders using purely health services and those using health and social services.

Table thirty nine: Case study area and service use

	North East	North West	London	South West
% using 0-2 services N=330	28	28	19	26
% using three or more services N =162	30	20	20	30
% using health services N=413	28	26	20	26
% using social services N=79	29	23	18	30

4.4 Chapter summary

Chapter four described the methodology and findings of a postal questionnaire survey exploring the relationships between self-reported general health, experience of LTCs, quality of life, 'activation' levels, demographic factors, social capital and interest in further research.

Overall, 65% of survey respondents reported living with a LTC. LTCs were associated with poorer self-reported health and quality of life, and with lower levels of social capital and reduced confidence in self-management abilities. General practitioners, practice nurses, hospital outpatients and pharmacists were the services most commonly used by people living with an LTC, with just one in six (16%) using social services. The survey findings highlight the importance of providing self management support as well as formal clinical services, particularly for people living with multiple LTCs.

Next chapter

Chapter five describes a qualitative interview study of older people living with LTCs, and with people caring for a person with one or more LTCs, identified from those who responded to the questionnaire survey. The interviews explore the impact of LTCs on people's lives, their attitudes and preferences with regard to self care and self management. The interviews also focus on the factors that influence people's ability to effectively maintain their own health, to self manage LTCs and to gain access to relevant support and services.

5. Qualitative study – older people and carers

5.1 Aims

5.1.1 Aims of interviews with older people

- To explore attitudes towards, and preferences for, an active role in self management of LTCs;
- To investigate older people's awareness of, and need for, information and support services focused on LTCs;
- To identify the factors that impede or facilitate self management and obtaining appropriate support such as;
 - The extent to which attitudes are shaped by perceived benefits or shortcomings of taking a more active role in healthcare;
 - The extent to which older people integrate self management into their everyday lives and what barriers they face in doing so;
 - Older peoples' experiences of receiving services across organisational boundaries;
 - Difficulties faced by older people in identifying and gaining access to the help that they require;
 - Involvement with existing support and social networks in the local community.

5.1.2 Aims of interviews with carers

- To explore attitudes towards, and preferences for, an active role in self management in those who care for another person;
- To explore how carers cope with caring for others with LTCs;
- To identify factors that impede or facilitate self management and obtaining appropriate support for them and/or the cared for person;
- To explore differences between self management by an individual and care given by carers.

5.2 Method

5.2.1 Older people with LTCs and their carers

Interviews with older people with LTCs and their carers were undertaken to explore their attitudes towards, and preferences for, an active role in self management. They also served to identify factors which impeded or facilitated self management and obtaining appropriate support for self management.

The topic guides used within these interviews with older people and carers are included in Appendices three and four respectively.

The target number of interviews per case study area was ten. However, we acknowledged that this may vary according to theoretical saturation and ease of recruitment.

Identification and sampling of older people with LTCs (Table forty)

A sample of older people with LTCs was identified from those who had responded to the questionnaire survey and were invited to be interviewed. A sample of carers was also identified and invited for interview from those who responded to the questionnaire survey. In all cases, the invitation consisted of a covering letter about the study and an information sheet describing the study and their involvement within it (Appendices six).

From this sample, we attempted to recruit older people from each case study area who were broadly representative of the demographic characteristics of the area. For example, the London area has approximately a 40% non-white population (Office for National Statistics 2009a). Therefore, we aimed to recruit four non-white older people within this area. We also tried to recruit interviewees who had a range of service use if possible.

As so few carers self identified via the questionnaire survey, we sampled carers to ensure that there were equal number of males and females and a reasonable representation across our three age bands (60-69, 70-79, 80 and over).

Recruiting older people and carers

A larger-than-required sample of older people was taken from the database initially to take into account participants declining, or being unable, to take part in the study. A sample of 10 participants was invited and if they were unable to take part, another participant, matched as far as possible in terms of age, gender, ethnicity and service use, was selected.

For the carers, we approached all of those who self identified within case study areas where very few came forward. In areas where enough carers came forward to allow us a

choice, we approached those who allowed us to ensure that as broad a range of carers was included as possible. All potential interviewees received a covering letter, a study information sheet and two copies of the study consent form (Appendices six). If they had not contacted the research team within one week of receiving the invitation letter, they were telephoned to see whether they would like to take part, and if so, to answer any questions and arrange a time for the interview.

Conducting the interviews

All interviews were arranged at a time and place convenient to the interviewee, usually their home. Prior to beginning the interview, the researcher received confirmation from the interviewee that they had understood their participation in the study, and had signed a consent form to take part.

Table forty: Target sampling frame for older people interviews

	North East	London	North West	South West
Age				
60-70	5	5	4	4
71-80	3	3	3	4
81+	2	2	3	2
Gender				
Female	5	6	6	6
Male	5	4	4	4
Ethnicity				
White	9	6	8	9
Black and minority ethnic	1	4	2	1

Semi-structured topic guides was used (Appendices three and four), and with the interviewees' permission, all interviews were digitally recorded. Interviews took around 45-60 minutes on average. Digital files were then transcribed. Topic guides were developed with reference to the previous literature and aims of the study, and by brainstorming within the research team.

5.2.2 Data analysis

- Data was analysed using the framework method of data analysis (Ritchie & Spencer 1994) and was facilitated using NVIVO (v8) software.
- Framework analysis includes;

- Data familiarisation: reading of complete interview transcripts, listening to original audio-recordings and use of field notes;
- Identifying a thematic framework: key issues, concepts and themes are identified and an index of codes developed;
- Indexing, whereby the index generated through identification of the thematic framework is applied to all data;
- Charting: a summary of each passage of text is transferred into a chart to allow more overall and abstract consideration of index codes across the data set and by each individual;
- Mapping and interpretation: understanding the meaning of key themes, dimensions and broad overall picture of the data and identifying and understanding the typical associations between themes and dimensions;
- The charting process provides an opportunity to code data from numerous vantage points, by demographic factors such as gender or age.

We selected the Framework method of data analysis as it allowed the research team to consider variability across the different types of participants i.e. service providers, commissioners and service users and case study areas (Ritchie & Spencer 1994). It also provided us with a transparent method of data analysis within the research team.

5.3 Results

Across all case study areas, we undertook 49 interviews with older people (38) and carers (11).

Table forty one: Number of interviewees by type within each case study area

	Older People	Carers
North East Case study	10	3
London case study	8	2
North West Case study	10	4
South West Case study	10	2

The characteristics of the older people interviewed as part of the study are described in tables forty-two to forty five; the characteristics of carers are described in table forty six.

Table forty two: Characteristics of older people interviewed within the North East case study area

	Age	Gender	Ethnicity	LTCs	Services used
Older person 0277	80	Male	White	High blood pressure, diabetes, eyesight problems, cancer, angina, digestive problems, high cholesterol, pernicious anaemia	GP, practice nurse, hospital inpatient, pharmacist
Older person 0283	78	Female	White	Arthritis, eyesight problems, angina, stroke, high cholesterol, bladder problems	GP, district nurse, home help, social workers
Older person 0358	63	Male	White	High blood pressure, arthritis, depression, asthma, prostate problems	Practice nurse, hospital inpatient, pharmacist
Older person 0326	69	Female	White	High blood pressure, arthritis, diabetes, asthma, hearing problems	GP, practice nurse, hospital inpatient, home help
Older person 0596	64	Male	White	High blood pressure, pain, arthritis, eyesight, angina, bowel problems, digestive problems, bladder problems	GP, practice nurse, hospital inpatient, pharmacist
Older person 0522	80	Female	White	High blood pressure, arthritis, eyesight problems, hearing problems	GP, practice nurse, hospital inpatient, home help
Older person 0525	79	Female	White	Pain, arthritis, eyesight problems, asthma, angina, digestive problems, hearing problems	GP, practice nurse, hospital inpatient, accident and emergency, physiotherapist, home help, pharmacist
Older person 0098	64	Female	White	High blood pressure, pain, arthritis, high cholesterol	GP, pharmacist
Older person 0104	63	Male	White	High blood pressure, pain, diabetes, asthma, hearing problems	GP, practice nurse
Older person 0341	66	Female	White	High blood pressure, eyesight problems, angina, high cholesterol	GP, practice nurse, physiotherapist, occupational therapist

Table forty three: Characteristics of older people interviewed within the London case study area

Code number	Age	Gender	Ethnicity	LTCs	Services used
Older person 14	81	Female	BME	Pain, diabetes, asthma	GP, practice nurse, pharmacist
Older person 0428	68	Female	White	Arthritis, depression, diabetes, angina, high cholesterol	GP, practice nurse
Older person 614	71	Female	BME	High blood pressure, pain, arthritis, digestive problems, high cholesterol, bladder problems	GP, practice nurse, hospital inpatients, accident and emergency, home help, social worker, pharmacist
Older person 0479	60	Female	BME	High blood pressure, eyesight problems, cancer, high cholesterol	GP, practice nurse, district nurse, hospital inpatient, hospital outpatient, physiotherapist, home help, social worker, occupational therapist
Older person 0172	72	Male	BME	High blood pressure, diabetes, eyesight problems, asthma, angina, bowel problems, high cholesterol	GP, practice nurse, pharmacist
Older person 0387	77	Female	White	High blood pressure, pain, arthritis, depression, factor XI deficiency	GP, practice nurse, pharmacist
Older person 0583	62	Male	White	Pain, arthritis, depression, diabetes, cancer, high cholesterol	GP, practice nurse, hospital inpatient and hospital outpatient
Older person 0364	85	Female	White	Arthritis, depression, digestive problems	GP, practice nurse, accident and emergency, home help, pharmacist

Table forty four: Characteristics of older people interviewed within the North West case study area

	Age	Gender	Ethnicity	LTCs	Service use
Older person 0004	92	Female	White	High blood pressure, arthritis, diabetes, eyesight problems, high cholesterol	GP, practice nurse, home help, day centre
Older person 0099	65	Female	White	High blood pressure, arthritis, cancer, high cholesterol	GP
Older person 0295	75	Male	White	Arthritis, cancer	GP
Older person 0464	64	Female	White	High blood pressure, arthritis, stroke, high cholesterol	GP, practice nurse, hospital in and out patients, physiotherapist, occupational therapist, home help, social worker, pharmacist
Older person 0442	69	Female	White	Pain, asthma, hearing problems	GP, hospital inpatient, pharmacist
Older person 0214	64	Female	White	Cancer, digestive problems, thyroid problems	GP, hospital inpatients
Older person 0547	73	Male	White	Type two diabetes	GP, practice nurse
Older person 0173	73	Male	White	Angina, high cholesterol	GP, hospital inpatients, physiotherapist, pharmacist
Older person 0561	70	Male	White	High blood pressure, eyesight problems, cancer, bowel problems, stomach problems, bladder problems	GP, practice nurse, hospital inpatient, pharmacist
Older person 00128	91	Male	White	High blood pressure, arthritis, cancer	GP, practice nurse, hospital inpatient

Table forty five: Characteristics of older people interviewed within the South West case study area

	Age	Gender	Ethnicity	LTCs	Services used
Older person 0007	75	Female	White	High blood pressure, diabetes, cancer, angina, high cholesterol	GP, Hospital outpatients
Older person 0063	77	Male	White	High blood pressure, angina, stroke, high cholesterol, bladder problems	GP, practice nurse, hospital inpatient, hospital outpatient, accident and emergency
Older person 0548	75	Male	White	Hearing problems, COPD	GP, practice nurse, hospital inpatient, pharmacist
Older person 0375	60	Male	White	High blood pressure, high cholesterol	GP, practice nurse
Older person 0619	61	Female	White	High blood pressure, high cholesterol, underactive thyroid	GP, practice nurse
Older person 0099	64	Female	White	Arthritis, asthma, Parkinson's disease	GP, practice nurse, hospital outpatients, physiotherapist, social worker, pharmacist, occupational therapist
Older person 0140	85	Male	White	High blood pressure, angina, digestive/stomach problems	GP, practice nurse, hospital inpatient, pharmacist
Older person 0220	65	Female	White	Pain, arthritis, depression, asthma, angina, digestive problems, high cholesterol, bladder problems	GP, practice nurse, hospital outpatients
Older person 0338	66	Female	BME	High blood pressure, high cholesterol	GP, practice nurse
Older person 0429	73	Male	White	High blood pressure, digestive problems	GP

Table forty six: Characteristics of carers interviewed across the case study areas

Code	Age	Gender	Ethnicity	LTCs
North East Carer 200	60-69	Female	White	Arthritis, high cholesterol, hearing problems
North East Carer 217	60-69	Male	White	Arthritis, depression, asthma, angina, bowel problems, digestive problems, high cholesterol, bladder problems
North East Carer 297	70-79	Male	White	High blood pressure, cancer, high cholesterol
London carer 25	70-79	Female	White	High blood pressure, persistent pain / arthritis, depression, angina
London carer 575	60-69	Male	White	Arthritis
South West carer 371	60-69	Male	White	Bowel problems
South West 143	80 and over	Male	White	High blood pressure, high cholesterol, bladder problems
North West 0331	60-69	Female	White	Arthritis
North West 0487	60-69	Female	White	High cholesterol
North West 0517	80 and over	Male	White	Angina, stroke, high cholesterol, vascular problems
North West 0545	70-79	Male	White	High blood pressure, arthritis, diabetes, cancer, stroke, high cholesterol, Parkinson's Disease

5.3.1 Description of LTCs

A broad range of LTCs (LTCs) were experienced by our participants, from cancer, stroke, and diabetes, arthritis to angina, high blood pressure and high cholesterol. The impact of LTCs varied both in terms of the number and complexity experienced by our participants. For example, many of those interviewed had multiple LTCs which they felt made their self management very challenging, however the impact of having just one or two LTCs for some of our participants could be just as great. Along with symptoms that were directly related to their LTCs, participants also reported associated symptoms such as depression and forgetfulness. Some attributed their forgetfulness to the multiple medications they were taking.

Some participants believed that they were able to directly attribute cause to their LTCs. For example, those in the North East who had worked in the pits, often attributed their breathing problems to the inhalation of coal dust. Across all of the areas, female participants tended to attribute their back problems to past pregnancies. Others had difficulty believing that their problems were caused by anything other than their age, believing for example that their pain was due to bodily degeneration.

Variations in the attribution of causes of LTCs have been noted in previous research. This was noted particularly in a vivid account by Gareth Williams (1984) of 'biographical reconstruction'. Within his study he noted various beliefs and views about the cause of illness, including political causes (the impact of working in hazardous industries such as mining) and more fatalistic, not to say religious, explanations.

5.3.2. Impact of LTCS

Impact on day to day life

The impact of LTCs often depended on the number and type being experienced. If an individual was suffering from multiple LTCs, the impact on their everyday life could be severe. For example, one very elderly woman was virtually immobile.

"I don't go out because I can't walk now....I can walk, but after a bit, it's very, very painful....I can't go to the shops...I can't get on the bus, I've had to stop going to church because the chairs are so hard." Older person 004 North West (92 year old female)

However, rather than the number of LTCs experienced, the key issue for many participants was perhaps the level of bothersome symptoms experienced by them. For example, a participant could have multiple LTCs with few bothersome symptoms, whereas another participant could have just one LTC with several bothersome symptoms.

The pain and decreased mobility associated with LTCs often meant that ordinary day to day activities such as cooking could become very difficult. In particular, many

interviewees spoke about the difficulties that their LTCs presented to them in looking after their grandchildren.

"I mean I've just come back looking after four grandchildren in London and my daughter lives in a house that's like got a lot of floors and I injured my left knee when I was there, so I know, and I've been in great pain, and I had to look after these children, well my husband was with me so it wasn't so bad and he did the top flights you know, but that I find difficult because I hate not being able to get around and do things." Older person 0098 North East (64 year old female)

Others attempted to minimise the impact of their LTCs by comparing themselves to people of similar ages whose health was worse.

In many cases, those who were interviewed still managed to live independently, with the help of their family if necessary. If they were receiving help from their family, participants often reported feeling guilty about this.

"It's very unfair that you're working a blooming sight harder now than you worked when you were at work.

Spouse - Yeah well, perhaps that's what keeps me going.

Well it's bound...it gets you as well dunnit?

Oh yeah, yeah, well it's bound to innit? It makes you tired and that, when I come in here every night you know, and sit in the chair, I'm gone but there you go". Older person 0099 + husband South West (64 year old female)

If their needs became too great, participants reported becoming dependent on personal carers for support with essential tasks. However, problems were sometimes reported with home care arrangements. For example, participants described how their carers failed to arrive at the agreed time and provide the agreed level of support.

"The first one that I ever had, she became a friend of mine, and she was marvellous. Then she left 'cos she had the offer of a very, very good job and I still see her, she'll come to see me and she left and got this very good job, much better than what she was doing, so that was it. So, of course, from then I had all different people come in but all those that come now like the one I've got here, I had her for a little while in XXX YYY Road where I lived but they're always in a rush to get out. From the time they're in the door, they're looking for the book to write down whether they've been or not, now I've given them a lot...and I've given her a lot of leeway. I've let her sign the book, I've let her sign the book and she's not been here, I thought 'oh well, it's her children' but I've been ?? But they don't like it if you say "oh no, you wasn't here Tuesday" then you get a bad name amongst the whole lot of them. " Older person 0364 London (85 year old female)

Far from relieving the stress of living with an LTC, such difficulties increased problems. The need for consistency and reliability in the provision of support for day to day living is underlined here at the outset.

Physical and emotional impacts

As well as pain and mobility problems, LTCs were also said to cause tiredness, sleep disturbance and a general lack of energy. However, the perceived impact of LTCs appeared to vary according to participants' expectations of growing older. For example,

those who had previously been in good health and who had expected to have a healthy retirement were more likely to perceive that their LTCs had a greater impact than those who had expected to have poor health as they aged.

"I feel as though I've been robbed of my old age, a healthy old age, because until 18 months before the onset of the illness I always had a very, very physically challenging job, just not a sit down job in a desk but I was dashing around with slide projectors and this and that and the other." Older person 0387 London (77 year old female)

This finding chimes with Bury's work on biographical disruption (Bury 1982 and 1991). Chronic illness was considered to disrupt people's assumptions about how their lives should be, leading to a rethinking of their biography and their self concept. Therefore, activities which had previously been taken for granted are likely to feel more onerous or difficult with the onset of LTCs, and to require a greater level of deliberation and planning rather than just to be part of everyday life. Charmaz in *Good Day, Bad Days* (1993) also noted the impact of chronic illness on everyday life.

If participants had not received a clear diagnosis for their LTCs, they appeared to be more likely to feel their effects. Without a diagnosis it was difficult to get referred to, or gain awareness of, the range of treatment options that might be available. Despite the generally positive experiences of support from GPs amongst our participants (as will be clear below) some participants reported feeling that they had been dismissed by their GPs, who simply attributed their symptoms to getting older.

Sometimes the lack of impact of an LTC could make it difficult to manage. For example, one participant with high blood pressure who did not have any major visible symptoms found it difficult to monitor her blood pressure as she found it impossible to tell when it was high.

"Yeah, I never know whether I've got high blood pressure, I think that's a total no-no with me because I can feel fine now and they could take my blood pressure and it could be high but it really doesn't give me any symptoms, it's not like I get a headache, I don't get headaches, I don't, there's nothing, no warning sign, so what do you do, I mean, just keep taking the tablets and hope for the best." Older Person 0098 North East (64 year old female)

The LTCs experienced by our participants also had a significant emotional impact. Emotional problems included embarrassment at the visible signs of their condition. For example, one interviewee described her reluctance to wear an appliance to relieve her lymphoedema because of the unwanted attention it drew to her arm.

"It gets hot and it gets itchy.....I don't wear it when I go out now because....if somebody's spotted it and I think, "oh no", you know." Older person 0099 North West (65 year old female)

The distress, anger and frustration caused by LTCs were also apparent. For many people, there appeared to be a clear link between their physical symptoms and their mental health. Anxiety related to your LTC and its impact could result in symptoms being experienced more acutely than in circumstances where an individual found their LTC less distressing. The following interviewee spoke of how she tried to manage the emotional aspects of her LTC but how she was very distressed about its impact on her life.

"As I say all I speak to myself in my head is got to keep going at all cost, I've got to carry on regardless. That's the only way I get through. Well you could sit down and cry, days and days I could sit down and cry my flipping eyes out..." Older person 0220 South West (65 year old female)

Others spoke about how their inability to live their life in the way that they wanted to had led to depression which further increased their difficulties in undertaking the activities of daily living.

"I should be out and cutting that privet for a start and everything is delayed action in relation to day and that, the same with the grass. I generally have that down but I keep saying I'm going to do it, I'm going to do it but it's still, I generally get things done you know what I mean.

Right and why do you think that is, is it just that...?

Well I think, I think what you do is you sit and, I don't know whether you say to yourself, oh will it set me back away or something like that." Older Person 0358 North East (63 year old male)

It was common for interviewees to talk about the impact they believed that the likely progression of their condition would have on their health and their life in future. For example, the following participant who had diabetes recognised that eventually she would need to have injections rather than take tablets.

"I think you've got to accept when you get to my age and you've got the diabetes, it's going to mean eventually having injections, I think you've got to be sensible because there's a limit to the amount of tablets you can have and if they're not doing any good, if they're not making use of the insulin that your body is producing, well there's no alternative really...." Older person 0007 South West (75 year old female)

These findings underline the interplay of emotional and physical aspects of living with LTCs, suggesting that support aimed only at physical symptoms may miss important dimensions of experience.

The issue of distress and discomfort caused by LTCs, may relate, in part, to the difference between 'consequences' and 'significance' of living with LTCs, as noted in Sanders et al (2002). That is, the practical effects of LTCs are what 'management' often refers to, but the significance of the illness – here its emotional dimensions in terms of reduced capacity, dependence and a sense of ageing – are often overlooked, but none the less important.

Impact on social life and social activities

The symptoms associated with LTCs could often curtail social activities which gave participants great pleasure. For example, bladder problems which required the need for participants to ensure that they were always near a toilet. Others reported how their enjoyment of dancing was limited by their health problems.

"[Referring to mobility problems] It's awful isn't it because we've been so, you know, we've been sort of always socialised so much in our life, we've had so many

friends, and you know, going to the dances and everything...But it has calmed our life down a little bit, it's restricted us." Older person 0063 South West (77 year old male)

One of the carers interviewed spoke about how she had witnessed her husband deteriorate: once a barrister with a fine brain he had become someone with major cognitive impairment following a brain haemorrhage and heart problems. Their life outside the home had become severely restricted.

"He keeps saying, "I can't read, can't remember....you say something and it's interpreted in a totally different way....he can't drive....so now we've got a wheelchair. So we don't go out very far." Carer 0517 North West

The interview data demonstrate the variability of the effects of LTCs on social life, from the relatively trivial to major restrictions on venturing out of the house.

Impact on carers of providing support

Amongst the carers interviewed the principal impact of caring appeared to be on their emotional well-being. Interviewees described feeling irritable, impatient, stressed and isolated. They also mentioned tiredness, difficulty sleeping, headaches and back ache as a result of pushing a wheelchair.

"I get a bit impatient because everything's slowed down in my life and I've got to do everything. And because I'm so stressed, I can't sleep properly at night time." Carer 0517 North West

Caring for a close relative inevitably affected their relationships. For example, one carer reported how she felt she had been cheated of the retirement that she had been looking forward to with her husband. Their exchange during the course of the interview indicated a low level tension borne out of the situation they found themselves in.

"Husband: She gave me depressant pills, which I take occasionally.

Wife: *Well you either take them or you don't take them. You don't take occasionally..... if somebody else tells him he accepts it more than if I say.*

Husband: Well we both suffer from that, don't we?" Carer 0487 North West

Taking on roles which were previously the domain of the cared for person was also felt to be a consequence of caring:

"And I mean by the old school where when you got married your men worked to keep you, the women, isn't that right? And the first few years he was unhappy because he felt as if he should be keeping me.

Sure, yeah.

But we're getting through it, aren't we?

Yeah.

We're getting through it but reverse roles, it's very hard." Carer 0217 North East

Finally, another carer mentioned the worries about the impact of a decline in her own health on her ability to care for her husband:

"It's worrying me much more in how he's going to manage if I'm out of action for a bit...it's more when I come back I think the problems will be you know, he will muddle around and our daughter will be marvellous and the neighbour but I think coming back and being very limited in what I shall be able to do." Carer 0143 North West

Financial impact of LTCs

One carer whose husband had Parkinson's disease described his vulnerability, lack of mobility and tendency to depression. But the couple seemed just as concerned about the financial consequences of his illness.

"Every penny we have to watch because so much more is going on the garden...we've had water coming in down the wall....but we've had to pay somebody to come in to take the paper off, somebody to do the gutter, whereas [husband] could do it all at one time." Carer 0487 North West

Respondents, understandably, may be reluctant to discuss financial matters with interviewers. This, in turn, may mask their significance in living with LTCs – a matter rarely discussed in existing research on self management, though wider social research on chronic illness has given some emphasis to material conditions.

Pound's widely cited study of older people living with stroke (Pound et al 1998) shows how chronic conditions can often be overshadowed by other problems in people's lives – especially in circumstances of low income and poor housing. This reinforces the need to see LTCs in their appropriate social context. Health may not always be the overriding 'disruptive' event, where other pressing problems of daily life dominate. The onset of an LTC may be yet another problem to be coped with.

5.3.3. General attitudes towards responsibility for health

A broad range of views were expressed regarding responsibility for health. The majority of participants believed that managing their health was a shared responsibility, but there were different interpretations of what this meant. Some participants accepted responsibility for avoiding an unhealthy lifestyle, by eating well or stopping smoking, but felt that they should be able to seek medical care promptly for their symptoms. At that point the responsibility for managing their condition became the GP's. Whereas others felt that sharing responsibility for their health included both living a healthy lifestyle and working together with health professionals to manage their LTCs.

Those who believed that the responsibility for managing their conditions rested with health professionals seemed to be less comfortable with the technical management and monitoring of their condition. Whereas those who wanted to share responsibility, seemed

to have greater confidence in their ability to monitor their symptoms and manage exacerbations, and were therefore more willing to learn how to do this.

“And how do you feel about making decisions, do you feel you’ve got the confidence to do that?”

Oh aye, I mean he’s explained everything to us about taking too many steroids and things like that, he’s good like that, if he’s gonna try something he’ll say ‘Are you willing to try it? Shall we give it a try and see what happens? Just try them every two weeks or three weeks and come back in three weeks and we’ll see if it’s worked and if it doesn’t work, come back straight away if it’s not worked.

I mean when you said you took the steroids that you had, I suppose I’m talking about when you’re monitoring your symptoms, how confident are you do you think ‘I know this, I know I need to take these now’.

That’s what I say, it’s like the blood monitor, if you’re feeling grouty, if you get up and you’re just lethargic, you don’t nae feel like doing nowt, I go and test my blood sugar and ‘oh that’s 11. summat, what am I doing wrong?’ because you’ve done summat to change it, do you know what I mean?” Older person 0104 North East (63 year old male)

Amongst our participants, those who had previously worked within the healthcare professions appeared to be most comfortable in managing and monitoring their condition.

“So it’s... you know I can more or less know myself if I feel a bit hypo or something. But I think for the ordinary person in the street it would be nice if there was a sort of walk in centre, do you know what I mean, a little walk in centre that they could just go to and sit and talk to somebody, you know that would be nice.” Older person 0326 North East (69 year old female)

The very process of being diagnosed with a LTC led to some people becoming more proactive about managing their health. For others, taking increased responsibility for their health became more important as they grew older and wanted to maintain good health for as long as possible.

Not all of those who were taking responsibility for managing their LTCs were doing so for positive reasons. Some were strongly motivated by their previous poor experiences with healthcare.

“I went into the local hospital, and I was finding I couldn’t walk the first few days, I couldn’t get out to the toilet, I couldn’t wash myself. But on the second day when they came round to wash me, I thought ‘I’ve had enough of this’, got a bowl, A bowl she’s got on the side and a flannel, no soap, perhaps the water was soapy, I don’t know, but of course, I was standing up, put the curtains round, she washed me face, washed my hands and that was all she did.

Oh.

So I said “would you mind washing my back please?” I said “I’ve been round here quite some days” I said “I’d like to feel a bit clean”, she made a bit of a fuss, you know, she went “oh, I don’t know if I’ve got the time”. I said “well if you haven’t, perhaps somebody” anyway she did it in a fashion, sloshed it all over, will a flannel, it wasn’t washed. That went on for about two days and then I thought ‘I’ve had enough of this, I’m gonna try and get out to the toilets and the wash place’. ‘I’m gonna try this, I’m gonna try my hardest to get out’ and I got out there but then it was such a little cubicle to wash yourself in, I had to put my stick up on the door and everything, I’m not very big and I’m sort of cramped. I

thought 'well it's much better doing it this way; I'll get on with it than have her performing'." Older person 0364 London (85 year old female)

The importance of being aware of and listening to your own body was emphasized by participants as this enabled them to identify when things were normal and when things were going wrong. The belief in the necessity of looking after yourself was matched by a sense of pride in quite small steps towards managing a condition.

"I walked a good ten minute walk I did, to the market from the hairdresser's and I was very, very pleased about that....and me blood pressure is perfect, it's been perfect for a long time...I'm very pleased with that now." Older person 0464 North West (64 year old female)

It was also felt that by being proactive, problems could be anticipated and avoided. Amongst most people there was a desire not to let their condition dominate their lives. This meant trying to avoid visits to the doctor or taking too much medication, whilst still accepting that there might be times when it was necessary to seek help.

"I don't live in the doctor's, far from it....I think it's my responsibility to look after myself...of course, it's a challenge and it's one I accept....if push came to shove and things really got into a mess, I mean, yes there is help available, but ...I don't expect people to have to come in and look after me." Older person 0295 North West (75 year old male)

Participants were less likely to take responsibility for their health if they thought that their GP already informed them of all of the help available and they did not need to try anything else.

Finally, some participants had a degree of fatalism in their attitudes to their health believing that their condition was unlikely to improve regardless of what they did. Others believed that they had brought their conditions on themselves, and so it was not worth doing anything to help themselves. One interviewee recognised that he had probably contributed to his own health problems whilst another felt it would be his own fault if his condition deteriorated.

"It's probably my business that I'm stuck with it [angina] in the first place...having been a fairly heavy smoker at one time, which I think is the prime cause of my heart problem". Older person 0173 North West (73 year old male)

"If I ever get to that stage I can only blame myself...It's like people who are obese and they do a lot of whingeing about...not getting the right treatment....it's down to them...so I've got that outlook on life, it's down to me." Older person 0547 North West (73 year old male)

The concept of fatalism has been widely noted in many previous studies on health beliefs (Blaxter 2010: 59/60) though, as discussed in this Report, Blaxter sees such beliefs as part of a wide range of illness attributions, including the constraints of poverty, heredity and stress. The moral dimensions of respondents presenting themselves as good 'active managers' has been noted in recent research in London by Radcliffe and Morgan (2009)

Our findings show that older people, despite some expressions of fatalism, were keen to demonstrate that they were as active as possible, and were managing their condition within the limits of physicality and age. As we shall see, however, confidence in managing the detailed practicalities of LTCs was more varied.

5.3.4. General experiences of care

With a few exceptions, participants were generally pleased with the care they received from the NHS, and in particular from their GP. In some cases they valued the relationship with their GP so much that they were willing to travel several miles rather than changing to a more convenient practice. For our participants, continuity of care was paramount.

"Mine's lovely. She's not local....it costs me £11 to go and see her in the taxi.....I've gone to see her since I've been in [case study area]And she was near my home....she is a very, very good doctor....she is so good and so helpful and she's so caring, I couldn't lose her." Older person 0464 North West (64 year old female)

People were particularly satisfied with their GP if he/she took the time to explain their condition to them and worked with them to find new ways of monitoring and managing their LTCs. They were also satisfied if they felt that they had been quickly referred to services, and if they were able to see a doctor of the same sex.

However, as we have noted earlier, not everyone was satisfied with their GP. Some participants felt ignored and dismissed, either because they were an older person who should expect to experience particular symptoms, or in one case because they were male and they thought that the GP did not believe that they needed support.

"I was walking a dog and some idiot walked, well I didn't know it was happening, they overtook a car up at local town there and he wiped the Border collie out and hit me with a wing mirror on this arm. I used to think I was only what an inch away of being wiped out myself. And I went to the doctors mind, mind these doctors here mind these, they're hopeless."

Right, I was going to ask you how they, how, whether you felt you had support from them or not.

I don't get no support at all. No. I said about, what's the word for it when you know if somebody's gone through a traumatic thing and you want a little bit of, what's the word for it, a consultation about it.

Counseling?

Yeah, and he just says, well I'm not doing owt. So well they must think because you're a man that you can come to terms with it." Older Person 0358 North East (63 year old male)

Others spoke about the difficulties in receiving a diagnosis for their LTCs from their GP and hospital specialists and the impact that this had on their ability to receive appropriate treatment for their conditions. One participant spoke about her frustration at an apparent failure to diagnose a chronic pain in her upper jaw, despite a succession of appointments with different specialists.

In general, however, lower levels of satisfaction were expressed with health professionals other than the GP, particularly within acute care. For example, in some cases there were long waiting lists to see consultants or for operations due to problems

in the local health care system. Interviewees also criticised the poor communication between different departments. In both the North West and North East case study areas, there was a perception that certain local hospitals were better than others.

"But I feel that the hospitals aren't doing what they should to her. We get better service if we go to North East town X rather than North East town Y, there's a bigger waiting list for operations. In fact, her daughter-in-law's sister is going into hospital for a new knee, she's only been waiting three months, and my wife's been waiting over two years. Different GP surgery, so whether the doctors are a bit lax in our surgery or not I don't know." Older Person 0277 North East (80 year old male)

Others spoke about a loss of faith in the medical profession, meaning that they felt uncomfortable either in going to the local hospital or in seeing particular consultants.

"He then told me that my kidney functions were down 50% and that I was deficient in Vitamin B12. Now I've been having blood tests for goodness how many years because of the prostate cancer and the other problems that I'd got and nobody ever told me. And I came to the conclusion I'm dealing with a lot of clowns." Older person 0561 North West (70 year old male)

Having said this, across all of the areas the support received from the pharmacist was, in general, particularly valued. Many of our participants were on multiple medications for their LTCs and a key way that they felt they could help themselves was by managing their medicines more effectively. In all areas, pharmacists offered medication reviews, medication deliveries and advice, and the tools to manage medicines.

"My wife made an appointment for me to see the pharmacist, so I said what for. She said well I'm getting a bit worried in case you forget one of your tablets and I won't know what to do, so they're liaising with my GP, and they're going to make all the medication, the tablets, and they'll bring me the tablets."

What, the GP is going to do it?

Yes, so they'll bring me a tray full of medication each Monday, so that's fine, because she hasn't got to sort it out, the tablets will be in each of the four compartments and she doesn't necessarily need to know what they are, as long as she knows that that's the morning dose and so forth.

In any case, we've a very good liaison with the chemists in North East town. If you tell her you've got a prescription in, they'll collect it from the doctors surgery and bring it up. I'm friendly with the chemist. And sometimes when I've run short of tablets I'll say can you just give me a couple to tide me over until I get a prescription, and he's very good, Dr XXX. So on the whole; I've got a good chemist service and a very good doctor service." Older Person 0277 North East (80 year old male)

However there were some problems with the support provided by local pharmacists. A particular issue in the North East case study area concerned the practice of issuing 28 day rather than three monthly prescriptions. This provoked a great deal of anxiety amongst older people who were concerned about running out of their tablets before they received their new prescription. Indeed, one participant described how they had often told the pharmacist that they had lost their prescription to obtain another set of medications, which they were then able to keep in reserve.

"I mean the other thing I've got a big problem with, I can only get a prescription for a month, that month goes (clicks her fingers) like that, and then I get to the point and they're for high blood pressure, these tablets, I'm frantic because I haven't got, I haven't got time to get there and of course I go to the chemist who knows me, I go calling them and I say 'can I borrow two tablets to see me over the weekend' and I know maybe I should be more organised but three months, at least if I wasn't organised I would only have to panic every three months..."

I took a week, well no two weeks supply and I said, and this is terrible because this is really putting myself in a bad, bad light, I just said 'could you, I've lost my tablets' so I've hoarded, that's what I've done, I've hoarded a fortnight's tablets so every time I panic that I can't get them..."

You know you've got some.

...I know I've got them. And if they think that's wrong, I think it's very practical because at least I haven't got this high blood pressure for 48 hours, you know."
Older person 0098 North East (64 year old female)

Participants spoke about the importance of the GP and the pharmacist having a good relationship. In the North East and North West case study areas, pharmacists were able to collect prescriptions from the general practice and make them up. The older person was then able to go to the pharmacist to pick up their medications, rather than having to visit both their GP and the pharmacy in order to obtain their medication.

The views of medicines use amongst older people within our study can be seen to relate to the need for what May et al (2009) have recently called 'minimally disruptive medicine', in which the importance of tailoring treatment regimes to the everyday lives of patients with LTCs is emphasized.

The majority of our participants appeared to be obtaining support from health rather than from social services. There seemed to be a certain reticence amongst participants across all areas to access support from social services even if the support offered was similar to something they could obtain from the health service. Clearly health care support is still seen as a right compared to the various negative associations attached to social services. However, those who were receiving support from social services were particularly satisfied if they were contributing towards the cost of the support provided.

5.3.5. Self care and self management activities

The self care strategies employed by older people were many and varied and perhaps can be most usefully separated into five types. Firstly, our participants saw general health living as a key part of their self care and self management. Secondly, participants spoke about the various strategies, aids and methods which helped them to maintain their independence. Thirdly, participants spoke about more formal self management activities such as monitoring their blood pressure, and attending self management classes. Fourthly, participants spoke about informal self care strategies which they or their friends and family had helped to develop. Finally, some participants spoke about choosing to experiment with complementary and alternative treatments.

Some of these strategies needed support for their implementation, either from a health professional or from a spouse or other family member. Support was most effective if

participants had a good relationship with the person providing support. Participants spoke about the need to know when to have battles with their GP and when to defer to their expertise, and about the importance of health professionals explaining their condition and their treatment as clearly as possible. Support from family members was particularly valued, perhaps because it was from trusted individuals and was easy to access. Participants gave a range of examples of how their family members supported them, including helping them to stick to their diets if they were diabetic, finding out information about their condition, and devising exercises for them.

"My eldest son, he insists on me walking.

Did you go for walks out?

No, we don't go to a long walk because he says "it'll put you off", so he'll walk me; we have a new Asda in?? and he...

Right and they're always massive (laughs).

Yes, and we have a big Tesco in North East City, 24 hour Tesco in North East City, so he sometimes takes me there, puts me in front of the...you know the trolleys? Which is much the same as that thing and then I can walk all round Tesco's and that's walking.

Absolutely, yeah, yeah. As I say, they're always massive so (laughs).

So his ingenious ideas of getting me to walk." Older Person 0283 North East (78 year old female)

Many of the strategies employed by participants were discovered through trial and error, observation or experimentation. Participants often relied on their knowledge of their symptoms and their body, and what did and did not work for them.

Some participants mainly focused on healthy living and the use of aids to maintain their independence, perhaps because they believed that more formal self management and self monitoring activities were the remit of their GP or practice nurse. Others were fairly actively engaged in self management and self monitoring and felt supported by their GP and family to do this.

The idea of lay people developing and employing 'strategies' in managing LTCs was part of Bury's approach in a review of current and future research on chronic conditions (Bury 1991). We briefly illustrate below the five types of strategy found in our data.

General health promotion / preventive health

Virtually all of our participants had taken on board the importance of eating a healthy diet and of exercising. In the case of the men interviewed, support to maintain a healthy diet was usually provided by their partners, although one single man had joined Weight Watchers to help him keep to a sensible eating regime.

"I mean I go to Weight Watchers, you know hopefully trying to lose a bit of weight, but it's always been a struggle that, so I do all my own cooking etc and I'd rather cook things myself than buy things in....it keeps me on me five fruit and veg a day sort of thing and I find that a big improvement anyway." Older person 0295 North West (75 year old male)

Those with diabetes appeared to have accepted the message that there are foods that are safe for them to eat and foods which are not, and that it is best to keep to the safe foods with the occasional treat.

Other general health promotion strategies included trying to get as much exercise as possible and preventative measures to ensure that symptoms do not develop or worsen when the immune system is suppressed, such as avoiding stress and taking vitamins and supplements.

"But if I get a cold I try and deal with it straight away, or try and get some antibiotics, which is a nuisance. I know they don't do any good for a cold, but it does stop a secondary infection should there be one." Older person 0214 North West (64 year old female)

A large part of the preventive health activity for older people meant ensuring that they attended medication reviews and regular check-ups, to obtain the support from the GP or practice nurse that they required.

Methods of maintaining independence

For participants, independence included being able to continue to live in their own home and to continue to do the things that they wanted to such as playing sport or travelling.

Participants in the oldest age group spoke about the importance of practical aids to help them to maintain independence, such as hand rails, grab rails, frames and walking sticks. Pendant alarms were considered particularly useful as they enabled participants to call for help if needed and provided a sense of security.

"You pay for this, £15 a month to the local Council, but its well worth it. It's well worth it because you have the telephone and you can get in touch with them if you wanted anything.

And you've got these pendants as well.

And I've got a pendant, so I think it's a good idea." Older Person 0283 North East (78 year old female)

Participants reported varying levels of difficulty in being able to access such aids. Some had been able to acquire them from social services following an assessment; others had purchased aids either because they thought that they were unable to access them via social services or because they were reluctant to approach social services.

Formal self management and symptom monitoring

More formal self management strategies included blood pressure and blood sugar monitoring, pharmacist devised or self devised medication taking systems, diary keeping of self management activities, and managing exacerbations with a home stock of medication. In general participants were keen to monitor their symptoms. However levels of confidence in doing this varied greatly. Those who were less confident were more likely to turn to their doctor, whilst those who were more confident felt able to manage at least minor exacerbations or symptoms.

"And at the doctors do they monitor you?"

Every year. The only thing is, I saw her about a fortnight ago and she said I think I'm going to get you to monitor your own blood pressure at home. She said I think yours comes up when you come to see me.

And how did you feel when she said can you monitor it at home? Did she suggest how or?

She didn't and I haven't heard anything since. But I thought so what; well what am I supposed to do? I don't know, I don't understand this. I don't know what you are supposed to do to alter your blood pressure anyway. Think nice thoughts (laughter) I've stopped smoking, I don't drink, so I can't... I mean, well what else am I supposed to do? Stop eating?" Older Person 0341 North East (66 year old female)

One very elderly woman, who had been a nurse, was fairly proactive in managing her arthritis and diabetes. Not only did she test her own urine and watch her diet, she also made sure that she took as much exercise as possible and kept her brain active by watching quiz programmes on television.

"About two or three times a day I do a round of walking for about 20 minutes on that [Zimmer frame] to keep my legs walking otherwise they soon pack in if you don't use them." Older person 004 North West (92 year old female)

A male interviewee with diabetes did similar things but was also monitoring his blood pressure and was keen to explore the possibility of checking his own cholesterol level.

"I've read recently that there is a little machine coming out that'll be able to do that....I'll definitely get one of those as well....but I know that my eating habits and my lifestyle, I know I can control the cholesterol dead easy....I'm always below 4, well below." Older person 0547 North West (73 year old white male)

Just two participants had attended a self management course which both found to be useful. They believed that the courses helped them to learn about their condition and its management, and increased their confidence in the ability to manage it. Although such courses were viewed positively, not all of the advice offered was thought to be suitable for older people, for example symptom diary keeping was considered to be particularly difficult to do, especially if suffering from something like chronic fatigue syndrome.

"It was useful, everything was very useful, yeah and we took everything in, it was very useful but it doesn't make any difference to the pain. You've got it; you know you've got it" Older person South West 0220 (65 year old female)

Similar mixed responses to self management courses such as the EPP have also been reported by Rogers et al (2007) and by Rogers, Bury and Kennedy (2009).

Informal self care strategies

Informal self care included strategies which have been developed by the older person or suggested by a friend or family member, such as stacking a pillow under the knees when sleeping to reduce pain, using heat and cold to manage symptoms, and knowing which receptionist is likely to be the most helpful and flexible at the local health centre.

Distraction was a key strategy for some participants. This included ensuring that they had enough pastimes to take their mind off their health problems. For example, one

participant described how she used distraction to help her through her first 'quit day' when giving up smoking.

"I planned it you see, so I planned to stop smoking on this particular day and all that so on that particular day I went somewhere where you couldn't smoke, the XXX Museum, and I spent the entire day in the XXX Museum, it's a huge place...

It is, yeah, yeah.

I took sandwiches for me lunch so I come outside in the beautiful August sunshine and eat me sandwiches and drink me drink, keep away from the people whom were sitting there smoking, then go back in to the XXX Museum so that was my first day of being a non-smoker and when I got home here oh I suppose, it was quite late I got home, I didn't have any cigarettes here, I didn't have no ashtrays, I didn't have anything here and so that was my first day and because I was tired I went to bed early and it was the next morning when I got up because you get up in the morning and you have a fag you see, so it worked out." Older Person 0428 London (68 year old female)

Another key informal strategy concerned maintaining continuity of care with their GP. Participants valued having the same GP who knew them and their condition inside out and who was able to provide a good level of support. In order to maintain this continuity, as noted earlier, participants reported travelling on several buses to see their GP, even though there may have been another practice nearer to their home.

"When I came up, I used to be living in West London but I had a bad marriage and I had to run so I was living at XXX Estate and I joined the doctors down there. They are good to me, I have no complaints, if it's anything for hospital, they'll send me to the hospital, they send me to the eye hospital, and I have no complaint. And if I'm not feeling well, I'll call them, they will come up here to me which is very good.

You said you have to go quite a way to get to your GP.

Yeah, it's from here...I have to change sometime, its three buses." Older Person 0014 London (81 year old female)

Informal strategies are, by definition, difficult to evaluate in formal assessments of self management activities, but they nonetheless remain important in everyday settings.

Experimentation with complementary and alternative treatments

Some participants reported trying a range of complementary and alternative medicine treatments even if they were uncertain as to how they worked. For example, those with chronic pain reported using TENS machines and magnetic wands because their pain was so severe. Others reported positive experiences of attending local training schools for low cost complementary therapies which gave them a great deal of symptom relief.

"I go to college on a Friday morning, local town, for massage.

Wow, that's nice, yeah.

They're brilliant and the students are brilliant and I'll say to them "get into here, get into here for me and up here, oh" I says "there's time I sit and nurse my neck" Older Person 0525 North East (79 year old female)

5.3.6. Factors influencing the decision to self manage

Several participants wanted to maintain a good level of health for as long as possible so as not to burden their family. In many cases this was related to participants' past experiences of looking after elderly relatives which had led to a belief that they did not want to impose on their own children. One participant had experience as a nurse and of caring for both her mother-in-law and her late husband. She was determined not to be a burden on her own family.

"I've always had to look after myself. I was married for 40 years and in that time, I only had 4 years when I didn't have an invalid to look after....so I've always had to tackle things myself, take responsibility for things." Older person 004 North West (92 year old female)

Others wanted to emulate the longevity of family members, and for this reason were keen to remain as healthy as possible for as long as possible.

"My father was a slimmer version of me to say the least because his side of the family there's quite a bit of longevity, he was 95 before he passed on, his cousins were in their early 90s...so I hope to emulate them...so yes, I think lose a bit of weight would be a good idea." Older person 0295 North West (75 year old male)

Related to this, if participants were concerned about dying at the same age as their parents, then reaching that age sometimes increased participants' motivation to remain healthy.

In some cases people's previous work experience seemed to influence how they managed their health. For example, it appeared that those who had assumed a relatively high level of responsibility brought the same approach to their health care. One woman described how she had recruited her own personal carer through the Direct Payment scheme.

"I worked for the Job Centre for 10 years.....I know how to interview so I mean I said that if I can't choose somebody thenI'm not worth anything." Older person 0464 North West (64 year old white female)

Some participants reported very bad experiences in accessing and receiving healthcare in the past which had led to disillusionment with the medical profession. This led one man to begin his own self management strategy for a range of health problems that did not seem to respond to medication.

"I used to be bouncy and energy and everything.....this is not me and so this is really why I decided well I've got to do something about this and if nobody will help me, I've got to help myself." Older person 0561 North West (70 year old male)

Factors, amongst a few respondents, influencing the decision **not** to self manage included feeling that you already knew everything that you needed to about your LTC, and that it would be unhelpful to know any more. Others spoke of a certain level of stoicism about having a health condition which was hereditary, and how they felt that

this might inhibit them from self managing, as they did not feel that there was anything that they could do to prevent their condition.

5.3.7. Barriers and facilitators to self care and self management

Barriers related to the LTC

The majority of participants appeared to be prepared to undertake some form of self care and / or self management, but they were also aware of the difficulties inherent in choosing to do this. The side effects of their medicines and the symptoms of LTCs such as weakness, tiredness and pain could act as a barrier to self management, as participants reported that they did not feel well enough to self manage. For example, pain could make it difficult to exercise, which in turn could make it difficult to lose weight and make joint pain worse. One participant spoke about the difficulties of exercising when she had actually been banned from the local leisure centre because her blood pressure was too high and it was considered too great a risk for her to exercise there.

"But the blood pressure, I went for years and I'm on the maximum amount of tablets and at one point they couldn't get that down, and they told us I was walking around like a time bomb. They banned us out of the leisure centre at the time because it was so high they wouldn't take the risk. So they sent us through to this professor at local town and he gave us another tablet and that got it down." Older Person 0341 North East (66 year old female)

Having a LTC under control and then becoming diagnosed with another problem (not uncommon in this older age group) could act as a barrier to self management. The individual might feel so overwhelmed by the symptoms caused by a LTC that he or she would not have the energy or ability to self manage.

Without a definitive diagnosis for their health problems participants were unsure as to the course of action that they should take in terms of self management. Sometimes they reported resorting to somewhat unsuitable solutions to their symptoms.

"The only comfort I get is eating and I'm eating too much.....I wish I was three stones lighter and I have to really do something about it.....I really feel eating makes me more relaxed." Older person 0442 North West (69 year old female)

The need to spend considerable time on treatment regimens could have unpleasant consequences. Respondents spoke about how they felt 'trapped' by their medicines and by their various inhalers and blood pressure testing equipment. Some reported how they had occasionally tried to do without them and how this had sometimes made them feel even worse.

Treatment regimens and their important consequences is an issue that has been prominent in social research since the pioneering studies by Strauss and his colleagues in the 1970s (Strauss 1975). It still needs to be taken into account in any evaluation of interventions with older people living with LTCs.

Carers' perceptions of barriers to self care and self management

Carers reflected on how the nature of the condition in the person concerned often made it difficult to encourage self management. For example, the mood swings associated with epilepsy meant that medication sometimes had to be enforced and commitment to courses and self help groups was difficult to sustain on a regular basis. For others a fear of falling and lack of energy meant that mobility was restricted and exercise had to be limited. One carer spoke of her husband's inability to perform simple tasks following his cerebral haemorrhage.

"He forgets the sequence of things.....you need to somehow just give him the prompts of what he should be doing or how to do it, it's not coming naturally like it used to do." Carer 0517 North West

Yet another spoke of the exercise bike and walking frame that remained unused. But there were times when this carer felt it would be counterproductive to try and encourage her husband to do more.

"We've been married nearly 50 years.....I think I know when he's ready for something or he's not....you've just got to play it by ear haven't you, it's sort of one day at a time isn't it?" Carer 0545 North West

Self perception barriers

The effect of a LTC on participants' self image could also determine their willingness to self manage. Some began to see themselves as older, and were perhaps less likely to self manage as they were uncertain as to whether it would be helpful. By contrast, others felt that they were too young to access some forms of support.

"At 65 I don't think I'm old, old enough for old age stuff if you know what I mean...I mean because of my health, yeah. I mean I need things but I don't feel old that I've got to go like the Age Concern. To me that's somebody over 70... 80 odd, you know." Older person 0220 South West (65 year old female)

Within the North East, some participants had been signed off on long term sick leave for a very long time, in one case for 25 years. This appeared to lead to a great deal of depression and anxiety in those who were affected and a cynicism about any support that was available.

"And I went down, I went down to the dole and there was supposed to be careers advice, and I says, I've come in, I've finished that course and there'd be careers advice. And he said to me "have you not got any health problems?" And I said "well why is that like?" He says well, he says "if I was you, you've got a bad back and this, that and the other; I would go down the doctors and get your sick notes out".

Sure, sure.

But the careers advice he said, I think the Conservative Government was in and them was that was for it to get the dole statistics down for you to claim sick instead of dole at that particular time.

And I ended up, I ended up I went to the doctors and I'm trying to think what year that was when I said, I don't know if it was about 1991/2/3 something like that. I think it was about 1993 and I ended up on the sick and now ultimately

I've been on the sick ever since. But they've tried umpteen times to get us off like." Older Person 0358 North East (63 year old male)

As children left home and lives narrowed, some participants felt they had lost their main reason to stay fit and healthy. One spoke about losing her motivation to exercise or eat healthily because she was no longer bothered about fitting into a new dress.

"I suppose when you get to a certain, you know, you always have the kids to run after and you've had a schedule where you've got to do this, do that, be on time for everything, and then all of a sudden the last one's left, she's just been married, so it's the empty nest syndrome so you haven't got any regime of keeping yourself fit. I mean I don't go to the gym, I don't do anything, I've got weights upstairs that I can do, but you know, I'm not organised enough and I'm not motivated enough, I find the motivation's not as strong as you get, I'm 64, when you get to a certain age your motivation's not as it used to be. You know, it used to be worried in case you need a new dress or whatever, you know, and you'd sort of go on diet and things and I don't do that now. So that is a bit of a sad part of life, you know, you just sort of think 'oh well'." Older Person 0098 North East (64 year old female)

Access and cost barriers

Some participants found it difficult to access support such as aids and adaptations for their homes.

"I'll tell you what I think is rather unfair though. I have a Piper alarm round my neck. Now my daughter....she had a new hip this year so she's got a Piper alarm. In [nearby area] she pays £16 a quarter for it....do you know how much we pay? £42.25.....I think that's an awful difference." Older person 004 North West (92 year old female)

Others had funded adaptations to their home using money from equity release on their houses.

"And we took an equity release on the house to have the kitchen done and the shower room and all the rest of it...and I lost a bit a Invalidity Benefit that I was having because they say I can cope now because I can reach [the cooker]...which to me is all wrong." Older person 0220 South West (65 year old female)

For those who were able to access and afford aids and adaptations there was sometimes a reluctance to use them due to the discomfort and embarrassment that they could cause. Related to this was anxiety about attending lunch clubs, or support options due to mobility problems. For example, some spoke about their embarrassment when accessing a building or transport to a particular facility.

In the North East, there was a particular problem with accessing various support options by public transport. Public transport provision in this area was poor and irregular, and many of the support options were located in just one town in the area.

"How easy is it to get your appointments?"

Well for local town two I've got to be taken with a car, when XXX goes, the friend across the way, her daughter or son takes us you see, but you see, she's had to have a break because she's been in hospital. So they're coming to take me tomorrow.

It's like the hospital taxi scheme in't it? I can't remember its name. The transport thing, isn't it? I've got a card there you know, I'm a member; I've got a card (looks for card). Travel Response, that's it.

That's the one, yeah.

Right, oh that's alright, and this is free, is it?

No, you pay so much, don't you. So much a mile.

Oh, is this the one that's about 50p a mile or something? Right, right.

Well it would work out very expensive to get to local town two.

I could have got him you see, to take me. Well 50p a mile to local town two, it's quite a lot of miles." Older Person 0525 North East (79 year old female)

Some participants in the North East and London areas did not want to attend self management support or general support groups if they were held in the evening. Their main concerns were the fear of crime and anti-social behaviour in their local areas.

"Well I did start going to one with XXX's church, it's call a Friends Group. But I'll tell you why I stopped going because it was always an evening and I really don't like to be out in the evening. I would rather get in at tea time, like thousands of other people, they lock the door and you know. Now we don't (sighs) well I can't say we don't have the problems here, we obviously we do, we have cars being stolen and you know you get crowds of kids on the corner and this kind of thing. And I prefer evenings in, now morning or afternoon yes, I wouldn't mind being in something like that morning or afternoon but evenings I'm quite happy to be at home. So I haven't joined any..." Older Person 0326 North East (69 year old female)

Within the London area, participants spoke about the difficulties in accessing GP care. Some who had recently moved house were experiencing difficulties in registering with a new practice. Others had been allowed to remain at the same practice even if they had moved house, but this often meant that they had to travel a long way to see their GP. Whilst we have noted that this was preferred by some respondents, others found the prospect daunting.

"And these polyclinics that they're talking about, we had them before, they used to call them hospitals, you know, they're called 'hospitals', and they're not even waiting for it to be built in nearby area, they're moving people about this end of case study area and you just can't register with a doctor in nearby area, you go and their lists are full, they haven't got enough doctors.

Yeah.

You know, you're chucked out the postcode you're in, you're registered with, into a postcode like here, over 50 years we've been with our doctor who's door to door on the bus that goes outside, he's 5 and they want to close the branch at, surgery there, you know, and we're to come back to nearby area, where?

So you've got to get a new doctor, is that what they're saying?

It's out the question, we can't walk anyway, to do anything, it's door to door on the bus here. But they'll have their way." Older Person 0387 London (77 year old female)

Also in the London area, participants spoke about the difficulties of getting support from their pharmacist. In some cases they were described as unwilling to deliver medicines or help with medicines management.

"I had the same chemist for years in XXX, on the corner. Up to six months ago, he started getting very shirty, 'I've got to go down to the chemist'...no, 'I've got to go back to the doctor to pick up the prescription and then I've got to bring it back to the surgery.' I can understand this 'and then I've got to bring it back to the shop and then it's got to be done there, then I've got to come back again to you', well I understand. The man was running off his feet so then I changed it, I thought 'well, I can't have the man keep moaning at me all the time' so I changed it to AAA's Chemist in XXX YYY Road." Older Person 0364 London (85 year old female)

The need for information and help with medicines and LTCs has also been called for by Barber et al (2004). Such support is especially needed when starting new medication.

Information, knowledge and confidence barriers

Although self monitoring devices were used successfully by some participants, others were concerned that such devices would be inaccurate, and so did not feel comfortable in using them.

Participants also reported difficulties in managing their medicines. Some participants believed that they were on too many medicines and had difficulty in knowing what they were for or in being convinced that they were actually effective.

"Well I've got so many and I keep going 'what the hell are they all for', you know, I can't seem to get to my doctor and say 'why do I keep having to take all these'. It's like you go down there with a headache and they give you an Aspirin and you're on it for the rest of your life, I never seem to come off of anything." Older person 0063 South West (77 year old male)

Participants believed that having more information about their medicines, particularly their side effects would be very useful. This increased information was believed to be very important in improving their ability to self manage.

Facilitators

Individual outlook on life

One of the main facilitators for self care was a happy, positive outlook on life often reinforced by supportive partners. Part of this positive outlook was having enough willpower to stick to any health advice that had been given.

"I work with a nurse....she looks after me. I haven't seen a doctor now for two years and I'm quite happy about that because she knows what she's doing, she specialises in diabetes." Older person 0547 North West (73 year old male)

However, many participants felt that it was important to give themselves a treat every so often to help them to maintain their diet or exercise regime and give them something to look forward to.

Technological facilitators

Participants reported how improvements in technology in recent years had made managing their LTCs easier, for example the availability of disposable needles for those who are diabetic, obviates the need to boil and reuse needles. Others spoke about the ready availability of inexpensive blood pressure machines which helped them to monitor their symptoms.

Receiving support from and giving support to family and friends

Although family relationships were central to many respondents' lives, it is important to note that the degree of support provided by friends and family very much depended on individual circumstances. It was clear that a supportive partner was an essential part of managing an LTC for those who were lucky enough to have one. Husbands, wives and partners offered practical and emotional support. They assisted in the management of medication. They were often principally responsible for the maintenance of a healthy lifestyle, and provided encouragement during difficult times.

"We seem to plod along at a steady place...if you can try not to worry.... [Husband]'s very conscious. He sort of tries to ...not keep things from me, but he'll say, "oh don't start getting upset over it...just don't think about it." Older person 0214 North West (64 year old female)

For those who lived on their own, this kind of support was lacking and there was a reluctance to rely too heavily upon children who might live some distance away or who were thought to be too busy with their own lives.

I've said that I don't want to be a nuisance to my family. Well, I've only got two, but one's 20 miles away and the other's about 58. Older person 004 North West (92 year old female)

However, others felt very supported by their children and reported that they would drop everything for them if they needed them to.

"And would you say there's anybody else other than your wife...the health services that you get, any support for your long term health problems?"

No, it's the shame, it's mainly by the kids, if owt ever happens then the kids are here straight away, but as I say, daughter just lives just over a mile up the road and son's down in London now, so it would be mainly her. The last time I took bad the boy was living at North East City, I think he was over the river somewhere, he was straight here like, and took me to hospital. But the wife, she keeps us right, if ever me problems?? I see Dr XXX, to me, he's good." Older Person 0104 North East (63 year old male)

Neighbours and good friends were also highly valued, particularly if they had also been through similar experiences.

"If it become so that I couldn't drive myself there...my friends said, "oh, don't worry, we'll get you there." In fact there was one day me car broke down and my friends...just around the corner took me up to the hospital and back again." Older person 0295 North West (75 year old male)

As well as **receiving** support from friends and family, participants also **provided** a great deal of support to their friends and family. Many reported how they enjoyed being able to do this and feeling that they were doing something useful. Some reported how they became disappointed when they started to find it more and more difficult to provide support as they grew older.

Although our participants were very grateful for the support that they received, they were also conscious that they did not want to be 'fussed over' and that they wanted to maintain their independence. Support was therefore particularly valued if participants knew that it was there if they needed it but that they did not feel overpowered by it.

Although support from family carers was beneficial to many participants, some of the carers interviewed reflected that a reluctance to agree to any external support could make it difficult to encourage self management.

"I don't think my mum had ever have anybody in to help because me dad again, it's all him, you know, she said 'oh he wouldn't like it' you know." Carer 0371 South West

Despite advice from health professionals or carers or family members, the cared for person still had the final say in whether or not to engage in self management.

"[Referring to exercises] He didn't do 'em and they kept saying to him 'you should have a walk round the block' because they were both OK then, but he never, ever done it. ... But, no he don't get, well he don't get about because he don't, he sits in the chair all the time, you know he don't want to." Carer 0371 South West

5.3.8. Current experiences of support

Most of our participants received support from their GP, practice staff and hospital specialists. As noted, community pharmacy services were also widely used for the collection and home delivery of prescriptions. With a few exceptions, people were completely satisfied with this support.

"He's [pharmacist] very good, he's like a personal friend really...I pick up the phone, ring him and say I need my new prescription...his assistant goes down to the surgery and puts the prescription in for signing and usually the process takes about 3 days and I pick up my pills." Older person 0173 North West (73 year old male)

However, some participants were dissatisfied with their GP care and were concerned that they were unable to challenge their GP about their medicines and the support they were being given. As their conditions stabilised, people talked of having some of this support

withdrawn and being left to contact professionals only when needed. The terminology used to describe this situation was interesting in that some participants appeared to feel that they were being abandoned.

"Once I've reached a certain stage they seem to be glad to be rid of me at the hospital, not "rid" of me, but glad to sort ofget you off the books sort of thing." Older person 0099 North West (65 year old female)

Several interviewees also received home care support from social services, despite the reluctance of many others to approach such services. Although the cost had risen and the carers changed from day to day, one was quite happy with the wide range of support they provided from help with personal hygiene to cleaning and shopping.

"The home help that comes in every morning....they're all different ones, but they're all alright....their manners are nice, they're kind, they don't object to doing anything." Older person 004 North West (92 year old female)

However, another interviewee had experienced problems in the past and now employed a personal assistant herself through the Direct Payments scheme. She had received help to set up and manage an account with social services from a direct payment advisor, but had recruited her current carer in a somewhat unorthodox manner.

"I was putting the advert in the Post Office, she works in the Post Office and she said, "Oh I wouldn't mind doing that". She came and we got on smashing." Older person 0464 North West (64 year old female)

5.3.9. Willingness to seek support

Participants had a range of different attitudes to accessing support. Many expressed a natural inclination towards privacy and self sufficiency, which manifested itself in a reluctance to join support groups or to ask for help. This belief that they were 'not a joiner' may have also reflected a lack of confidence in attending support options. Some became reluctant to seek support particularly if they had lost a friend or spouse whom they would normally attend such things with. Others were simply unsure of what support was available or chose not to look for it until there was a pressing necessity. This may have been related to a wish to maintain their independence. However, many were unwilling to seek any further support as they felt that they were currently receiving all of the support that they needed from their GP, from other health professionals or from other family, friends and neighbours. Others did not want to access support as they did not want to label themselves as being a sufferer of a condition.

Joining groups and wider social support may be related here to social capital issues. Of particular importance may be the need for trust in people that are turned to in local areas, and in wider contact with the formal institutions on health and social care (see Blaxter 2010: 124).

Some participants were unwilling to seek support as they didn't feel that their condition was sufficiently serious or disabling enough. For example, one felt that her arthritis was not disabling enough to justify her attendance at an Arthritis Care group, whilst another felt that she received all of the support that she needed from the patients she met in the outpatients clinic.

"I felt that the people there might have looked at me and said, "not much wrong with her"...sort of style....they seem to be a lot more ill than I was....I went to one meeting....but I didn't think it was quite for me." Older person 0099 North West (65 year old female)

"It's funny, when you get tothe haematology clinic at the local hospital, there's all sorts of people with all sorts of different things, and you talk amongst yourselves.....and really there's no need to take it any further.....I'm not a joiner of groups." Older person 0214 North West (64 year old female)

Participants appeared to be more willing to seek support if they had a good relationship with their health professionals. Some reported that they were willing and wanted to seek support but that in some situations they experienced difficulties in finding it. They were also more willing to access support if the advice that they were offered made sense to them and felt possible to implement.

Patient organisations seemed generally unappealing to the carers we interviewed. Although they were usually aware of the local branches of the appropriate charity, they seldom contacted them.

"How can they help? I just don't know how they would go about help, other than maybe just talk to you. I haven't got time. I'm sort of thinking when I've finished the garden so to speak." Carer 0487 North West

However, a person's willingness to seek support was not set in stone, and fluctuated according to differing needs and beliefs. For example, one interviewee was quite prepared to seek support from social services but felt that she was too old to seek counselling help for a mental health problem.

Amongst the carers interviewed, not all felt in need of accessing particular support for carers, as they felt that they were simply 'helping out' friends in need on an informal basis:

"No, because to be quite honest I haven't done it on any sort of professional basis, I've only just sort of had friends that have come a cropper in one way or another and I've just sort of thought well what can I do, but I well, maybe somebody hasn't got transport so I've said "Can I take you shopping?", or "can I do shopping for you?", or you know, something like that but really only what any sort of human being would do for another, I'm nobody's saint." Carer 0393 South West

5.3.10. Ease of obtaining support and services

Most of our participants were able to give examples of how it was easy to access support although some difficulties were experienced. For example, in the North West case study area, the frailest person interviewed spoke of the availability of transport to a weekly day centre, annual social service assessments and even an odd job man. Several examples were provided of easy access to health professionals in particular.

"My GP....particularly, he's very aware of the problems, and he said you don't even need to make an appointment if you feel there's anything you might want to talk about or need anything, just come in." Older person 0214 North West (64 year old female)

However, some did experience difficulties in accessing support. Difficulties occurred when participants had recently moved house and needed to register with a new general practice. Difficulties were also experienced if participants had not received a definitive diagnosis for their LTCs. For example, one participant with chronic undiagnosed pain, found it virtually impossible to get any help to relieve her symptoms, and felt she would like more information on the medication she had been prescribed.

"When you go into the pain clinics, they should do more than just giving you tablets. You might have physiotherapy or something like that....it hasn't been offered at all." Older person 0442 North West (69 year old female)

Ease of accessing the GP was particularly variable across the case study areas. Some participants reported having excellent relationships with their GP who was also easy to access, and others reported having so many difficulties that they had to develop strategies to ensure that they could see 'their GP', or receive a prescription in time.

"But Dr XXX will say, 'if you want owt under here, see receptionist and she'll get you it', you've only got to look on the screen and you get everyone sorted, the?? says 'come back tomorrow' 'how can I go to the chemist with that?' with a prescription not signed. She says 'take it over there, he'll give you the medicine but they'll send it back for me to get signed later on' and that's all you want. But some of them just 'no, you can't have it, no, can you come back Monday?' 'But its nae good on Monday, I've run out' 'yeah? Well you've got to see your doctor' 'well make us an appointment'?? Whereas the other two, Receptionist X and Y are just...they'll fix you up, if?? the medication, they'll say...they'll run the prescription off and then they'll get it signed later on. You get your medicine and the chemist will bring it back" Older Person 0104 North East (63 year old male)

For those who were unable to drive, transport to support options was particularly difficult. In the rural case study areas (South West and North East), some participants reported how they had to take several infrequent buses to get to support options. Those who felt too unwell to travel had another access barrier. However, in the London area, public transport links were much better and this was considered to be less of a problem.

Many of our participants reported the difficulties that they had experienced in trying to obtain benefits. They found the very lengthy forms tiring and confusing to complete especially if they were feeling unwell.

"I did actually apply for disability allowance, but I got knocked back."

Why's that do you think?

Well you know, I didn't know, they asked how long I could walk without the pain, and you know I said well about 100 yards, and evidently I should have said fifty metres." Older person 0583 London (62 year old male)

Difficulties in accessing hospital treatment were discussed by some participants. Even ensuring that they had enough money for car parking could be stressful when attending an outpatient appointment. Some also described difficulties in using hospital transport.

"But if I had to go to hospital, then they'll send a vehicle for me and bring me back. I went to the chiropodist this week and they was such a long time getting here, I thought well, I kept phoning up. Eventually, when she got there, she said "gosh" you know, she couldn't find the place so I said "and you're a driver and you can't find the place?" I said "we're very, very late" and like gets me there, when it comes to coming back, it was a half past three appointment or quarter past three it might have been, by the time I come out of the chiropodist, they're supposed to shut at five, well it was nearly five when I got out of there. And what with the traffic then at that time of the day, it's full up with traffic; I got home here about half past six, seven o'clock." Older person 0364 London (85 year old female)

Many participants spoke about the difficulties in getting personalised and tailored support. When home carers failed to take notice of their individual preferences for care it was difficult for people to obtain the help they considered appropriate. Participants also reported that they often received the package of help the local authority wanted to give them rather than the help they actually needed.

"They kept saying 'do you want help in the house' and I kept saying 'no I don't', not because I'm house proud or think that I can do it, but the things I need help with they don't provide. I need somebody who will climb a ladder, you know, and on a good day I can clean the floor myself, mop the floor or Hoover, I need somebody who can climb a ladder, clean the light fittings, clean the window frames, you know, and I say oh no, but they keep saying, you'd think they were partners with the private contractors that they will send, you know you'd think that they work on commission, they don't listen to what you want." Older person 0387 London (77 year old female)

One carer in particular was finding it very difficult to cope with the emotional demands placed upon her, but did not feel that it was easy to access this kind of support even when she was prepared to pay for it.

"I suppose it's like a counsellor really. I'm saying I'm not wanting National Health help, I want someone to say, "Well, why don't you go and pay to go and see this person".... I don't know where to go, whether it should be the Citizens' Advice Bureau or, as I say, just go through the Yellow Pages and, to be honest with you; I feel sometimes that I do need emotional help." Carer 0517 North West

There was a strong sense from many participants that despite feeling entitled to services, in reality they had to battle to get any support at all. Some reported that they were sometimes offered services by health and social care professionals but were not actually referred to them, or had to pester health professionals to be referred. Others reported how difficult it was to receive the support that they needed when they were offered little information from their GP on the services available.

5.3.11. Acceptability and usefulness of advice and support

There were varied responses to the advice and support that older people had been offered to help them manage their LTCs.

Useful support

Participants spoke of helpful literature on discharge from hospital, useful aids to help with domestic chores, and exercise regimes provided by physiotherapists that assisted recovery and maintained flexibility.

One participant with severe arthritis spoke positively of the exercises she had been prescribed and the aids provided by occupational therapists, but she was less happy with the support offered from her practice nurse when she developed an allergic reaction to nicotine patches.

"A grabber that I can pick things up with.....and I was given a loop thing...like a riding crop....and you put it on your leg and get into bed....it's brilliant....."
"I had seven square patches where the patch, red and they were burning and itchy....never said what to do with them and in factshe said, "I'll give you some more patches"....so I rang the firm who made the patches and they said stop taking them straightaway." Older person 0464 North West (64 year old female)

Others did not view the exercises that they had been prescribed positively; they felt that it was a waste of time to go to the physiotherapist because many of the suggested exercises were things that they could have developed themselves at home.

For many of our participants the advice and support that they received from their GP was considered to be sufficient and they did not feel the need to seek any additional support elsewhere. However, others did not feel that their GP knew enough about the various support options available to them.

Unhelpful support

Some forms of support were rejected because they were felt to reduce the individuals' sense of independence or were inappropriate. For example, one participant who had difficulty walking was still reluctant to use a wheelchair, whilst another thought that exercise classes for older people would be too gentle for him.

"I hate it in a wheelchair; I don't like it at all. I'm too independent in a way I suppose. I do know one who offered to push me in the wheelchair up around the shops. I'm not going, no, no." Older person 004 North West (92 year old female)

"I think the sort of exercise I want is probably more vigorous than they do....I don't see myself doing gentle exercises, it's not in my nature." Older person 0561 North West (70 year old male)

Another participant felt that the only support she had been offered was more medication.

"That's it, only tablets." Older person 0442 North West (69 year old female)

Of the few who had taken part in self management courses, one interviewee with chronic fatigue syndrome acknowledged the value of keeping a diary of her symptoms, but found it difficult to do. None of the older people in the North East and South West case study areas had experience of self management courses. Although one interviewee thought that they might be useful for some people, he felt that he already managed his condition well and would therefore derive little benefit from them.

"Going to a group to discuss diabetes I wouldn't get anything out of it....I'm not being big-headed....it's just that I'm so confident in the diabetes nurse." Older person 0547 North West (73 year old male)

Again, the variable value of formal self management courses has been noted by other researchers (Newbould et al 2006; Rogers et al 2009).

Some of the carers interviewed felt that the support they had received from the health service had often been unhelpful and inappropriate. Parents caring for a son with epilepsy described their GP as "quite good" but believed that their son's consultant merely prescribed strong and unpleasant drugs, and appeared to have little understanding of the triggers for his fits and mood swings. They also disliked local support groups that tended to focus on the problem rather than try to identify solutions. In contrast, they found alternative therapies very helpful.

"He has herbal treatment and we see the herbalist every month....she's very good, very understanding and very helpful. We see an acupuncturist frequently and he's very good....and we also are going to the BIRD [Brain Injury Rehabilitation and Development Institute]." Carer 0331 North West

Advice that failed to take into account people's personal situation and lifestyle was generally considered to be unhelpful. For example, physiotherapy exercises to help mobility were often difficult to do when there was a lack of space at home. However attending local exercise classes was not an alternative when they did not seem to be aimed at their age group or fitness level.

"I've been down to the baths because they do exercise programmes you pay for and you can go out, I think it's about £3 for an hour session on these exercises you see, but they're geared for the younger woman, you know, whereas these exercise plans are for the old, fat women you know, and that's what I want to get on, whereas I went to one of the sessions where they did these, they play about with these balls, it was quite fun but it was too vigorous because you had to swim and I can't swim and so I was stuck at one end of the pool while everybody else was dashing up and down doing these exercises and I was down one end of it so it wasn't geared for my age and..." Older person 0428 London (68 year old female)

Within the London area, interviewees from ethnic minority communities spoke about the difficulty of adhering to dietary recommendations when they did not take participants' traditional diet into account.

"Is there anything else you do that you do to make yourself feel better? Any special diets?"

Not during winter time but I do long walks in summer, of course, she's very (laughs) like to do walking.

Don't like walking?

(?) Doesn't like, I do a bit of walking and food, of course, I'm not particular like. mumbles).

Sorry, say that again.

Food thing, you know.

The food?

Yeah, I'm not particular you know, mostly I'm used to the food that we had back in our country.

Right, yeah.

From Sri Lanka.

Right, okay, yeah. So do you have to be careful about what you eat with the diabetes? Have you changed anything?

Yeah, a little bit careful, alright and that's it." Older person 0172 London (72 year old male)

5.3.12. Awareness of local support providers

Despite some problems among individual participants, there seemed to be a widespread awareness of the well established sources of support, such as general practice, community pharmacy and large national charities like Age Concern. Awareness of other support services was more limited, either because people had still to investigate them, or because they used their GP as their sole contact point. Participants were therefore very aware of the services available via their GP, but were less aware of services that that could be accessed independently. Some gained awareness of local service providers by talking to friends and neighbours as well as to health professionals.

Participants often became aware of the support available simply because their condition precipitated the arrangement of a range of measures to enable them to continue living independently, sometimes after discharge from hospital. One elderly woman in receipt of health and social care services seemed very informed about the local support available.

There's another one of the day centres you can go to.....but I'm quite happy with one a week. And we have outings.....Round Table are very good, they finance one of the outings.....Age Concern, they run it and marvellous women they are. Older person 004 North West (92 year old female)

Two participants referred to their first introduction to some of the newly created roles in primary care: medicines managers and health coaches. Another was going to explore the possibility of exercise on prescription.

The only problem is that they [medicines] need renewing at different times. So when I saw the doctor....he said, "Ring up somebody called the Medicines Manager".....and she's going to synchronise them for me. Older person 0128 North West

Sure, how did you hear about the exercise stuff originally, was it through the GP or...

No, no it wasn't, it was, I went down to the, when I went down for these balls and I did all this, I came out and there was these, a lot of old black women all outside on the steps and they were all going in and I said to one of them "Do you go to an exercise class?", and she said "Yeah, they have one of these", and I said "Oh, I think I'll come back in", you know, so she said "No, you've got to have it on prescription", and I said "Oh right", so she said "Yeah, you go to your doctor and tell him you want an exercise prescription", I didn't quite understand what she meant but I said thank you very much, anyway, so next time I went to the doctors I said "Is there such a thing as an exercise prescription?", and he says "Oh, do you want to do exercises? Yeah, I can put your name down and they'll get in touch with you" it's not sort of advertised, well, because they haven't got the places, I mean. Older Person -0428 London (68 year old female)

5.3.13. Carers' awareness of support options

There was some awareness of condition oriented voluntary organisations such as the Epilepsy Society, the local heart support group and the Stroke Association amongst the carers interviewed but not all became actively involved in their activities. Knowledge of support services was often acquired in a variety of informal ways. For example, one carer had gathered together a lot of information as a result of her husband's hospitalisation. But she, like others, had also found family members, friends and neighbours very useful guides to further support.

"My sister said get in touch with them [Carers' Association], so I did and they send me their literature." Carer 0545 North West

"Friends....and they came up to me and they said, "I've been trying to tell you that you ought to claim attendance allowance." Carer 0487 North West

Parents who were caring for their son who had epilepsy seemed to have no knowledge of potential support from social services or of personal budgets and direct payment schemes. They and one other carer were however aware of the disabilities services provider in the case study area.

"There's asort of disabled advice centreit's a question of going through and making an appointment and discussing through with them because they would be the people I think to advise us...." Carer 0331 North West

When asked why support services were not used, one carer began by saying that she thought that she and her family coped well without support, but then went on to state how her mother was reluctant to accept help, and how this worried the interviewee.

"I suppose at the moment we're coping, you know...'Cos she wouldn't, you see, she wouldn't... When they said about, you know, send him home and there'd be, you know, you can get help off them obviously, and they got a Social Worker but

she's never had them round, you know ... I said to her do you want them to come round 'oh I'm alright you know' she'd say (laughs) you know. But I think I'm sort of a bit scared of, you know, what would happen if something happened to her, that's what worries me, you know, because she's keeping everything running..."
Carer 0371 South West

5.3.14. Beliefs about future support needs

In many cases participants did not seem to want to think about their future support needs and it was particularly difficult if the person felt they currently had everything under control. Even so, participants did recognise that they were likely to become less self sufficient in the future and that they would probably need more support.

"Well obviously I worry about the future, what things are gonna be like in the future and how I'm gonna manage when things do get worse. But there's nothing I can do about it so there's no point in worrying really. I'll wear out meself. You'll just meet it when it comes." Older Person 0341 North East (66 year old female)

Some participants also expressed a certain degree of fear about the future, for example when they saw people who had similar health conditions and who were housebound. They expressed particular concern that deterioration may mean moving home, a change of lifestyle or losing friends. Others were concerned that they would not be able to cope with increased medication in the future and that they may not recover so well from future exacerbations.

5.3.15. Wider social networks

Social networks varied greatly across the four case studies and were not necessarily related to the affluence of an area. In the South West and North West, participants reported how their neighbours were a good source of support, sharing advice and information about their LTCs and letting people know that they would be about if they needed them. However in the London area, participants felt that this support was not so readily available.

"All closed doors, you don't see anyone, not unless they want something or, information I mean, information, they'll come and knock on the door and ask me and I say "Yeah, well you know, you got the booklet like I had, you got the numbers that I have all you've got to do is pick up the phone", "But it costs money doesn't it?", and I say "Well when you come to me it costs me money".
Older person 0428 London (68 year old female)

Within the North West, many of those interviewed appeared to have a relatively active social life and to be well connected to local networks. Although some of this revolved around charitable organisations like Age Concern, more were related to individuals' particular interests and were not specifically aimed at older people or those with LTCs. There was also evidence that where they were able, people volunteered to support others who were more elderly or disabled.

A 92 year-old woman, who was unable to leave her home without assistance, spoke enthusiastically of the Age Concern day centre she attended every week and the activities associated with it.

"I go to the day centre on a Thursday...they're all people of my own age....you have your breakfast when you go there and we can either talk or have dominoes or have a bingo session." Older person 004 North West (92 year old white female)

Whilst a younger woman in her 60s volunteered at the local Age Concern lunch club and had graduated from preparing the vegetables to cooking the meal. She described a very active social life in addition to this.

I go swimming on a Friday. I go Scottish country dancing on a Monday, I go to a quiz on a Thursday and then on a Wednesday I've got me retirement club, but that's only once a month. And then the Tuesday I do the Age Concern. Older person 0099 North West (65 year old female)

The positive impact of these social connections on people's general well-being was readily apparent. They were usually, although not always, related to social class. In contrast, the one person whose social life was quite restricted by her condition lived in an area that felt unfamiliar and unsafe.

I've got no friends round here....I wouldn't go out really in the dark round here...it's full of drugs this area. Older person 0464 North West (64 year old female)

In the North East area, people did have access to social networks, but several reflected on how the area had changed since the closure of the pits in the 1990s. One male participant regretted the loss of the working men's clubs and the social life they had provided.

"Working men's club or did you let anybody down there?"
They're all dying off. When the pit was working, I used to down there, I used to be treasurer of the union. If ever you wanted owt doing in the club, see him and he had the colliery electricians, the joiners, anybody went across and did the job, if you'd got light fittings, you got everything done. And they made me treasurer of that club but as I say, when the pit closed, everything went downhill, there always used to be an association of clubs, there's nine clubs and I think there was four or five pubs, my friend joined us as well because if you caused trouble in one, you were barred out the lot." Older person 0104 North East (63 year old male)

Several participants talked about the networks that they had established by doing voluntary work for local charities and local colleges, and the personal pride that they felt from doing this work.

"I've got to teach two classes, Tuesday and Wednesday afternoons and it's a social thing as well because they are all lovely people and they all come together every week and we have a good laugh and sometimes we've got something to

show for it, we can print something out, and most of the time we haven't but it doesn't matter because they've still enjoyed it and they've learned a thing or two. So you know it keeps you going." Older person 0341 North East (66 year old female)

Support from the wider social network was valued even if it was low level such as a neighbour popping in once a day to say hello and buying a newspaper, and in some cases participants appeared not to want any more support than that. But in the London area, some participants spoke at great length about a loss of community spirit since they were younger. Some spoke about the difficulties of filling their time when there were no clubs for them to join which were easily accessible and in which they felt comfortable. Community centres appeared to be aimed at particular groups within the population and older people often seemed to be neglected in favour of the young.

"This isn't an estate that's very, it's not integrated at all, there's no, there's nowhere where you can go, there's no focus point on the estate, years ago we used to have community centres and things like that, we've got a community centre that are all locked up and they open up to have a fun day in the summer and a Christmas part for the kids in winter..."

And that's it?

You know and, you know, it's a shame, one of the community centres they tried to get things going but it's all bit one sided, they've got a football time, very successful, and they're very good but that is all, it's all young, it's all young, there's nothing for, I talk to my brother, he lives over at XXXX Road. "And I couldn't tell you any of my neighbours", he says "Because they've changed over the years", and he says "They don't want to talk", he says "They don't want to talk and nor do I", you know and I thought isn't it a shame that it's got to come down to this..." Older Person 0428 London (68 year old female)

"Yeah, Yeah, a community centre because that would, to give you a reason, you see there are some not community centre clubs you can go to but they're all geared, Mrs. XXX who lives down there, she goes to a Caribbean club every Friday afternoon and she goes there and has lunch and then they do something afterwards, I don't know, there's another club that the man in the front goes to but that's for people who can't walk you know like got no legs or can't use their legs all wheelchairs, they send an ambulance down and pick people up and take them off."

A day centre type thing?

Yeah, but they're all, they're all geared for specific groups you know, and I suppose that's the way things are going, it's going to be you know, those sort of things you know, yeah, so, no I can't see anything changing. Older person 0428 London (68 year old female)

However, not everyone felt this way, as several spoke about the pensioners' clubs they were members of and the valuable contacts and new friends that they had made through attending an Expert Patients Programme or support group.

"And it's not age related, not the chronic fatigue syndrome because on the course I was on there were people on the course ranging from 24 you know, 24 years of age to 77 years of age, and it was, that fatigue syndrome was affecting us all,

with a variety of illnesses, not just what I've got, and it made me very happy that course, because I found out I was not unique, I didn't have an undiagnosed condition, as I had been with the trigeminal neuralgia, you know, so the course made me very, very happy. Older person 0387 London (77 year old female)

Within the South West, there appeared to be a strong sense of community with neighbours being considered to be a strong source of support and friendship in both towns and villages. However, there were some transport problems with buses no longer stopping directly outside the hospital and some participants reported difficulty in having to walk the extra distance to get to the hospital. Buses in general were felt to be infrequent and uncomfortable, and the distance needed to travel meant that journeys were often long. Others reported difficulty in parking sometimes, even if they had a blue disability badge because of the high number of blue badge holders in the area.

Although poor transport links could lead to social isolation, some villages had very good amenities such as post offices, general stores and pubs, which meant travel into larger towns was not needed regularly.

5.4 Chapter summary

Chapter five has considered the reported experiences of living with LTCs and of seeking support for the individual concerned and for others, especially families and friends.

After a brief note on the way respondents accounted for their illnesses or conditions we discussed the impact that LTCs had on everyday life. This varied with the number and complexity of conditions and with the level of bothersome symptoms experienced, and also reflected participants' expectations of ageing.

Most participants believed that maintaining health was a shared responsibility, between the individual and the health service, although there were different interpretations of what 'shared responsibility' meant in practice. Being willing and able to self manage LTCs seems to be closely linked to confidence in the ability to self manage. Participants who wanted to share responsibility seemed to have greater confidence in their ability to undertake practical tasks, monitor symptoms and manage exacerbations than those who believed that health professionals were responsible for managing their conditions.

We then discussed the general experiences of care reported to us, followed by the central issues of self management and self care strategies employed, and factors influencing decisions to self manage.

With some exceptions, participants were generally pleased with the care and support that they received from general practitioners and pharmacists, but less satisfied with acute care services. Participants described a variety of self care strategies for maintaining health and independence, monitoring and managing their conditions, minimising symptoms and maintaining continuity of care by general practitioners.

We then considered the barriers and facilitators to self care and self management, and then the respondents' current experience of support.

As described above, lack of confidence in the ability to self manage is a substantial barrier. LTC symptoms, complex management regimes and medicines side effects can also make it harder to self manage. Other barriers include damage to self image, loss of motivation to maintain health and wellbeing, lack of money, and difficulties gaining access to transport, leisure facilities and services.

Factors that participants reported as facilitating self management include having a positive outlook and a supportive partner, technological solutions that solve practical problems, support from health and social care professionals, and being able to give support to family members as well as receiving support from them.

This was then followed by considering the willingness to seek support and ease of obtaining support, together with the acceptability and usefulness of support to those living with LTCs. We also considered people's awareness of local support and views about future needs, especially linked to wider social network dynamics.

Most participants were completely satisfied with the support they received from general practitioners and practice staff, hospital specialists and community pharmacists. Some did however describe feeling 'abandoned' when their condition stabilised and support was withdrawn.

Participants varied considerably in their willingness to use statutory and voluntary sector support services and in the personal and practical reasons for not seeking support. Willingness to seek support could change as circumstances changed, and was influenced by the quality of relationships with health professionals. Many participants, particularly those with well controlled LTCs, preferred to focus on the present rather than thinking about future support needs.

Some participants reported difficulties in getting support, particularly those with no definitive LTC diagnosis and those needing to register with a new general practice after moving home. Difficulties with transport, and the cost of transport and hospital parking, also prevented participants from using support services.

Participants used a range of formal and informal means to find out about support services. Many described battling to find information about available support services and having to be persistent in requesting referrals.

General practitioners clearly play an important role as information brokers, and for some participants were the only source of information about available support services, particularly statutory sector services. Participants were generally less aware of open access services provided by voluntary sector organisations, and did not necessarily engage with these organisations even when aware of them.

Where available, participants placed considerable value on the support offered by their wider social networks.

Next chapter

Chapter six describes a qualitative interview study of commissioners and service providers involved in commissioning and providing support to older people with LTCs. The interviews explore their beliefs about self management, their experiences of providing and commissioning support for self management, and their beliefs about the barriers and facilitators to providing self management support. Potential interviewees were identified from the mapping work and from snowballing in our interviews and older people and their carers.

6. Qualitative study – service providers and commissioners

6.1 Aims of interviews with service providers and commissioners

- To explore the organisations' perspectives on the principle and promotion of self management and greater responsibility for health;
- To explore interviewees' experiences of planning and delivering self management support;
- To explore the challenges that interviewees face in identifying local support needs and providing appropriate services;
- To explore interviewees' attitudes towards, and practice of, working in partnership with other local service providers;
- To explore the extent to which a coordinated approach is pursued and the barriers to pursuing a coordinated approach with other agencies;
- To explore the organisations' future plans for the area in terms of service provision and service development.

6.2 Method

The service provider and commissioner interviews were undertaken to develop a description of the network of support available to older people to help them to self manage their LTCs, and to explore the challenges and facilitators in providing this support. We felt that it was important to represent a broad range of services in the study rather than reaching a thematic saturation point with particular types of health professionals and service providers. The topic guides used within these interviews are included in Appendix five.

Identification and sampling of service providers and commissioners

Service providers and commissioners were identified from the mapping work and from interviews with other service providers and older people. Primarily, we aimed to broadly represent the area in terms of the types of services provided locally, but we also invited similar service providers or commissioners in all four areas to allow comparisons between localities.

Recruiting service commissioners and providers

A database containing the details of service commissioners and providers within each area was developed as part of the mapping work (Chapter three). This included the following: contact name, details of service; type of service; funding source for service; referral/access to service; links with other agencies.

An initial sample of service commissioners and providers within each area was selected, based on the guidance sampling frame, and invited to take part in the study. Potential interviewees received a covering letter, a study information sheet and a consent form. These documents explained the study and stated what their involvement would entail (see Appendices six). The covering letter contained contact telephone numbers of the research team in case of any queries. Participants were offered £20 in gift vouchers to compensate them for their time.

If participants had not replied within one week of receiving the covering letter, they were telephoned by the recruiting researcher, who ascertained whether or not the service provider was willing to take part, and if so arranged a time and date for the interview.

Conducting the interviews

Interviews were conducted at a time and place convenient to the interviewee, usually at their workplace. Prior to beginning the interview, the researcher received confirmation from the interviewee that they had understood their participation in the study, and had signed a consent form to take part.

A semi-structured topic guide was used (Appendix five), and with the interviewees' permission, all interviews were digitally recorded. Interviews took around 45-60 minutes on average.

6.2.1 Data analysis

Data was analysed using the framework method of data analysis (Ritchie & Spencer 1994) and was facilitated using NVIVO (v8) software.

Framework analysis includes;

- Data familiarisation: reading of complete interview transcripts, listening to original audio-recordings and use of field notes;
- Identifying a thematic framework: key issues, concepts and themes are identified and an index of codes developed;
- Indexing, whereby the index generated through identification of the thematic framework is applied to all data;
- Charting: a summary of each passage of text is transferred into a chart to allow more overall and abstract consideration of index codes across the data set and by each individual;
- Mapping and interpretation: understanding the meaning of key themes, dimensions and broad overall picture of the data and identifying and understanding the typical associations between themes and dimensions;
- The charting process provides an opportunity to code data from numerous vantage points, by demographic factors such as gender or age.

We selected the Framework method of data analysis as it allowed the research team to consider variability across different types of participants i.e. service providers, commissioners and service users, and across the case study areas (Ritchie & Spencer

1994). It also provided us with a transparent method of data analysis within the research team.

6.3 Results

Across all case study areas, we undertook 36 interviews with service providers and commissioners.

Table forty seven Number of service providers and commissioners interviewed within each case study area

	Service providers and commissioners
North East Case study	7
London case study	8
North West Case study	11
South West Case study	10

The characteristics of the commissioners and service providers interviewed are described in table forty eight.

Table forty eight: Characteristics of service providers and commissioners interviewed across all case study areas

	North East	London	North West	South West
Service provider one	Healthy Living Centre coordinator	Expert patient programme coordinator	Community pharmacist	Community matron
Service provider two	Expert patient programme coordinator	Healthy living consortium coordinator	Falls prevention coordinator, Age Concern	Health programme advisor for PCT
Service provider three	Age Concern Locality Manager	Exercise for older people programme coordinator	Age Concern Deputy CEO	Director of Nursing
Service provider four	Health development Specialist for older people	Practice Based Commissioning manager	Breathe easy support group leader	Senior ward sister
Service provider five	Respiratory nurse specialist	Age Concern Chief Executive	PCT Health Improvement Coordinator	GP
Service provider six	PCT director of planning	Joint health and social care commissioner for older people	GP and Chair of Professional Executive Committee	Practice nurse
Service provider seven	Practice Based Commissioning manager	PCT head of prescribing and pharmacy	Locality manager, Older People's Services Purchasing, Social Services	Age Concern Services manager
Service provider eight		Local GP	Manager, disability advice centre	Practice Based Commissioning manager
Service provider nine			Community matron	Head of older people's strategy
Service provider ten			Community nurse	Local stroke support group leaders
Service provider eleven			PCT director of strategy and redesign	Popp community leaders

6.3.1 Meaning of self management and self care

We should say at the outset that, overall, service commissioners and providers held positive views about self care and self management and recognised their role in supporting and encouraging it. For example, in the South West area, and especially within practice based commissioning, a section on the commissioning application form was being considered where each requested service could identify how they would address, promote and support self management.

Both service providers and commissioners generally saw self care and self management as taking responsibility for one's health, being empowered to make decisions and maintaining independence and control. However, one provider stressed the fact that "managing" might mean different things to different people.

"It depends what you call managing....because I know quite a lot of ...older men...if you went into their house..., you might be absolutely horrified. But to them, that's managing....they are warm enough, they're eating, they've got some sort of social system.....and yet there's women....you can go into their house and it's beautiful and spotless but they're absolutely so lonely and desperate for social support." Service provider three North West (Age Concern Deputy CEO)

In practical terms, one community based provider saw self managing as recognising trigger factors and knowing who to contact and when. For another it meant that people should have developed an understanding of their LTC and be able to engage productively with healthcare professionals.

"What it means to me is that the person understands what their problems are, understands what they need to do to reduce the impact of those problems, understands ...when they start to get into difficulty so they seek help early enough and know enough to want to engage with their therapist around improving their care." Service provider six North West (General practitioner / Chair Professional Executive Committee)

From this we can see that some service providers and commissioners may take self care and self management to be interchangeable terms, where others (such as the GP above) may restrict self management to the more focussed actions older people may take in dealing specifically with their LTCs, - an approach drawing on EPP or 'Lorig-type' actions - rather than with general self care in everyday life. In the following text, we were obliged to follow the definitions our respondents used, however variable they may have been. In the main, we were keen to explore aspects of self management in the more focussed sense, and as we shall see this approach has now become part of the professional lexicon. But interview discussions often overlapped with self care issues defined more generally. Where necessary we point out this tension as we proceed.

6.3.2 Beliefs about the usefulness and effectiveness of self management

Beliefs about the usefulness and effectiveness of self management in general

Amongst the service providers and commissioners interviewed, the benefits of self management appeared to be well rehearsed, both generally and in terms of the benefits to individual patients. Self management was thought to enable older people to maintain a greater say over their own lives, stay at home longer and preserve their independence. Furthermore, it reduced fear and doubt if people understood their condition better and meant they are likely to stay healthier for longer.

"Well I think they feel empowered by it. It's something they're doing for themselves; they don't have to rely on other people. You know as you get older, you don't want your choices taken away from you....you want to be able to make your decisions about you own life as long as possible." Service provider nine North West (Community matron)

Service providers and commissioners also spoke about the implications of self management both for the healthcare system and for the individual patient. For example, some spoke about the likely consequence of self management reducing dependence on the NHS and other external care.

"As soon as they start to improve, re-enable them and encourage that and sometimes they're not happy with it and you really have to work very hard to help them understand, you almost have to challenge...They will never get it back again if you create a dependency." Service provider nine South West (Head of older people's strategy, Local authority)

I guess it's come around reducing length of stay, if I was being honest, and trying to get people out quicker because we know hospitals are not the healthiest place to be in. Service provider nine South West (Head of older people's strategy, Local Authority)

However, not all providers were convinced that self management could reduce demand on services, and one did feel that further evidence of this was needed. As one interviewee put it:

Whether it actually impacts on reduced hospital admissions, reduced utilisation of healthcare resources, I think the jury is very much out on that. Service provider six North West (General practitioner / Chair PEC)

Related to this was the belief that there was a contradiction between the government's push to improve access to health services and in providing lots of medical advice for patients about their care options and promoting choice, with the self management agenda where individuals are being told that they can deal with minor illnesses themselves.

"I think there's a bit of a dichotomy though between the government's push over the last ten years for improving access and NHS Direct and in providing an awful lot of medical advice, pushing the demand led bit. So you know, thinking that patients want choice, that's the important thing, they can have choice, they can access it when they want, on the one hand seems slightly to go against promoting a kind of 'don't go to your doctor with minor illness, come on, you can cope, you can manage your own hypertension better'. It's a bit contradictory because what we see is we have very good access here and you know, I put my head in my hands at the end of a morning surgery sometimes thinking 'I have literally this morning seen children who've had a temperature for four hours'."
Service provider eight London (General practitioner)

At the same time, many providers clearly believed that there were likely benefits of self management for individual patients. Self management was believed to empower people and help them to feel more in control of their health. Adopting a self management approach was also thought to have a positive effect elsewhere in people's lives, making them feel generally more in control.

"Benefits for people are that they... their self worth and the ripple effect of trying and succeeding actually have a knock on effect elsewhere in their lives so they'll try something else and succeed more. Just being in control, feeling supported to be in control so that they take more and more personal... what might have been perceived as 'risky steps' previously become less risky and family relationships could improve." Service provider two South West (Health programme advisory for PCT)

However, some service providers in the London area were concerned that they may be 'preaching to the converted' in terms of self management. They believed that they may be accessing the group who might already be very receptive to self management messages, that they didn't want to add to them, but instead actually provide the services for older people that would translate information into practical interventions.

"So we're catering to a group maybe that is already receptive to those messages, and obviously we're providing opportunity, the ideas, when people do get a health scare and they're going oh my god I'd better sort this out, we're there, you know. Like I say, we kind of felt well there's so many messages that we don't need to add to it, [laughs], we'll just provide the classes and the services that they can use, and preferably as near to them, to make it as easy for them to get there as possible. And the information, so they know what's there, but we'll wait for them to be ready to use it if you like." [laughs] Service provider two London (Healthy Living Consortium coordinator)

Beliefs about the usefulness and effectiveness of providing self management support to older people

Although many of our participants believed that self management had a number of benefits, some expressed concern that providing support to older people to self manage might be difficult. Reasons for this included a belief that although people may understand the consequences of their unhealthy behaviours, they may still choose to do them; an outlook, of course, not confined to a particular age group. Some also believed

that older people may be unwilling to adopt self management strictures as they may feel that they are being told to look after themselves as a substitute for receiving treatment from health professionals.

"There's also a sort of polemic about whether people feel that people are being told to look after their own health as a substitute for being helped. And there's nothing wrong with looking after your own health, I mean ultimately it only works if you look after your own health and take management, but about whether this is a substitute for care, and people are concerned, that really what they're saying to us is you need to look after your own health because in the end we're not going to give you any help." Service provider two London (Healthy living consortium coordinator)

Some providers believed that promoting self management was only useful for older people who had a low level of health care need, and that it would not be useful for those who had very intensive health care needs, especially those who have previously been hospitalised but were now being cared for in the community.

As well as self management not being suitable for older people with a high level of need, there was also a belief that some self management messages may be unsuitable. For example, a GP may consider it less important to reduce a 90 year old's cholesterol level, if he considered that by the time she had reached that age it was a low priority; a cream cake might be well deserved!

"I had a 90 year old the other day who rang me up because we'd done her bloods because she's hypertensive and she was told her cholesterol was a bit high and she rang me up nervous, 90, 'what does it mean that your cholesterol is a bit high at 90'..."

It's very good for you at 90.

Go and eat your cream cake.

Yes.

(Laughs) And yet you know then I kind of think oh God, I shouldn't be ageist, my goodness, no, I should be getting her cholesterol down to nothing and you know, this poor old lady who doesn't actually like taking her Statin and you know, gets hypertensive with all her post MI drugs and wonders if she could stop one and you know, I think she's going to have a GI bleed because I'm giving her Aspirin and I wish I could just stop it, and does it really matter (laughs) if you're 90! What are you going to die from? I think, I mean that's the other thing we never talk about, we're all going to die and you know, goodness me (laughs) that's the best thing to die from! (Laughs)" Service provider eight London (General practitioner)

Family support was considered to be crucial in helping older people to continue to live at home and increasing their level of control over their health. However, if family support was not available, some service providers considered that it might actually be more costly to keep someone in their own homes.

"When you've got family support it's great, when you haven't got family support it's much more of a challenge. Service provider five and six South West (General practitioner and practice nurse)

I think you can always get to a stage, well I know you do, where it's more expensive to have someone maintained in their own home than it is to have them

funded, but that then doesn't take into the human choice part of it. Service provider" one South West (Community matron)

Here we can see that general approaches to promoting self management raise specific questions when applied to older people and especially the very old. The limits of self management might easily be reached at advanced ages, especially where family or informal support in the community was not available.

Beliefs about the usefulness and effectiveness of particular self management services

As well as expressing beliefs that not all self management messages are suitable for older people, participants also expressed a range of beliefs about the potential effectiveness of the programmes and services developed to support self management. For example, in the North West case study area, interviewees spoke about their decision to abandon the Expert Patients Programme (EPP), as they believed that its main success lay in the breaking of negative cycles and patterns of isolation rather than in the actual course content.

"I've sat in on several and there's lots of generalisations. They use very, very basic stuff and it's astounding really how people claim to have been totally empowered by it....which is why my guess is because it's making them feel less isolated...they're actually getting out...and it could be the content is almost secondary." Service provider five North West (PCT Health Improvement Co-ordinator)

Within the London area there was also some scepticism about the EPP. For example, service providers were uncertain as to whether the benefits of the courses were purely social or whether they were due to some other active ingredient. They were also uncertain as to how people were selected to attend the course, and were concerned about some people missing out who may benefit from the course.

"It's like a lot of stuff isn't it, I don't know whether it's the purported objectives that are being successful or whether it's the ancillary stuff, so it's the having the chat, it's knowing 'I've got to be somewhere at 11 so I will get out of bed this morning and take' you know, 'I won't be so lonely, it's the first person I've talked to for you know a day', all that kind of ancillary, social stuff (laughs) so you know it's less old and awful than a day centre, it's you know, it's those, I mean most of my elderly patients can't bear places like that, so why would you want to sit with a whole load of old gaga people as they would say it, playing bingo but actually." Service provider eight London (General practitioner)

"Each of the programmes seems on the face of it to be quite good. And they do work within a particular model, but it doesn't seem overall that it's clear how it's supposed to work, how it all fits together. It's been unclear why the particular people who have been doing them have been doing them, and they're contracted outside the borough. But then my main concern is, that I'm just now clear how...where it goes and what happens, are the individuals followed up, what did they get out of it, how are we learning the lessons from what comes out of these things. Service provider two London (Healthy living consortium coordinator)

In the London and North East areas where the EPP was running, the course coordinators believed that the nature of LTCs sometimes meant that it was difficult to keep the self management courses full, as individuals were likely to drop out along the way due to ill health, and sometimes volunteer tutors were unavailable to deliver the courses due to their own ill health.

"We had to cancel a course because of tutor illness and it wasn't one, it was actually two because we deliver in two's and both were ill but it was over winter which is why we've got more tutors now." Service provider two North East (Expert Patients Programme coordinator)

The London EPP coordinator believed that a referral from a patient's GPs might increase the likelihood that they would attend the course for the full duration; however she did recognise that such patients would not be making an empowered choice to self manage.

"We would like the courses to be full, and often they are full initially, but because of the nature of people having long term chronic conditions, people drop out. And some people attend and it's not what they were expecting, and again they drop out. It's not for everyone, but I don't think we're reaching everyone. I wish there was a more sort of referral on to us from the medical profession, but it is mainly self-referral, as I said. There is an argument that if people are referred by their GP or by their consultant, that they're not actually self-electing, they're not self managing, they haven't taken that first step, they have been told." Service provider one London (Expert Patients Programme coordinator)

The EPP coordinators also spoke about the importance of ascertaining the expectations of those attending courses. This was considered to be particularly important as participants were thought to be unfamiliar with the jargon that was used within the course. For example, they spoke about the importance of talking about 'looking after yourself' rather than using the term self management with course participants.

"I was ringing round everybody on all the courses in my area, you know, what are your expectations, what does self-management... one of the questions are what does self-management mean to you.

Yes, that's an interesting one.

But you see, this is quite a sort of jargon to a lot of people, they have no idea what you're talking about, but if you put it in another way they would know exactly what you're talking about, but I had to ask the question that was stated. And some would say don't know, and others knew exactly what it was, but most people that said they didn't know, actually if you probed a bit they did know. But that's our jargon, self-management, it's not the average user's jargon, to say I'm a self-manager, they just say, you know, I look after myself, I'm doing okay, you know, they would use different language. "Service provider one London (Expert Patients Programme coordinator)

Both EPP coordinators were concerned about the lack of opportunity to follow up course participants after the end of the course. They considered that the initial benefits of the course might wear off if there was little opportunity for follow up.

"On the pilot we were doing, I think there is a six month follow up, so these people are phoned to see where they're at. Whether that continues I don't know, because its very paper and resource intensive doing that on each of the courses I mean, some arguments in the field is well they've done the course, they've been given the tools they need and it's up to them now to take it forward and self-manage. Others argue that there still needs to be some sort of intervention to keep that going. I don't know what the answer is really.

No, some people might need a safety net and other people might not really.

Yes. Don't know. And again, you know, it all costs money, it costs money to do that. I know in another area that the PCT actually pays for the support group, organizes it and delivers it, and they invite people. They contact them, and every three months I think there is a meeting, and they go along to that meeting, and they have speakers come in every three months, and the group is apparently surviving very well." Service provider one London (Expert Patients Programme coordinator)

However, despite these concerns, the coordinators and other health professionals often believed that self management courses and support were better for people than taking tablets, and were less expensive. Whether this view is justified is, of course, another matter, but the belief that self management might be able to offer a nonmedical approach to LTCs in later life was widespread. The presence of peer support in such interventions was also thought to be helpful in raising the level of people's confidence.

Service providers believed that a key aspect of support provided at self management courses was in helping people to deal with this GP. This support was particularly important if they had not received a diagnosis and felt dismissed by their doctor, a matter we have seen emerge among a minority of our interviews with older people.

The effectiveness of other forms of self management support was also discussed, for example community matrons, though this is perhaps more appropriately associated with case management. In this approach, senior nurses help people with more complex health problems to continue to live in their own homes and where possible stop inappropriate hospital admissions. Beliefs varied about the success of this role. Some believed that success depended crucially on the characteristics of the individual doing the job. For example, one GP spoke about the need for the person to be very proactive.

" You have to have people that consider it their job to manage these people rather than just do, as I said, just be task led, and it's very difficult, they're usually, you know, within the nursing hierarchy the management is they're just so unresponsive, unresponsive, inflexible, protocol driven again, protective, it's always protective, protective, protective, you know that's why they have all those silly books they write in all the time and nobody ever reads, it's all, it's awful.

I'll give you an example, so our community matron, one of the community matrons we deal with, I contacted that person to say 'I've got this elderly lady, again she's 92, she's demented, she's got an abdominal aneurism which is going to pop at some time, she wants to stay in her flat, so we need to review the care package, we need to work out how we can best help this lady'. So what I get back from them is 'oh I've spoken to Social Services, she should go into a home'. I think OK, well I've just known this lady twenty years, but you know, fine, she

should go into a home, does this mean I'm to put her there now or you're going to put her there and have you asked her, because she'll tell you where to go. So, OK, they go and do a joint visit, she tells them where to go and yes, she is demented, so then I get a communication saying 'oh she won't go into a home, what are we going to do?'. Well, you know, why don't we all go round there and have a conversation with her and see just some little things. So, so unimaginative. Service provider eight London (General practitioner)

Clearly, inter-professional rivalry is evident here, but the quote does provide an example of everyday decision making that is involved in supporting older people, especially the 'oldest old' with LTCs. Here self management moves across to managing the person within the resources and professional frameworks existing in a given locale.

From the voluntary sector viewpoint our evidence illustrates similar difficulties in providing support to everyone who may require it. One of our Age Concern interviewees, for example, felt that some people may slip through the net because they were not considered to be a high enough priority to be helped by the overstretched service in question. For this reason, she spoke about the importance and usefulness of a 'gate keeping' system within the voluntary sector, where those who may not be considered a high enough priority for immediate help are at least directed elsewhere.

"So she introduced a gate keeping system where she checked and only took priorities, but in refusing people she sent them off to other places. I suppose in a way that's the nearest we've got at the moment to sort of self care, but that's not the self care that the government is thinking about in terms of peer groups for health and things like that, but that was a sort of form of empowerment, you know, I can't help you at the moment, if you do this you can help yourself, if you do that you can help yourself. But in reality what happened was, people helped themselves temporarily, and then waited until the new financial year was open, and then we helped them." Service provider five London (Age Concern Chief Executive)

Beliefs about the usefulness and effectiveness of particular self management techniques

Participants gave several examples of the ways in which specific self management techniques and devices could be useful to older people with LTCs. For example, medicines management teaches the purpose of medication, advises on possible side effects, reduces unnecessary medication and promotes concordance.

Others remarked that these techniques were perhaps unsuitable for those who were old and frail. For example, telecare was thought to be unsuitable for those who did not have a high level of cognitive function and manual dexterity.

"Well it's suitable for some and not for others. They have to have quite a decent level of mental acumen really and quite a lot of manual dexterity to flick buttons and follow the sequence." Service provider nine North West (Community matron)

6.3.3 Perceptions of service users' expectations

Service providers and commissioners perceptions of service users' expectations

Expectations of care were perceived as variable and complex. One provider commented on the problems of "lumping" all older people together, as an individual's expectations at 60 will inevitably vary from those of someone in their 80s or 90s. A certain stoicism was perceived in older people who had lived through a world war and only sought help as a last resort. Voluntary sector providers also spoke of the stigma that was still associated with social care. This, together with the fear of losing their independence and even their home, was thought to explain people's reluctance to seek or accept social care support.

"I think there's still a large proportion of older people around.....who went through the last war and have a very strong sense of responsibility and are very proud and don't want to take benefits...want to cope and manage on their own.
Service provider three North West (Age Concern Deputy Chief Executive)

The Health Development Specialist within the North East case study area believed that some GPs may have stereotypical views of older people and may assume that they do not need or want particular types of healthcare advice because of their age.

"But I think some are more enlightened than others about the stereotypical view of older people, and I've heard with my own ears different comments about even smoking. One GP said to someone at an event where we were talking about smoking cessation, and he said to this old gentleman "well you know at your age, you know, it's (smoking's okay" Service provider four – North East (PCT Health development specialist for older people)

However, service providers believed that the younger old and the next generation of older people were likely to have very different expectations and to be more assertive and knowledgeable about their conditions. For this reason, they believed that services would need to become more flexible to meet changing demands. This growing assertiveness has already been noted by providers. Some reported greater health awareness and self motivation as a consequence.

"Over time, people become expert patients, they become informed about their condition, they become informed about choices, and they will ask your opinion and then they'll challenge it." Service provider eleven North West (PCT Director of Strategy and Redesign)

Others felt that a growing sense of entitlement could mean higher expectations and less willingness to take responsibility for their own care.

"I think traditionally the older generation were very much..."I don't want to rely on the state too much", but I think attitudes have changed very much in the last 10, 12 years since I've been working, from.... "I want to do as much as I can on my own" to being, "well, I've paid into the state for long enough, I'm going to

use it as I think I should." Service provider one North West (Community pharmacist)
Health professionals' beliefs about older people's expectations of them

Health care professionals referred to a culture of "doctor knows best" and for this reason felt that some patients almost needed to be given permission to self manage. One health care professional tried to encourage a partnership approach to disease management, but was aware of the dangers of older people becoming too dependent upon her.

"It's hard because initially....you are "doing" for them and I think it's a weaning off process after that....and it's about education. Okaythis is the phone number for Age Concern and this is the phone number for the Red Cross service....instead of them phoning me." Service provider nine North West (Community matron)

Another service provider wondered whether they may have fostered high expectations and a consequent dependence by providing too much support:

"...we do provide quite a good service...I know from other people who've got aged parents in other areas...they don't get the service that our population get here...so yes, we do breed that high expectation. Service provider nine. South West (Head of older people's strategy, Local authority)

Other providers commented that hospital care raised expectations which had to be discouraged in order to promote independence.

"It sounds awful, but we make them walk as much as they can. So there's been a massive cultural shift in encouraging [service providers] to not be too kind which patients struggle with at times, I think it would be fair to say, but to try, but it's all about trying to make patients much more independent. ...It takes a lot of encouragement, doesn't it, for some patients to get them wanting to do it when they don't really want to...it takes longer, but it's worth it in the long run." Service provider five and six. South West (General practitioner and practice nurse)

One provider described how some service users were sceptical as to whether they, as more 'able-bodied' or younger users, actually needed the service, and wondered whether they should be accessing it. By the same token, younger elderly people may be reluctant to use services if they are only accessed by the very old and frail.

"They're a very needy lot. It's quite a surprise to get someone in who's in purely for a social reason who's very able bodied. We've got someone fairly new at the moment, and it's quite hard work persuading other people that he needs to be here. Service provider three. South West (Director of Nursing)

Finally, we have already stated that there is a tension in current policy and service provision between promoting choice and personalised services, and encouraging self management. Our interviews also revealed a belief among some providers that although the government has been trying to promote the choice agenda, in fact many people do not want to have too much choice. Instead, it is believed that many older people want

the GP to give their professional opinion as to the best option for them. Again, we have seen evidence for this view among our interviews with older people.

6.3.4 Background and rationale of self management support and services across the case study areas

South West commissioning strategy

Within this area, GPs are formed into geographically based commissioning groups, but for all of these groups the rural character of the area is a common theme as are the difficulties of accessing services, particularly for older people with respect to transport.

The PBC groups are required to assess the needs of the local population and commission services accordingly. Using available data they then prioritise the services required. Many of the commissioned services are common to all of the commissioning groups, but each also has services which are responsive to the needs of their local populations.

"Some things are priorities across the whole PCT ...but some things have a very, very local flavour and sometimes it's below that consortium locality level." Service provider eight South West (Practice based commissioning manager)

Another organisation within the case study area is able to commission local services. They aim to spend 80% of their available funding within the voluntary sector and like to focus on pump priming services which can then sustain themselves:

"We wanted to make sure that something like 80% of this finance we got was spent in the voluntary sector and we've achieved that...I'd like to see the community pump and priming cash support initiatives in community." Service provider two South West (Health programme advisor for PCT)

South West Services

The practice-based commissioning function within the PCT receives requests from GPs to commission service for their locality which have been identified from a local need using various data sources such as hospital statistics, Quality Outcomes Framework results and epidemiological data. Within the case study area there was also a project run jointly by the PCT and the County Council, which had the function of commissioning services or funding initiatives through a process of bidding.

A range of local service providers were interviewed, including a health advisor working for the PCT, and two local project community leaders who worked with a country-wide initiative which was set up to promote and increase social cohesion within communities. The aim of the initiative was to reduce isolation and hospital admissions and to keep older people living at home for longer. Two primary care service providers were also interviewed, a GP and a practice nurse, in addition to three community NHS staff: a community matron, a nursing manager and a ward sister.

Two local service coordinators were also interviewed. One was a services manager for a charity run day centre, which held lunch clubs, therapy services, and rural shopping services and acted as a social point. It was run by volunteers but overseen by trained managers. The service was used mainly by the older age group (85+) and those in lower socioeconomic groups. It was accessed by older people as somewhere to go instead of being alone at home, to have a nutritious meal, and for a minority, to provide respite for carers. In this sense a broad supportive role for self care rather than specific LTC self management was being pursued here.

The second was a coordinator of a local disease-specific club run by volunteers. Its aim was to provide a social network for people and their carers, whose commonality was the health condition. It was set up because the need was identified in a particular town, and because the organiser had previous experience setting up a similar group in another county.

The area also ran the Expert Patient Programme although we were unable to interview anyone from this programme as part of this study.

Other services within the area included a service which provided advice, information and signposting to general and health related local services. Finally, the Alzheimer's Society, Breast Cancer Care, Parkinson's Disease society, MS and ME Societies all ran support groups within the area.

North West commissioning strategy

In taking account of the significant projected rise in over 85 year-olds in the local population, the strategic commissioning plans for the PCT have taken the view that current service levels will quickly become unaffordable and that alternative solutions must be found. One commissioner thought that this would inevitably mean more emphasis on health promotion, prevention and self management.

"If we expect people to fall over at the rate they are currently falling overthe levels of dementia to continue etc., cancers, then we will have to have a significant shift of prioritisation and provision to meet that demand. The alternative to that is to maintain the population healthier for longer...and that's our strategy basically, is to maintain people's health and independence for...much longer than is currently the case." Service provider eleven North West (PCT Director of Strategy and Redesign)

The PCT has recently reconfigured its commissioning arm so that instead of having discrete responsibilities for older people's services or LTCs, these responsibilities are now spread across all the functions of the commissioning cycle. This covers procurement, performance management, information, governance, and redesign and strategy. A PBC consortium made up of all 38 practices within the PCT has been established. It has the primary responsibility of leading the redesign of services along patient pathways but also helps practices feed back to the PCT on performance issues. Self management has been embedded within the pathways for all practices.

"We see the pathway as starting at home, and including people, who don't need medical intervention, don't need services, but just need information about how to access care for themselves. Also when patients are actually being medically managed, that ideally they would be able to own that management plan themselves.....and have less ...reliance on the NHS. So we're trying to build services such that we can maximise patients' ownership of their own conditions wherever possible." Service provider eleven North West (PCT Director of Strategy and Redesign)

Half of the GP practices within the PCT are taking part in a pilot study with the organisation Health Dialog. This study involves extracting from various databases and understanding of the most needy in the population.

"We're doing this project with Health Dialog UK, Staying Healthy programme. Part of that is to look at your population and stratify it in terms of risk. So who are your patients, what are their problems, where are the gaps in care, and to use it as a commissioning tool to ensure we have the right service in the right place." Service provider six North West (General practitioner / PEC Chair)

The establishment of a "disease pyramid" will lead, we were told, to the commissioning of different levels of provision to meet the needs of the patient – from health coaches for those who simply need telephone advice, to the future possibility of testing services in their local pharmacy, to the GP for more dependent patients and community matrons for active case management.

The hope for the future, as stated by our participants, is that more money will be invested in primary care and community services rather than in secondary care where it tends to be spent at the moment. Stroke and diabetes care services are being restructured on the basis that patients will need education to better understand their conditions. Increasingly, the quality schedules in GP and pharmacy contracts will, it appears, specify the requirement to advise and educate patients. Whilst we cannot know how far this will be realised, the views expressed indicate that self management has at least become part of the professional rhetoric in the commissioning field.

I'd like to think that we could secure a lot of the benefits of patients managing their own conditions through core services. Service provider eleven North West (PCT Director of Strategy and Redesign)

The implications of the personalisation agenda are becoming apparent within the case study area social services department, and provide some opportunity for reconciling the tensions identified earlier – those between enhanced service use and choice, and promoting self management. One provider here saw their commissioning role diminishing as individuals take more control of their own service provision, but confessed that they were still trying to second guess what was likely to happen.

"We can commission some things like brokerage, but ...I don't see how we can commission a care agency. I mean we can regulate, but we can't say to care agency A from now on you'll have the business in [neighbouring town], because that's for the individual to decide. You're [service user] in charge, not us. We'll

give you an assessment, we'll give you advice, we'll give you an allocation of funding, we'll give you an approved list of agencies, we'll give you all the support we can to enable you to get on with it, but then you've got to get on with it."

Service provider seven North West (Locality Manager, Older People's Service Purchasing, Social Services)

This interviewee described a careful balancing act between spending money now on services for people who are not yet in critical need to reduce their demands on services later. One such area where there has been increased investment is extra care housing.

"That's a huge great financial investment at the moment and I think it's a wonderful model, but in terms of getting my balance sheet right...we've got to pay out millions...and then the benefits will come in over the years. Service provider seven North West (Locality Manager, Older People's Services Purchasing, Social Services)

Both health and social service commissioners talked about the drive towards greater integration of services for older people across health and social care sectors that will result from single assessment, unified information systems, joint provision and common prioritisation processes. Again how far such sentiments will be translated into new support services is difficult to say from the interviews conducted.

The provider market within the North West PCT area was also considered to be under-developed, as the diversity of provision is perceived as poor, there is no real challenge to the strong acute Foundation Trust and the third, voluntary sector is weak. The financial problems of the recent past have meant there has been little investment in community provider services. Those providers that do exist are seen by many in the area to be failing to respond in an innovative way to the PCT's commissioning aims.

"Providers should increasingly come up with ways to deliver what we want. The current situation is that our providers need to be toldbecause they're not sure, they can't work it out "Service provider eleven North West (PCT Director of Strategy and Redesign)

It is, of course, not for us to judge the rights and wrongs of such an outlook, but it indicates that when interviewed, providers are keen to present themselves as wanting to see innovation in support services that will meet the demands of older people in the future.

North West services

Instead of providing more and more illness care, commissioners within the North West stressed developing an increasing number of wellness and prevention services.

For example, the local PCT employs seventeen community matrons and is currently piloting a telephone based service offering advice and information to people via health coaches.

"Every patient of every practice that's involved has access to a health coach and can at any time ring that health coach for adviceCOPD patients can be rung when there's a cold weather front coming in....saying have you got your inhalers ready...you do know to take a double dose on a cold day." Service provider eleven North West (PCT Director of Strategy and Redesign)

Also within the area, practice based medicines managers organise blister packs, note any changes in medication and answer queries from patients, whilst community pharmacists offer a dispensing and delivery service to the housebound and Medicines Use Reviews to people on multiple medications. The aim of these reviews is to ensure that people understand the purposes of their medications and take them correctly, with the ultimate aim of being able to highlight problems and reduce wastage. We were told that older people tend to be the main beneficiaries of these reviews as they are often on complex medications.

One general practice had developed a service aimed specifically at older people with LTCs which is delivered by a care of the elderly nurse. The service was developed as a result of recognising that there was a cohort of patients who did not have access to the basic information and support that they required. Although the service worked primarily within a medical model, patients were able to raise other issues too, and much of the work involved tailored education enabling the nurse to meet each individual's agenda for self care.

"You have to ...tailor the education to the individual patient, but particularly...when they are first diagnosed with a condition like diabetes, to give them information step-by-step." Service provider ten North West (Community Nurse)

Other services developed by the PCT to promote self care and independence included a "sloppy slippers exchange" which hands out new slippers to older people in community halls and other meeting places, and Books on Prescription whereby health professionals recommend self help books that are available at the local library.

Having decided to opt out of the Expert Patients Programme, the PCT instead planned a local equivalent. Although these sessions were initially targeting a particular geographical community, our interviewee felt it would be perfectly possible to target older people in the future.

"What we're hoping to do is run a series of sessions where we involve a small core group ...of people with LTCs, but not under the name of Expert Patients.....where the group actually comes up with their own ideas of what they would like to happen during the six weeks, and also for the group to actually name the group as well and have some ownership of it." Service provider five North West (PCT Health Improvement Coordinator)

Providers from the third sector in the case study area described a further range of services offered to older people. Many of these are delivered by the local branch of Age Concern.

"Support for self management is probably the keyand I suppose that's a lot of what Age Concern is about on a local level...providing preventative, rehabilitative support systems to help people to stay in their homes and to manage." Service provider three North West (Age Concern Deputy CEO)

In addition to traditional day care and drop-in centres, the services provided included a low cost falls prevention service for the over 60s at risk of falling, a Get Active project offering a range of exercise sessions for older people, and a good neighbour service which offers assistance with transport and odd jobs.

The government's agenda to encourage more people onto a direct payment or personal budget system had also led to the development of Age Concern's brokerage service for older people. This service helps older people to navigate a system which may otherwise appear rather daunting.

Another third sector provider explained the rationale behind the local Breathe Easy group which offers peer support as well as educational talks for people with lung disease.

"It's really that they come here and they support each other. They see people that are similar to themselves because being breathless you can get extremely isolated and so even if they can't come to meetings, they get a newsletter." Service provider four North West (Breathe Easy support group leader)

A disability services facility in the centre of the area aims to help people to live independent lives. It provides an on-site café which helps combat social isolation, advice on welfare benefits and disability rights delivered via a drop-in service, telephone or home visits, and a Shop mobility service. The centre is staffed primarily by volunteers, 70% of whom have a disability or LTC themselves.

"It started up many years ago as a place where disabled people and older people would come together for a cup of tea and a biscuitWhilst people were sharing their experiences....learning from other people, that has developed into a full-blown advice and information service.....I think we do a lot of work here to support people's health and well-being." Service provider eight North West (Manager of disability advice centre)

During the interviews, reference was also made to a number of other locally available services developed to support older people. These include pulmonary rehabilitation courses at the local hospital and telecare, a service operated by a local company on referral from social services, which provides an alarm system for older people living at home.

North East commissioning strategy

There are no quotes presented within this section as notes were taken of both interviews rather than the interviews being audiotaped.

The PCT has a director of planning and commissioning who has an umbrella role working with frontline commissioners to develop annual commissioning plans. Across the PCT there are a number of people who lead on commissioning in the following areas; a)

acute care; b) primary care; c) long term conditions and d) joint commissioning with social care.

In terms of LTCs, all of the LTC pathways were undergoing redesign at the time of the fieldwork. This involved mapping the existing contracts with providers and deciding which of these contracts should undergo contestability. Within the PCT, they are attempting to modernise the pathways which they believe will lead to new providers being asked to tender for the available work.

As for LTCs and older people, work at the time of interview was focused around addressing policies in relation to dementia care. PCT commissioners were also mapping the existence of local voluntary organisations and their activity. The PCT was opening up discussions with the voluntary sector regarding tendering for providing services. In particular, they felt that they were looking at innovative ways of working with service providers.

The PCT commissioner was concerned about the future development of health services because of recognition that there will be little growth money within the NHS from 2011, which will require a significant restructuring of current provision. He believed that savings would result from moving services from secondary care into the community. And that maximising primary care services and self care would help to save money in the long run.

Self care and self management was thought to be likely to have a larger profile following the Darzi review, and that it would be sensible and cost effective to use high street locations such as pharmacies to promote self care. The PCT commissioner was however concerned that it may be difficult to implement self care within a socially deprived area such as the case study area.

Within this PCT there are six practice based commissioning clusters one of which shares boundaries with the case study area. Each of the PBC clusters has a cluster manager plus administrative support.

The commissioning board has a commissioning chair and all final decisions about commissioning are put to the vote at the commissioning board. All constituent GPs for the PBC cluster have a vote on the commissioning board. Local practices initially put in individual business cases but, we were told, did not hear anything about them. They then bonded together to be able to compete with others who also might be tendering for services.

Prior to the development of the PBC clusters needs were identified by talking with GPs and using secondary care data to identify need. This has now changed and practices across all of the clusters are providing primary care data to inform needs assessment. Needs assessment is carried out by the cluster managers in collaboration with GPs, and PCT public health staff.

In terms of their relationship with secondary care, the case study area is so far away from the local teaching hospital, and so the PBC manager felt that it was often difficult

for the PCT and the PBC consortium to negotiate with the local teaching hospital regarding service provision.

Another concern was that the people in the case study area were very different in terms of their needs and expectations than the people in other areas of the PCT, who were considered to be more demanding and highly educated, and therefore to be more likely to want more care and demand more from services. Indeed in the case study area the population is less mobile and family support is likely to be relied upon a lot more.

Within the area, joint health and social care commissioning had been in place for some time. However, the area has recently become a unitary authority which has led to a rationalisation of the number of posts involved and more joint commissioning appointments. The PCT commissioner felt that now the case study area has become a unitary authority that this has made joint commissioning easier, as the PCT just has to deal with one organisation rather than several borough councils. Joint planning posts have been established between the PCT and the new unitary authority.

North East services

Within the North East case study area there was a local Healthy Living Centre which had been developed to improve the accessibility of local services. The original idea for the centre came from the needs identified by the local PCT. The centre has been funded by a range of sources, including the PCT, Local Strategic partnership and a corporate partner. The needs for the service were identified via a series of consultation events which were held within the local community.

"We had a tea dance at the college and we invited all our over 50s along to this tea dance where we, again had the road show with our partner organisations and everything, said, you know, same thing again, these are the plans, this is what we think. And we got some good feedback from them as well. And we had about, I think there was over 150 people came along to that event." Service provider one – North East (Healthy living centre manager)

A key aim of the centre is, we were told, to increase the level of communication between services, and a key mechanism for doing this is co-locating services within the building. The partners represented within the Centre included, Age Concern, the Expert Patients Programme, and Stop smoking classes, among others, and in its second phase of development local GPs will also be represented there with the aim of providing GP care outside of usual practice hours. As well as providing support within the purpose built building, other support sessions were available elsewhere in the area under the name of the Centre. In this way the Centre provided support for the whole community and not just for older people in the area.

Age Concern is also very active within the case study area, and provides health, social well being and financial support to local older people. For example a 'Good Companions' scheme is run which aims to increase older people's confidence in undertaking activities outside of their home and to increase their social support. This was partly developed as Age Concern recognised that a key barrier for older people in accessing services was a

lack of confidence in attending services and that they needed support to increase their confidence.

"It's called the Good Companions, its recruiting volunteers to go out and visit people at home, befriend them, build up their confidence to get out and about, and then taken them to taster sessions so that they'll start going out and living a life again" Service provider three – North East (Age Concern locality manager)

A key role for Age Concern within this area is providing benefits advice. Age Concern also runs many consultation groups to find out what older people's needs within the area are, but also to find out their views on particular issues of importance to older people.

Within this area, the Expert Patients Programme is embedded within the PCT, in that it is coordinated from the PCT offices and run by staff employed by the PCT. The PCT coordinator also manages two other members of staff who have a role in promoting the programme to general practices and to community groups and service providers locally. The EPP covers the whole PCT area. The PCT coordinator believed that she did not have problems in attracting people to the course as there was a great need for it within the local area due to the high prevalence of LTCs. Nonetheless, they often had difficulty in keeping the course full as a result of participants dropping out because of ill health, and in some cases the volunteer course also dropping out for the same reasons.

The PCT also funds a health development specialist for older people whose role is to work with others within the PCT, social services and the voluntary sector to develop public health initiatives for older people.

Key priorities in terms of LTCs within the area are the management of COPD and coronary heart disease. The PBC consortium have redesigned the COPD pathway as COPD patients within the area previously had difficulties in receiving nursing care in the community. The location of the case study area means that COPD patients are sent to a hospital which is outside of the PCT area, meaning that the integrated care team had to pick patients up from the hospital which often made their condition worse. However, we were told that if patients have an exacerbation then the ambulance that picks them up now calls the integrated care team to help manage them rather than them being referred to the hospital, thereby keeping care closer to home.

Finally, within the local area, pharmacists were carrying out a lot of work in connection with medication reviews for older people which were reported to be very beneficial by many of our interviewees.

We should note that other services within the area included DESMOND and DAFNE self management courses, deaf and hard of hearing support and breathe easy and arthritis care support groups.

London commissioning strategy

Within the case study area, general practices are organised into eight Practice Based Commissioning (PBC) consortia. These consortia work with the PBC manager, a local social enterprise, the public health department, local GPs and information providers to

identify needs within the area, develop service specifications and tender for services. The initial PBC priorities were based on the QoF, but the PBC manager felt that there was a need to balance demand management projects with those which are focused on delivering good care, as he saw it, in a sensible and economically viable way. As the initial PBC strategy was shaped by the needs of the QoF, GPs were concerned that there may be a disincentive to provide services which were not tied into such targets. All of their incentive payments were being tied into these targets. Therefore, the commissioners focused on commissioning those services that they were afraid were going to be lost.

The PBC manager felt that GPs sometimes identify a need for services which might exist within their practices but may not be an overall population need.

"Yes, because I know from working with the GPs, they will tend to say yes, we know what our patients need, and you have to respect that on the one hand, but actually sometimes when you've then asked them but what are the numbers, no, the GP with the best will has seen several patients maybe with a particular need, but that doesn't really translate into something that requires a service to support." Service provider four London (Practice based commissioning manager)

The initial services developed by the PBC consortium were focused on reducing inappropriate admissions, but later services have been focused on improving the quality of patient care without any direct knowledge of whether they will have an impact on hospital admissions.

Tendering for services created some anxiety for GPs as the services that they were considering commissioning might not necessarily feel like 'their' services, as they are shared by a number of practices. As a result, they may not necessarily have control over who is the provider.

"And I think sometimes its taken time for the practices to be comfortable and to realise that it's not going to be their person in the true sense, but need quite fairly I think to be assured that they will have a process in terms of selection of the individual or whatever, that it's going to support them etc. Yes, they're keen to kind of know more about the tender than it's probably right for them to know, because their interest is high and understandably." Service provider four London (Practice based commissioning manager)

Within this area, self management courses and support groups are often funded via PBC savings for short periods of time and have to prove themselves before receiving more stable funding.

The practice based commissioners have developed several LTC services including those aimed at anticoagulation and diabetes. In particular they have focused on commissioning services which had previously been provided in secondary care and are now part of primary care aimed at improving patient outcomes.

In terms of social care commissioning, this area has a joint health and social care commissioner for older people who was accountable to the older people's board which is part of local strategic partnership. The commissioner saw her role as promoting joint working rather than strategic commissioning. She believed that as well as a lack of 'joined up' care that there was also a lack of joined up commissioning, with some things being seen as the responsibility of health, and others being seen purely as the responsibility of social care. A particular issue in this area was considered to be the difficulty of getting services commissioned for older people as strategically the area is seen as a borough for young people.

"It's about promoting joint working; it's about promoting joint thinking. So I have a role around looking at what is in the whole system and promoting that joined up thinking, whether it's jointly funded or not. It doesn't need to always be jointly funded, you could have separate services but who actually and because at the end, if you're looking at the end product which is your customer or your patient, how is it for them and would we better organise our services to work a bit more closely together so there's a partnership working but there also is a joint, an aspect of the joint work which is funded, so we have a Section 75 between the Primary Care Trust and the Local Borough, this is in older people's services and that covers a number of formerly integrated or joint teams." Service provider six London (Joint health and social care commissioner)

London services

Within this area, there is an active ageing centre for people aged 50 and older, which runs classes across the area every week. The centre is funded by the Big Lottery Fund as a healthy living network and coordinates the activities of several partners including Age Concern, Stop Falls Network, Stroke support, and an Asian Women's project. The healthy living network has a coordinator who works with all of the partners to plan and coordinate projects. The partners' priorities are identified by outreach workers who go out and meet local groups of older people to identify their needs and interests. Using this information, the partners then work together to plan services and deliver support.

"No, basically, we get together and we plan, certainly with the patches. We've actually done all of the patches now and this is a final year of that funding. So what we did do with the patches was we get together the demographic thing, where the older people were, what they'd need. We have an outreach worker go out and meet local groups and see what they were interested in doing, and then the partners altogether would sort of plan where we put services and what we're going to put in. So our patch was a quarter of case study area, which again is a big area, so the impact we made isn't as great as we would wish, but it was as good as we could do with the money, if you see what I mean. Service provider two London (Healthy living consortium manager)

One of the partners of the active ageing centre is focused on providing exercise centred activity, which aims to provide people with affordable health opportunities. This partner was also attempting to link together several of their courses into one package, for example bringing together exercise classes and healthy eating demonstrations to combat obesity.

Age Concern has a strong presence in the community, running 12 projects funded from a range of sources. Age Concern's work within the area is focused around three elements which are; a) Health and Wellbeing; b) Income maximisation and c) Alleviating poverty. They run coffee mornings and surgeries to offer people advice and information so that older people can come to have both their needs met and to engage with others. Quarterly meetings on estates that are undergoing regeneration are held to involve people into looking at the redesign of their estates. Age Concern also runs the Age Well programme which works to introduce older people to the services available that can increase preventive care, for example, by making it easier for older people to join leisure centres.

Another of the programmes run by Age Concern is Link Age, which aims to introduce and track people through activity programmes. It aims particularly to make contact with isolated older people by using outreach workers who are of similar demographics to those whom they are serving. The following quote illustrates the efforts and complexities involved in developing such services.

"Link Age has been... as I say, there's been a budget ring-fenced within case study area to deliver Link Age. They're going to do it, in a nutshell, it was originally supposed to be an equivalent of a One Stop Shop, so that people could come to a building and find all their needs and be... and find out where to go to get what they needed, rather than to go to 10 different places. In London borough b there were eight hubs, and each hub has a coordinator and an Outreach worker. The coordinator is supposed to find out all, make links with all the agencies that work for older people.

Right and the Outreach work is supposed to drag in the customers?

Yes.

Right, got it.

And is it working well, and does it relate to this reference group?

Well one of the reasons... it hasn't happened yet in case study area, and one of the reasons the Reference Group is talking about it is because in London borough b the pilot was working well, its been tendered and there is discomfort with the lead agency at the moment. And because our chair of the OPRG, Dr AAA BBB, actually is involved in the Link Age in London borough b, she's very keen to see that the same mistakes are not repeated but that they...

But the idea is that the Outreach worker speaks to older people, says what do you need, how can I facilitate this, and the coordinator makes sure there's no two line dancing classes going on at the same time in the same area. And the idea is that you do not introduce new things necessarily, but you make the most of existing opportunities, which actually makes a lot of sense. Service provider five London (Age Concern CEO)

Arthritis Care has been commissioned within the area to run the Expert Patients Programme. They deliver three courses which are; 1) "Challenging you condition" (an Expert Patients oriented programme); 2) "Challenging pain" – a two day course on the self management of pain and 3) "You can break the pain cycle" – a one day course on the self management of pain. They normally identify participants via newspapers advertisements but are also looking to identify people from hospitals. In terms of the EPP, Arthritis Care originally wanted to run "taster" sessions to attract people to the course and to also offer follow up sessions to the EPP course, but the PCT was only willing to fund the usual six week course. The coordinator believes that the group

processes within the course help to change people's behaviours, as the interaction with others help to overcome feelings of isolation. If they see other members of the group doing well then she believes that this would motivate course participants to try and improve their health and do things for themselves.

Within the case study area, because of the National Service Framework for older people, the PCT has carried out a lot of work on medication reviews for the over 75s who are on multiple medications. However, the PCT does not have particular medication related policies for older people and people with LTCs.

Other services within the area included DESMOND and DAFNE self management support for those with diabetes, GP led chronic disease clinics and support groups run by organisations such as Arthritis Care and the British Heart Foundation.

6.3.5 Process of identifying need for services

Needs identified by commissioners and service providers

Across all areas, service providers and commissioners described a range of methods used to identify service need, including case finding, cross referrals, older people's networks and patient satisfaction surveys. Service providers and commissioners interview data suggested that services identified within the case study areas tended to be needs-led, or at least had a system whereby needs could be identified. For example, in all areas, when attempting to get services commissioned, staff were required to use data sources such as public health epidemiological data and QoF data to demonstrate the case for a particular service. However, some spoke about how problems could arise when the local population changed demographically and consequently so did local needs. This was a particular issue within both the South West and the London case study areas.

"So they're using ... the epidemiological surveys etc to find out where the need is, which I think is the right way of doing it, because there's no point in putting a COPD nurse everywhere...But where the population has changed or there's been an alteration in sort of demographics, then they haven't necessarily plugged that gap with a service and, because they haven't seen the need for it." Service provider five and six South West (GP and practice nurse)

When identifying needs, the importance of ensuring that just one set of priorities did not take precedence was highlighted, particularly within practice based commissioning, and as GPs may identify a practice based need which is not a population level need.

Needs were also identified by building on work that had previously been successfully undertaken and for which a need still existed. For example, one area spoke about the continuing need to fund GPs and hospital consultants working together on shared care pathways.

"So at that point again the PCT thought well we need to be thinking about demand management, enhanced services, plus other possible like the use of gypsy services, of opening a locomotor service. These demand management related projects then got side kicked off, to actually think of how do we ensure that we're delivering good care in a sensible way economically, rather than just letting it all arrive at the hospital. And so when PBC came in, we already had some of the GPs working with the consultants in the hospitals to think about pathways, to think about services and to try and see what balance and shift could be created." Service provider four London (Practice based commissioning manager)

Appropriately identifying needs is important to ensure the effectiveness of commissioning decisions, as services will be judged on whether they are meeting the perceived needs of the population that they are meant to be serving. The need for services is often explored by running pilots to see whether the service makes a difference to healthcare use and to the quality of life of its users. If services are shown to be working then they will be likely to receive more funding from the PBC consortium and will eventually be funded as a locally enhanced service.

Within the North West case study area, the PCT was using Health Dialog's "Staying Healthy" programme to identify need from existing databases, with those with the greatest need being directed towards community matrons and the less needy being offered support from health coaches. Community matrons also talked to GPs to find out who are the high intensity service users and accepted referrals from social workers, hospital nurses and friends and neighbours.

"I do worry still that we've not identified everybody....maybe we need to look at self-referral...a bit more....I don't know how that [would] work, opening the books totally, would we get flooded from it?" Service provider nine North West (Community matron)

In all of the areas, a case finding approach appeared to be used successfully as a way of increasing people's awareness and use of services. For example, within the London area those with diabetes were identified from GP records and were sent invitations for assessment and referral to appropriate services. A particular aim of case finding here was to reduce referrals and to try to avoid any unnecessary hospital admissions; again community matrons were used to support frail older people. In the same area, the PBC practices were keen to try to identify need and promote services to the over 75s, and so they used their commissioning money to visit people at home to identify any ailments which required intervention. The older people's commissioner had emphasised the importance to them of communicating information about services to older people when undertaking these visits.

"Recently, and in other words something that we're working with the GPs at the moment, is they want to try and do more to identify need in this over 75 age group. So using their PBC money they're looking at going out to visit people. If I've got my understanding correct, the GP contract says to the GPs you must go if somebody calls you if they're over 75, but they wanted to be more proactive,

and the thinking is that there will be people out there with ailments in a fairly stable fashion who aren't turning up to hospital or aren't going in to their GPs. So they're looking to go out more assertively to try and find people and see what needs there might be. Our commissioner involved with care for the elderly has basically latched onto that and said well as you're going out make sure that you communicate this and make sure that there's good signposting of the various services, whether its swimming or whatever, to actually support or help people". Service provider four London (Practice based commissioning manager)

Within the North East area, the Health Development Specialist for Older people felt that she had a role to play in highlighting older people's needs to GPs. For example, she felt that she needed to highlight certain issues to GPs as being health related rather than social issues, for example fuel poverty.

"I've realized over my years here that it really takes some people banging on about certain issues because it's still, you'd think that there wouldn't be as much of a disease model, but even within public health they have to really, really push the issue if you want to be heard" Service provider four – North East (Health development specialist)

Needs identified by older people

In all areas, opportunities exist for older people to highlight unmet needs. For example, the South West had a strong network of local community forums which represented the needs and views of older people and provided information to service providers about what was needed locally.

"Partnerships are critical to having the conversation with older people... we've got some very able and valuable members, very valued members of those community groups who actually take part in and participate in and contribute to the debates about life in [the county]." Service provider three South West (Director of Nursing)

Within the North West, an Age Concern Scheme with 700 members provided feedback on services. Older people's resource groups meetings in different parts of the case study area were consulted for their views on health and social care. Social services also held consultation exercises and the local disability drop-in advice service held meetings to enable people to voice their concerns.

Within the North East, the healthy living centre coordinator felt that she identified need across all sectors of the population by undertaking consultation exercises and providing those who are using the centre with plenty of opportunity to feedback their thoughts. Age Concern within this area also regularly used consultation groups to determine older people's needs.

As before, we cannot be sure from these interviews how successful such activities were, but our impression was that considerable effort was given by a number of agencies to provide older people with at least a degree of consultation about service development.

Needs identified by joint working with social services and the voluntary sector

Networking and joint projects within the voluntary sector also led to the identification of particular needs.

"It's very good networking, because obviously when we're out therewe might meet someone who's got Parkinson's or whatever, that's missed out on the things that we can offer." Service provider two North West (Falls Prevention Co-ordinator, Age Concern)

Within the London area needs were identified through multi-sectoral working. For example, Age Concern monthly bulletins were considered to be useful for organisations and individuals working in other sectors to identify the needs of older people in their area. Age Concern's websites also provide updated information on national and local issues. The local pharmacy advisor within the London area also carried out needs analysis and talked to local charities and voluntary sector organisations to establish the need for services.

Within the London area there was a concern expressed that identifying needs which are focused just on the over 65s may mean that those who are slightly younger but who are experiencing problems which are normally experienced by older people may not gain appropriate support.

"You know if they're an older, if they're a service which is supposed to be funded just for older people then how do they deal with people who exhibit conditions which they normally deal with in older people but are actually experienced by younger people. So for instance around the dementia issue our older people's mental health services has a protocol with the adult mental health services because the expertise within adult services around dementia is minimal and they are brought in. " Service provider six London (Joint health and social care commissioner)

Nevertheless, lobbying for older people's needs was considered to be particularly important as it is often seen as problematic in areas where the greatest need is perceived to be for services to support younger people. For example, in the London study area the local strategic plan has only included one indicator for older people after much lobbying.

"We are now at the beginning of a second three year strategic plan. The first three year plan for case study area did not mention older people at all, and had to come back to take cognizance of their needs because the government itself insisted that certain indicators had to be met, but they were secondary. This time round, as a result of lobbying, not just from ourselves but also from key members at lower level, then the strategic partnership, which is Team case study area, has included one indicator for older people, PS17 Service provider five London (Age Concern Chief Executive)

6.3.6 Challenges to providing services

Participants identified a number of challenges to providing services, many of which were systemic and related to inadequate funding, access to users, and an underdeveloped community based provider sector.

Financial issues

The North West area PCT reported having experienced major financial difficulties in the recent past and so did not have a great deal of funding for developing new services. This meant that although there was a belief in self management that potential resources for educating, informing and engaging patients were taken up by the more urgent needs of the population. This situation was exacerbated by a strong secondary care provider and comparatively weak community sector.

"We're in the position where we have virtually a £7million overspend on our acute contracts, which hand to mouth we have no money to invest in prevention and avoidance. The trick is how to switch over to a different model." Service provider eleven North West (PCT Director of Strategy and Redesign)

Funding for services was also an issue within the South West. As mentioned elsewhere in this report, a particular issue was transport, due to the large size of the area, its rural nature and the large distances that needed to be travelled to access services. There were difficulties both for service users in being able to afford to pay for transport and for service providers in being able to fund free transport to their services.

"Transport in [the county] has always been the biggest issue and the biggest cost... We're a trustee run as a charity, and about 18 months ago we did a massive transport survey, and the trustees reluctantly took the decision not to take people [who lived outside of the central] postcode unless they would fund their own transport, which was a hugely difficult decision." Service provider one South West (Community matron)

"It's transport essentially and transport and mobility. So the transport needs to be disabled transport and we could double our numbers if we could get the people up from [local town]...My heart sinks every time she says they live in [local town] because I can't get them here. We just don't have the funding to get them here." Service provider ten South West (Local stroke support group)

On a number of occasions we were told that a lack of funding resulted in a lack of resources which led to difficulties in running and sustaining services. For example, within the London case study area there was a concern about the usefulness of self management courses, as the local PCT was unable to fund a follow up group for those who had attended the six week self management course. This meant that course participants were often left to their own devices to organise further support which appeared rarely to happen. Without further support, however minimal, course participants were reluctant to run their own follow up groups, partly as a result of the continuing impact of their LTCs on everyday life, and partly because of the practical responsibilities involved.

In all of the case study areas, financial constraints meant that social services had to prioritise those with the greatest need. This, we were led to believe, has resulted in an increasing number of referrals being passed on to the third sector and Age Concern in particular. For example in the North West case study area, the Age Concern falls prevention service has seen the number of referrals from social services grow over recent years. This has implications for the service in terms of time and money.

"I feel as though probably at the moment it's just the time factor...we're ...really, really pushed." Service provider two North West (Falls Prevention Coordinator, Age Concern)

"There's always criteria for services and I suppose in the third sector...we've always tried to be as loose about those as we can...but I think increasingly and I think as money gets tighter...it becomes difficult for us to provide the service to as many people." Service provider three North West (Age Concern Deputy Chief Executive)

Funding for many voluntary organisations is invariably short-term with all the uncertainties that that brings. One provider within the London area was waiting to hear whether rolling funding from the PCT would be continued. However, another third sector provider also discussed the implications of the move towards a commissioning agenda. In the future funding is likely to be converted into competitive contracts for specific services rather than general grants as before.

"They'll be more focussed on outcomes and outputs....I'm not saying that there aren't, at the moment, targets and expectations, but it will be much more rigorous.....it'll be a different ball game if you are submitting in a competitive tendering environment and will be required to deliver particular outputs rather than ...just getting grants for doing worthy work." Service provider eight, North West (Manager of disability advice centre)

Maintaining the funding to sustain services was another challenge faced by service providers across all of the case study areas, sometimes threatening the overall sustainability of the service.

"We do reasonably well in getting contracts actually for the activities, where there's an issue for us and particularly in our department about full cost recovery, of their not being able to afford to meet the proper cost of doing things. So the cost of my salary and XXX, who just rang, salary, tend not to get built in. And the issue will be in the longer term that the PCT are saying either we fund a few people properly or we fund everybody really badly, so that's going to be an issue. There's also going to be pressures... this is where we shape the scores, pressure for organizations to grow in size so there are fewer people to contract with." Service provider two London (Healthy living consortium manager)

Several service providers commented on the difficulty of linking self care and self management to cost savings such as prevention of hospital admissions, which inevitably had an impact on the future funding of the service.

"The difficulty with things around self care and self management are that they don't have that direct correlation with secondary care activity. They have a clear implication for reducing non-elective admissions but it's much less tangible and much less obvious...I was pleasantly surprised that when it came to looking at extending the funding for [the service]...it was very encouraging that ... the people who had the purse strings actually said "okay, yes let's run with it" . Service provider three South West (Director of Nursing)

Some spoke about the difficulties they experienced in meeting the demand for their service as they did not have enough space to accommodate all of the potential users.

"Tomorrow morning I could have four phone calls with new referrals. And obviously we have to wait for someone to go into care or to die basically...we're not big enough physically to have more people in wheelchairs." Service provider one South West (Community matron)

Resource issues – staffing and administrative burden

There were some services that providers would have liked to have offered but due to a lack of qualified staff they were unable to do so.

"We would want it to be fully funded, because I don't think you could run a service like that with one member of staff, volunteers, because most of the volunteers are as old and as frail [laughs] as the people who come in, and we're providing a huge need for volunteers. Service provider seven South West (Age Concern Service Manager)

Staff shortages also made it difficult to provide self management support, as it took less time to provide care to a patient rather than to encourage them in their self care activities.

"It is much quicker to do to than facilitate...[as] much as they might want to be facilitators [they] sometimes just get on and do it, because that's the only way to manage the workload." Service provider five and six South West (GP and practice nurse)

In the South West area the workforce was not available to deliver the services and the low pay available to do what could be a very difficult job was considered to be insufficient to attract potential workers. This is likely to be a problem across the board and not just within a particular area.

"There are some absolute home care black holes in very deeply rural [county] but there just aren't... because young people have moved out of villages because they can't afford to live there anymore, there isn't the workforce, it's all retired people, so there's cost to bussing [carers] in." Service provider two South West (Health programme advisor for PCT)

At the same time, it should be noted that not all services suffered from staff shortages. Some voluntary services seem to be particularly well resourced, though often with a

considerable with more than enough volunteers, making them highly dependent on particular individuals within the community. If these were no longer available it was often difficult to main the support service in question.

"But it's also fair to say that you will find that there may be three or four prime movers for a particular village, and they lead, and if one of them fell over, that is probably where you'd have the problem, because they have been the prime movers, they managed to galvanise other people within the village. And if they fell over, it's finding the leaders to replace them that may be the problem." Service provider seven South West (Age Concern Services Manager)

And for some service providers, being able to expand the service provision within the local area was not always possible, in spite of local needs because of the procedures and administration required.

"A lady did come and talk to me about opening [a group in local town], but when she realised how much paperwork was involved, you know Health & Safety and all that stuff, I mean it all has to be properly done and she decided not to do it." Service provider ten South West (Local stroke support group leader)

System and service reorganisation

Within the North West county council, the move to a new unitary local authority in April 2009 and a certain resistance to the personalisation agenda amongst social service staff were seen by one commissioner as barriers to providing support for self management.

"I think the financial barrier is going to be a big one because we're moving to this new organisation and there's going to be implied financial constraints.....I think reluctance to take on the personalisation agenda when it is actually in people's best interests is probably another one." Service provider seven North West (Locality Manager, Older People's Services Purchasing, Social Services)

But even if more people opt for direct payments and personal budgets, some providers were not convinced that the local market was ready to meet these demands.

"I think one of the challenges under personal budgets.....will be the fact ...that...there won't necessarily be the services out there for a while that they actually want to buy because I think that the market isn't stimulated enough to actually respond to those needs." Service provider three North West (Age Concern, Deputy CEO)

6.3.7 Challenges to promoting services

One of the greatest challenges to promoting services was considered to be getting people to understand the need to manage their own condition, particularly in poorer communities where people may think that they only go to the doctor when they feel ill.

Services across all of the case study areas seemed to be fairly well promoted, although their uptake depended on the willingness of potential users and how pro active service leaders were. For example, in the London case study area the EPP coordinator was working with the information officer at a local hospital to promote the EPP course to patients.

"So we're trying to feed people in from the hospitals into the... that's the theory behind it, you will engage people at the hospitals with our information stand there, and try and get them to feed into the courses if they're interested in attending the courses through the hospital information point. So its new and it's a new approach, and we're trying to see how it works, because we normally promote the courses just in the newspapers, normally that's our biggest way of getting an interest, through the newspapers. We don't have a foot in the door with the NHS as such to feed people into us, refer people into us, so we tend to... and a lot of the courses don't run within NHS settings either, they're community settings." Service provider one London (Expert patient programme coordinator)

Local services were also promoted within GP surgeries, libraries, existing community groups and natural meeting points. Although there was a wide range of activity regarding promotion of services, there was an acknowledgement by one provider within the South West that there will always be some people in the area who will never be interested in particular services and who cannot be reached.

"I think without doubt there will be people who will be isolated...they can say well X doesn't come...and basically he likes to be by himself and we can't get him out....they will know who is not and who is isolated...the neighbours will still be looking out for those individuals, that they're not keeling over, but they can't get them out." Service provider seven South West (Age Concern Services Manager)

However, it appeared that many older people were interested in hearing about services, as within the North West case study area, one commissioner who had recently attended a stakeholder engagement event was surprised to discover that the older people present would prefer more money to be spent on promoting existing services rather than developing new ones.

"They were talking about TV adverts, backs of buses...radio campaigns...and I thought ...that would take an awful lot of money... and the old people...on my table said we would rather you spend less on services and advertise the ones that are available better, such that we knew which choices we had." Service provider eleven North West (PCT Director of Strategy and Redesign)

Interviews with other providers gave some insights into why people might feel this way as newer roles such as the community matron are not well publicised other than on the internet, which will not be very useful to those older people who do not use computers.

Some services across all sectors may have not been very well promoted, due to a concern expressed amongst some service providers that too much promotion of their services might lead to increasing service demand to a level that they would be unable to meet. Such a view may act as a disincentive to actively marketing and promoting

services. For example, within the North East, the Age Concern locality manager spoke about her concerns about advertising their Good Companions scheme, as she did not want to raise people's expectations about what it could offer until she knew how much volunteer time it was likely to require. This led to an ironic situation where a lack of advertising threatened to undermine uptake of the service as whole:

"We didn't want to advertise it, because we thought we don't want to raise people's expectations, especially the type of people that we were dealing with. So we were at a loss as to what to do because we weren't getting anybody. It was quite a while before we had a referral." Service provider three – North East (Age Concern locality manager)

Within the North East, one service provider spoke about the difficulties of promoting services to particularly hard to reach groups and how they had made a decision to concentrate initially on promoting services to those who were easier to reach to ensure that their service had an initial impact.

"But we thought, right, there is that population of hard to reach people, we know they're out there, we know that they need to be reached, but it's very much a long term, how do you reach people like that? So we've almost decided consciously, we saw in the physical activity stuff, for the moment to focus on the people either one who are already in groups. So we've had a bit of a re-think as to rather than banging our head against the walls, how do we get to the people who aren't participating ever, because we know we need to, but just given the capacity that we have...." Service provider four – North East (Health development specialist)

Despite these problems, there were examples of positive service promotion. For example, the North West PCT advertised events and programmes like Active Ageing through posters and leaflets in community halls, libraries and GP surgeries. Within the London area, a local older people's healthy living consortium advertised their services via mail shots, and by working with a range of agencies who visited the housebound to advertise their services. Within the North East the healthy living centre coordinator offered people a free smoothie when they came into the centre, and when they were in the centre they were able to offer other services to them. Whether smoothies count as a healthy living option we leave the reader to decide.

A key issue in the successful promotion of services to older people was considering how services such as exercise were 'sold' to potential participants. For example, some older people may be put off by the term exercise class but may be perfectly willing to attend a tea dance.

Some of the voluntary sector service providers spoke about how promoting services could be facilitated by multi-agency working. For example, they spoke about the difficulties of providing support to the housebound due to difficulties in gaining access, and their attempts to work with those who were more easily able to gain access to the housebound, for example district nurses, to promote their services. In many cases though, it proved difficult to gain the assistance of those who were able to gain access to the difficult to reach groups.

"And I think that will help us reach more people that are isolated at home, because none of our agencies, all like one and a half people, we have done door to door leafleting, but its not something we can do often, you know.

No, its labour intensive to say the least.

Yes, certainly. We have relied on pharmacists, meals on wheels, basically those kinds of agencies that are going into people's homes to distribute the information about what else is there. Mobile library, they've been very handy and helpful.

So you were saying... sorry, just to recap, it was difficult to get people to take the home based exercise on board because...?

Not the people themselves. To get referrals, because they're isolated they're isolated and it's not worked in terms of... people must know who they are, but its not coming through.

But it's the same with the complementary therapies, it's always been a struggle to get home based, to find the home based people..." Service provider two London (Healthy living consortium coordinator)

A range of strategies were used by service providers to make accessing services easier for people. For example in the London area, the Age Concern Link Age programme provided a one stop shop for people when accessing services. Self management course providers spoke about how they ran self management courses in the spring and autumn as they were more likely to get people to attend at these times of year, and how they had developed a range of different self management courses which varied in length and content to suit a range of different needs.

There was also recognition that although providers may be successful in promoting their courses to older people, some may be unable to attend as they may have transport difficulties, and more often than not, the course organisers are unable to pay for transport as well as the costs of running the course.

" But for some people, for the other courses we're doing in London, we don't have the money to provide transportation for them to get there, and often it's the people that are at home are the ones that really need to be there, people that are isolated and at home are the ones that need to be there and are the ones that are not there. I think, you know, as I've said, just finding a decent venue really with access, good access, disabled toilets, kitchen facilities, not a noisy environment in London is very difficult. So people that can't manage on the London transport, its survival of the fittest isn't it, trying to get onto a bus or the train..." Service provider one London (Expert Patients Programme coordinator)

Across the case study areas, and as mentioned earlier, service providers reported on the potential benefits of running 'taster sessions' to get people used to the courses without feeling that they needed to commit themselves greatly. However, more often than not it was impossible to run such sessions due to a lack of funding.

Within the London area, representatives from the voluntary sector talked about the difficulties in increasing service providers' awareness of their services and in getting them to refer patients to them. Even if they did receive referrals, they felt that they

only certain service providers referred patients to them, and that if these providers left then referrals would be likely to dry up.

“Yes. And in terms of how are the GPs, are they sort of using you do you think?”

We have some that use us and some that wouldn't come near us basically. We send out stuff to them, not continually but often. Same as social services, we had a fantastic guy at the access team last year who put loads of referrals our way, like quite a few a week. He got promoted and they kind of dried up. [laughs]

It's always the way isn't it, it's personality driven.

Yes, so we're not part of the system in the way that we've been trying to get ourselves to be.

Yes, yes, I know. So why do you think some GPs use it and some GPs don't?

I guess it's again personality really. I mean, I think some GPs really do just focus on the medical and not think about the social, and others are... They have sort of GP forums where we've managed to get along. It's not that easy to get into them. [laughs]

[laughs] No.

Managed to get along to speak and we put out these, we send them a calendar every year that's got all the organisations on it. And the ones where they do refer and we're able to let them know the outcomes, you could build up quite a good thing. But where they're just not ever referring... Service provider two London (Healthy living consortium coordinator)

Within the North East area the need to promote services not just to older people but also to potential referrers had been formerly recognized. As the EPP coordinator was managing two part time members of staff, one of whom had a role in promoting the programme to GPs and other primary care staff and the second who had a role in promoting the programme to local community groups. The coordinator felt that these roles appeared to be working as she had received lots of referrals from the local modern matrons and the GPs.

6.3.8 Role of service in relation to other support options

Facilitators of joint working

As well as the North West study areas, two of the other three had new unitary local authorities introduced in April 2009. There was a belief amongst our interviewees that under the new unitary local authority, health and social care would be brought closer together. Commissioners were generally positive about the future prospects for joint working, but it was clear that there is some way to go.

“The way the new local authority will be ...has been shaped by us, so it's been shaped by health. That's not that common in my experience, in that a new local

authority will probably choose its own shape and form, thank you very much. But our Chief Executive has done a very good job of getting in there early and securing agreements on joint partnerships, potentially joint provision, and our community provider would be a joint provider with the social care provider.

Service provider eleven North West (PCT Director of Strategy and Redesign)

The community matron role was also seen as a facilitator of joint working, bringing together the jigsaw of health and social care provision into a coherent whole, including primary and secondary care, social services, housing departments, voluntary agencies and community pharmacy. Within the North West this process was facilitated by the diverse backgrounds of the 17 community matrons, from former podiatrists, occupational therapists and district nurses, to some who have worked in social care. Whilst it appears that there are good relationships on a personal level, it was felt that health and social care are not yet joined up at the finance and policy levels.

"On a personal level, myself and whichever social worker ...has always been good – we've done joint visits, we're doing joined-up working, but at the end of the day ...when the finances come down to it, health and social are still split."

Service provider nine North West (Community Matron)

Social services have a big investment in the third sector and there was evidence of this from both sides of the equation. Tighter budgets have meant stricter criteria for social service support and so more referrals are being made to voluntary providers.

Organisations such as Age Concern were aware of a tendency for the voluntary sector simply to be regarded as an extension of social services. Potentially, this conflicted with their policy and campaigning roles, although individual social workers were often willing to receive the support of the voluntary sector in challenging existing patterns of formal provision.

"We have quite a fewservice level agreements with social services to provide services to older people....but we also do have a policy and campaigning role so we are challenging them as well and obviously as advocates, we're challenging practices and systems on behalf of older people. Service provider three North West (Age Concern, Deputy CEO)

Nonetheless, there is a desire within social services to spread some of their work more widely across the voluntary sector.

"We've got...a lot of investment with Age Concern. I mean I'm quite keen to try and spread that, not to take stuff away from Age Concern, but to encourage other groups to get involved as well. Service provider seven North West (Locality Manager, Older People's Services Purchasing, Social Services)

The individual voluntary sector providers we spoke to gave various examples of the way they work together with a network of cross referrals both inside and outside the sector. First and foremost amongst these is Age Concern who carry out a number of joint projects, listing the Alzheimer's Society, the Stroke Association, and the Parkinson's Society amongst local organisations they work with. More ambitiously, projects involving

organisations such as the Fire Service provides, in one instance at least, a solution to the problem of accessing older people described earlier in the report.

The disability services provider within the North West area worked with a number of other support options, for example, Citizen's Advice and Arthritis Care through its Shop Mobility scheme. In some parts of the country, advice workers are based in local GP surgeries. In the North West there is no capacity for this, but we were told that there would be scope for a peripatetic service if the funding became available. The provision of information on people's rights to social service assessments is provided for by Arthritis Care, but like Age Concern, they are sometimes called upon to advise people who may want to challenge decisions and outcomes. They are currently working with the local social services department to put together a directory of services available to the community. One provider also highlighted the difficulties inherent in relating to the private sector.

"We are also courted by a number of, for example, independent care providers, because obviously we have a common client group. But they will be providing care services which people will be expected to pay for. And we need to be careful not to be seen to be favouring one particular organisation." Service provider eight North West (Manager of disability advice centre)

The London area has a joint health and social care commissioner for older people whose main focus is around promoting joint working. She has worked in the borough on a long term basis, and so is a useful focal point for information when a health professional is trying to contact a specific older person.

Within the North East area, the Healthy Living Centre coordinator believed that the centre could provide a mechanism by which service providers from different sectors could work together towards common goals. Facilitators for this were believed to be being located within the same building in the future, thus making regular meetings together more feasible. However, there was a belief expressed that it was sometimes difficult to get GPs to work together with other health professionals as their established patterns of work was as independent practitioners.

Examples were also given within the North East area of how the work of different service providers could complement one another. For example, the Age Concern locality manager believed that Age Concern had a very good relationship with the local GPs as they had been able to demonstrate their worth to them. She felt that they were able to provide a more holistic approach to providing support to older people than GPs who may be more disease focused. She also felt that they had been able to establish themselves as the local experts on older people's needs, and in that way they were able to provide a great deal of support to the local PCT and local authority.

"We like to think that we're the experts in our field with older people, and if an older person's got a problem, or if they need to know anything, we've got our groups, or we can go out and put the questions to the groups" Service provider three – North East (Age Concern locality manager)

Barriers to joint working

The evidence from the interviews suggested that GPs work very much on their own and do not always think about the voluntary sector as a resource on a day to day basis. When they do involve other support options they tend to delegate responsibility for this to practice staff. Referrals to Age Concern were invariably from practice nurses, hospital doctors and only a few GPs. A disability services provider thought they had not had a particularly good response from GPs.

"I don't think we work as well as we should do with social care....once upon a time we used to have a social worker who used to come to the surgery....and so it became a more personal relationship.we've delegated that to the elderly care nurse and she has good relationships with the social care systems because she contacts them regularly." Service provider six North West (General practitioner / Chair PEC)

It tends to be the practice nurses. Some GPs will pick up.....but I suspect they're receiving so much stuff that you know it's just a nightmare for them, isn't it? Service provider North West (Falls Prevention Co-ordinator, Age Concern)

Furthermore, although community matrons were considered to have good working relationships within the voluntary sector, particularly Age Concern and the Alzheimer's Society, it was considered to be difficult for community matrons to have a comprehensive knowledge of all the support groups in the area. Practice nurses also appeared to rely heavily on the same few organisations such as Age Concern and the local carers' association.

Within the London area, the voluntary sector representatives interviewed recognised the importance of publicising their services to health and social care professionals. But they tended to believe that health and social care professionals were mostly concerned to know what services were available rather than being interested in forming partnerships with the voluntary sector.

Despite many of the voluntary sector organisations interviewed being in financial trouble, many expressed the view that they would survive in the future, if only because they were providing a service that both health and social services needed. Simply put, if they didn't exist the social and health services would have to find some way of providing these services themselves.

Within the South West area, we did not identify many examples of consistent integration or cooperation amongst local service providers and services. For example, a secondary care service provider felt that they didn't have a great deal of contact with other organisations within the local community.

"Very little with charities and...very little contact with, even Age Concern in [county], we don't hear much from them at all, other than referring them to the day centre. They don't feel very proactive but whether that's because we haven't invited them in...they might just link in better with primary care..." Service provider five and six. South West (GP and practice nurse)

However, there were some example of joint working, the following service provider felt that she had several dealings with representations from the voluntary sector, and the second provider spoke about the multidisciplinary team that she was part of.

"Well certainly the social services-run day centre we have a lot of dealings with, a lot of two way referrals. The volunteer centre. With the local Alzheimer's, Parkinson's, the forum." Service provider one. South West (Community matron)

"Everybody is invited to [be part of the multidisciplinary team], the core membership would be medical and nursing and ... we have three Health and Social Care offices ... the Community Mental Health Team for the elderly, the Community Psychiatric Nurse has always been very supportive." Service provider nine South West nine (Head of older people's strategy, Local authority)

One provider talked about the challenges of overlapping with other service providers and duplication of effort in the care of older people.

"The other problem is the medication. It's in such a mess when I get there, they've had lots of doctors visiting you know because they can't get to the surgery, so they just have the out of hours or the on-call doctor, usually a different doctor each time gives them another pill. Doesn't stop...you know doesn't look at the others, well he does look at the others but don't feel they know the patient well enough I suppose to start stopping and reviewing because they know they're not coming back for the next time." Service provider one. South West (Community matron)

Finally, another provider talked about the recent changes in her role and how this had affected her relationships with other health professionals, as she was no longer able to carry out her previous function.

"We were taken out of [one role] and not replaced ... so we were very much aware of that and that caused bad feeling with [that] service." Service provider one. South West (Community matron)

Overall, there was a concern expressed that there was a lot of rhetoric around joint working but that not much seems to be happening in practice as many organisations and people are not communicating with one another.

There was some suggestion that relationships could be strengthened between the health and voluntary sector if patients were directly referred to voluntary sector services by their GP rather than having the service suggested to people followed by self referral.

There was also some suggestion that joint working could be strengthened by having a care coordinator for patients, a professional who talks to everyone else if someone has complex healthcare needs. Problems inevitably occur if there is a high turnover of staff and the care coordinator leaves.

6.4 Chapter summary

In this section of our report we presented the findings of interviews with service providers and commissioners across all of the case study areas. Having first commented on the meaning and definition of self care and self management, the analysis and discussion of the interview material was constructed around six key themes, generated by our initial interests and the data collected: 1) commissioners' and service providers' beliefs, attitudes and experience of self management; 2) perceptions of service users' expectations; 3) background and rationale for support in the case study areas; 4) the process of identifying needs; 5) challenges to providing services; 6) the role of services in relation to other support options.

Participants generally held positive views about self care and self management, as a means of enabling older people to maintain control and independence. Some used the terms self management and self care interchangeably, while others distinguished between specific tasks to manage LTCs and more generic self care tasks.

Our interviewees discussed the potential for self management to reduce dependence on health and social care services, reflecting national policy themes and goals. They also discussed the implementation, uptake and effectiveness of self management support services and programmes.

Some service providers and commissioners were sceptical about whether self management could substantially reduce demand on services. There were particular concerns about the difficulties of providing self-management support to older people, raising questions about the relevance and utility of self management as an aim for older people with more intensive health care needs and for very elderly and socially isolated people.

Current service users' expectations of care are seen as variable and complex. For the future, some service providers believed that self management support services would need to become more flexible to meet the changing expectations of more knowledgeable, more assertive and more motivated service users. In contrast, some participants believed that a growing sense of entitlement to health care could reduce people's willingness to take responsibility for self care.

Our interviewees described a variety of methods and data sources used to identify new and ongoing service needs. These included public health data sets, local service pilots and evaluations, case finding, various involvement and engagement initiatives, and work with local voluntary sector organisations.

Participants described numerous challenges to the provision, staffing and sustainability of LTC support services, notably inadequate and uncertain funding, competing priorities for available resources, and the relative strength of acute sector providers compared to community based services.

LTC support services seemed to be fairly well promoted in all the study areas, with uptake depending on the potential users' willingness and service leaders' approaches. Some service providers were concerned about over-promoting services and generating demand for services which could not be met. In some areas, particularly poorer communities, promoting the very concept of self management was identified as a major challenge. Participants also highlighted the importance of considering how best to describe services to appeal to older people.

In discussing the role of LTC support in relation to other support options, participants discussed the potential for developing truly joined up local health and social care provision. In practice, the overall view is that the rhetoric of joint working is outrunning reality. Participants identified a need to improve individual and organisational communications and to strengthen relationships and working arrangements between statutory and voluntary sector providers.

Next chapter

Chapter seven provides a detailed discussion of the findings of the questionnaire survey and the qualitative studies with older people, carers, service providers and commissioners.

It concludes by discussing the methods used in the study's mapping work, survey and interviews and examining the strengths and limitations of the research design in answering the research question.

7. Discussion

7.1 Questionnaire survey

7.1 .1. Prevalence of LTCs, demographic factors, health outcomes, social capital and willingness to self manage

The overall prevalence of LTCs in our sample of respondents was 65% which compares to the prevalence of 65% identified in the Health Survey for England's Survey of chronic diseases amongst older people (Becker & Choudhury 2005). The most prevalent LTCs were arthritis / rheumatism at 53%; high blood pressure at 51% and high cholesterol at 31%. Again this follows a similar pattern to the Health Survey for England's survey of chronic diseases amongst older people (Becker & Choudhury 2005). The profile of LTCs that we identified may have differed if our survey respondents had been older. For example, we may have found a higher prevalence of stroke.

Within our survey the overall prevalence of LTCs and the number of LTCs increased with age, despite us achieving a lower response rate within the older population groups. This finding is similar to other research in this area. We also found that women were more likely than men to report having multiple LTCs. This may have been due to our female respondents being older than our male respondents and therefore being more likely to experience multiple LTCs. These findings suggest that those who are older and women may require more support to self manage their LTCs, as they may be more likely to adopt a passive approach to their care.

Having LTCs also appears to impact negatively on people's perceptions of their health in that those with LTCs were more likely to view their general health and quality of life as being poor and to feel more limited by their LTCs. Perceptions of poorer health and poor quality of life increased as people experienced more LTCs. These negative perceptions may impact on people's confidence in self management, meaning that those reporting poor general health and a poor quality of life may be more likely to rely on formal management of their LTCs rather than adopting a self management approach. Further evidence for this is provided by our analysis of patient activation amongst those with LTCs. In that those who were older, and who were experiencing multiple LTCs were more likely to view their general health and quality of life negatively and less likely to feel willing and confident enough to self manage.

There were no significant differences between those of white and non-white ethnic groups in the prevalence and number of LTCs. This may have been due to the low number of participants from black and minority ethnic groups who had replied to our questionnaire rather than representing any true differences. Those with LTCs reported lower levels of social capital than those without LTCs, despite being older and reporting living in their case study area for a longer time period. It might be reasonable to expect that those who had lived in an area for longer would be more likely to have stronger social networks. However, the lower social capital scores of those

who were older and who had lived in their local area for a long period of time, may demonstrate the limits that having LTCs places on people's social relationships and their ability to be part of a social network. Amongst those with LTCs this may impact negatively on their ability to exchange information locally with a social network about ways of managing their LTCs. A reduced social network may therefore act as a powerful barrier to self management. However, these findings may also reflect that those who were living in more socially deprived areas were more likely to report suffering from LTCs, and therefore regardless of whether they had LTCs they may have been more likely than those living in the more affluent case study areas to view their area negatively. Further evidence for this is provided from our qualitative study of older people (reported in section five). This study found that those living in less affluent areas appeared to view their areas more negatively in terms of the sense of community spirit and in some cases a fear of crime.

As described above, those reporting LTCs had lower patient activation measure scores than those who did not report LTCs, and patient activation levels decreased as the number of LTCs increased. This suggests that the actual burden of the type and number of conditions experienced by older people will impact negatively on their willingness to self manage and may increase their reliance on formal healthcare. Finding methods of encouraging those with multiple LTCs to self manage is therefore likely to be particularly challenging. It may be necessary to provide support for self management before they feel overburdened by being diagnosed with multiple LTCs. For example, it may be necessary to encourage a self management approach when people have been diagnosed with just one LTC, in the hope that the skills at this stage may increase people's confidence in managing any additional conditions that they are diagnosed with.

We found that those reporting LTCs were also more likely to report that they were beginning to take action regarding the self management of their LTCs, but that they felt that they lacked the confidence and skills to support and maintain any new health behaviours, particularly in times of stress. This suggests that this may be a key stage to intervene with individuals to try and increase their confidence in self management.

These findings demonstrate that although older people may have the greatest need for support to help them to self manage their LTCs, that self management may actually become very difficult due to their increasing lack of confidence in their abilities to self manage, which is likely to be compounded by getting older and being diagnosed with multiple LTCs. Finding methods of increasing this age groups' confidence in self management particularly is likely to become increasingly important.

7.1.2. Service and support use amongst older people with LTCs

Within our questionnaire survey respondents, those with LTCs were most likely to have consulted the GP, practice nurse, hospital outpatients and the pharmacist for their LTC recently. Those reporting having LTCs were also more likely to report that they were just using health services, with just 16% reporting that they were also using social services. Again, this may be a reflection of the age profile of our sample, as support from social services appeared to be obtained mainly by our respondents who were older and whose health was frailer. However, within our qualitative study of older people we identified a

strong stigma attached to obtaining support from social services amongst several of our interviewees which may have impacted strongly on their willingness to access support from social services. There also appeared to be a perception that support from social services was more often required by those who were in the greatest need.

Those reporting having three or more LTCs were also more likely to report using more services than those reporting fewer LTCs. This suggests that as people are diagnosed with more LTCs that they may be more likely to rely on formal healthcare to manage their LTCs. As our data suggests that those reporting more LTCs are likely to feel less confident in self management it seems reasonable to suggest that the majority of those reporting multiple LTCs were likely to be accessing more services for formal healthcare as opposed to self management support. However, if this is the pattern of healthcare use that is likely to occur as people are diagnosed with multiple LTCs, this highlights the importance of these services offering some form of self management support to people using them as well as formal healthcare. For example, evidence from our interview study with older people suggests that our respondents were obtaining a great deal of self management support from their local pharmacist, as well using them for more usual reasons.

7.2 Qualitative study: interviews with older people and carers

Our sample of interviewees ranged from people in the 60s to their 90s, had a broad range of LTCs, and many had multiple LTCs requiring multiple medications. They also had varying expectations of what their health should be like, and varying experiences and expectations of support providers. There was also a range of beliefs about responsibility for health across the sample, which impacted on people's willingness to self manage. The characteristics of the areas in which they lived also appeared to influence their beliefs and expectations of support. For these reasons there was a great deal of variability in their expectations of support and their perceptions of their support needs.

7.2.1 Influences on participants' beliefs about support needs

Expectations of their health in later life were likely to be a powerful influence on people's beliefs about their support needs and expectations of service providers. For example, those who felt that they should be in better health at their age appeared to be more likely to seek out support to return them to their previous health state, than those who did not have high expectations of their health in later life. However, people's expectations of their health were not necessarily a function of age, in some cases they were influenced by their perceptions of the health of their peer group within their local area. For example, one participant in his 60s from the North East area who had previously worked in the local pit, reflected on how he felt that he was in relatively good health compared to many of his peers who were either in much poorer health or had died quite soon after the pit closed in the 1990s.

Beliefs about responsibility for health were also a powerful influence on participants' beliefs about their support needs and expectations of service providers. As described earlier, almost all of our participants believed that managing their health was a responsibility that they shared with service providers. However, the concept of shared responsibility was interpreted in a number of ways. For some people, taking shared responsibility was learning about the technical aspects of monitoring their LTCs as well as leading a healthy lifestyle, but others considered that they were sharing responsibility for their health if they led a healthy lifestyle and left the technical management of their LTCs to health professionals. This suggests that there may be a need for service providers to try to ascertain people's willingness to take responsibility for at least some aspects of the management of their LTCs, and to provide support accordingly. This may mean that service providers need to clarify whether people are unwilling to take more self management responsibility or are simply under-confident. If people are just under-confident then service providers will need to work with them to increase their confidence and skills to self manage.

As well as having varying beliefs about the level of responsibility that they should take for their health, our participants also had a range of beliefs about the role that their LTCs should play in their everyday lives. For some people, their LTCs were a dominant feature in their lives around which all other aspects were organised, and for others their LTCs were something to be managed so that they impacted on the rest of their lives as little as possible. It may be useful for service providers to take this into account when providing self management support to those with LTCs, to ensure that people receive the level of support appropriate to their needs and lifestyle.

There were also some issues regarding support access that were relatively common across the case study areas. For example, interviewees felt that it was easier to identify potential support options for their LTCs if they had received a diagnosis for them, or if they felt that they could attribute their LTCs to a particular cause. This may reflect the fact that many medical research charities offer disease specific support groups, and it also may be a reflection of the need to have a diagnosis in order to be referred to a particular specialty within medicine. Across the board, there was also a belief that obtaining support to self manage could become more difficult as participants were diagnosed with more and more LTCs, as the burden of ill health then made it difficult to self manage.

7.2.2 Impact of LTCs on participants and their everyday lives

Our participants were able to describe eloquently the impact that their LTCs had on their everyday lives, and for service providers and commissioners these descriptions may provide useful insights into the support needs of older people with LTCs. LTCs were considered to affect all aspects of people's lives, from the social and emotional to functional aspects.

Support for the emotional impact of having a LTC appeared to be a great need for many of our participants and their significant others. However, some of our participants described the difficulties that they had in expressing the emotional impacts of their LTCs to both family and to service providers. This may be related to people wanting to be

seen as coping with their LTCs, or perhaps feeling that neither family nor service providers will be able or willing to help them with how their LTCs are affecting them emotionally. Our data also highlights the importance of considering the impact that LTCs have on people's relationships with their significant others, many of whom were also providing care. In particular, some participants spoke of the difficulties of adapting to the changes in role that occur at the beginning of a caring relationship. For example, men spoke about starting to do more of the housework than at any other time in their lives.

LTCs were also considered to impact significantly on people's social lives. In some cases this was due to a lack of confidence, embarrassment related to their symptoms and a general reluctance to join organised support and activities. Without looking at ways to increase people's confidence in joining particular support options or social groups, it may be difficult for service providers to attract and retain group participants.

Finally, LTCs also impacted significantly on the function and mobility of our participants. On the whole, our participants appeared to believe that they were well supported within this particular area, but comments were made about the difficulty of incorporating the advice given into their lives. For example, several participants spoke about being prescribed exercises to help with their chronic pain which were difficult for them to do at home, either because they did not have the space, or because they felt that they were too busy with the rest of their lives. There may be a need for service providers to work more closely with older people to ascertain their goals in relation to their health, for example, some of our participants wanted to be able to look after their grandchildren more easily. Realistic goal setting would seem to be an essential ingredient of support to older people with LTCs.

7.2.3 Factors influencing participants' decision to self manage

An understanding of the factors influencing people's motivations for deciding whether or not to self manage their LTCs may be useful to those either designing or delivering services to support self management. Within the qualitative analysis, we attempted to identify both barriers and facilitators to participants' decisions to self manage. A key factor may be the impact that being diagnosed with a LTC has on their self perception. For example, some participants reported how being diagnosed with an LTC had made them feel older and they doubted that anything could be done to help them feel better, particularly if they had been diagnosed with another LTC on top of what they already had. In this case, the older person may require the support options to be described to them at some length by a trusted health professional, and they may also need 'taster sessions' of potential support options to help to persuade them that the support may be of some use to them.

Our participants also spoke at length about the various access barriers to self management support. In all of the case study areas, one aspect of social capital – the availability of transport in order to access the support option – was an issue which in some cases preventing people from attending. For example, some participants did not feel comfortable getting on a bus, as they were embarrassed about some of the symptoms associated with their LTCs. Others felt that paying for transport to get to the support service was beyond what they could afford. Others were concerned about their

ability to physically access venues. This is a key issue in terms of ensuring that support services are used and sustainable, as if it is difficult for people to access services then the services are unlikely to be well used and to be considered a successful service which needs continued funding.

One of the most frequently heard phrases during our interviewees with older people was that they did not access services and support because they were 'not a joiner'. In some cases this was true and perhaps highlights a need for less group – based more individually focused support for self management, perhaps personalised to the individual's needs. Service providers may need to assess people's levels of comfort with group support before suggesting it to them. In other cases, the feeling that they were 'not a joiner' may mask their anxieties about new social situations, and concern about the exact nature of the self management support on offer. This suggests that as well as needing support to self manage, that some older people may also need encouragement to access particular support options. A good example was provided by Age Concern in the North East case study area, where volunteers initially spoke to older people in their homes about the social support options that were available, provided transport to the support option and provided them with support in actually entering the room where the social group was being held.

Family members were great motivators for self management across all of our case study areas. Many of our participants spoke at length about the advice and support that they received from family members, even if it is just over the telephone. For those who were married or in a long term relationship, their spouse or partner could be a key supporter and motivator of self management. Children were also helpful, but often at a distance. Working with family members, so that they can help provide better support for self management for those with LTCs, is clearly needed among service providers.

Participants were concerned about accepting support which they did not feel was likely to continue. They were particularly concerned about feeling abandoned and being left to fend for themselves if the support option was withdrawn. This of course may be unavoidable depending on the resources available, but it emphasizes the importance of service providers establishing reasonable expectations of their services amongst their service users.

Finally, service providers may need to take into account people's perceptions about their wider social environment, as these may sometimes impact negatively on their willingness to access services and support, particularly if the support services are not provided in easy to access locations at times when people would feel comfortable in attending them.

7.2.4 Potential providers of support for self management

Within the interviews we asked participants about their general experiences of care and about their experiences of receiving support for the self management of their LTCs. It will be clear by now that participants' accounts highlighted the importance of the general practitioner within their support network, and the potential for the general practice as a site of self management support. On the whole, our participants appeared to trust their

GPs greatly, and in several cases spoke about the lengths that they had gone to in order to maintain continuity of care with 'their GP', which in some cases included travelling on several buses to their GP practice. GPs appeared to be most effective at providing self management support when participants felt that they could trust them and that their GPs trusted them, and when they felt that their GPs knew them and their health issues inside out. Continuity of care was at the centre here, where a GP was felt to know the person well and was thoroughly familiar with their health history. In the other part of our qualitative interviewing, several of our service providers reflected that a GPs recommendation of a particular service could make it more attractive to potential participants. However, a minority of our participants reported having a poor relationship with their GP and were therefore less likely to accept self management support from them. Some participants felt they were treated dismissively by their GP, and in some cases were not trusted. Providing self management support was difficult if not impossible in these cases.

The local community pharmacist also featured strongly in participants' accounts of their self management support. Support from community pharmacists was perhaps so highly valued because they were considered to be easily accessible, and to offer very useful support in terms of medicines management. Many of our participants were taking multiple medications, and for this reason establishing a system to manage their medicines and ensure that they always took them was a high priority, and perhaps one of the more tangible aspects of day to day self management. However, some problems still existed. In one of the case study areas the issuing of 28 day prescriptions was considered to create a great deal of unnecessary anxiety about running out of their tablets for some of our participants.

Some of our participants spoke about the support for self management that they had received within hospital settings, for example diabetes clinics, but the majority of the support for self management appeared to be community based. In the main, the hospital was not seen as an appropriate site for support for self management, although some support groups such as pulmonary rehabilitation and heart support groups were run in hospital settings. Our interviews, of course, were with people with LTCs that were not, in the main, in need of immediate disease management interventions.

The role of social services in providing support for self management was discussed by some of our participants. Views about social services varied across the sample. Some participants were willing to access support from social services mainly in the form of adaptations and aids to their home, whereas others seemed a little reticent to obtain any support from social services, preferring to pay themselves for aids such as stair lifts. This suggests that stigma associated with accessing support from social services within this age group persists, which may need to be addressed to increase the likelihood that older people will use the support services offered by social services.

Finally, use of support provided by voluntary sector organisations was discussed by some of our participants. Across all of the case study areas, the most frequently mentioned voluntary sector organisation was Age Concern. The range of services provided by Age Concern appeared to be particularly valued, as social, emotional and practical support was available. Other support providers within the voluntary sector were less frequently mentioned by our interviewees, as it appeared that they mainly relied on

health and social services for their support, although some of these may have been provided by voluntary organisations on behalf of health or social services.

As the majority of our interviewees appeared to be mainly accessing their support for self management from the GP, pharmacist and the hospital, it seems logical for those in the voluntary sector to work with these groups more closely to promote their services to older people. However, there is a need for GPs, pharmacists (as well as hospital services) to be more aware of voluntary sector organisations and their activities and be willing to promote them. Our interviews with some health professionals suggested that they were often not aware of all of the services offered by the voluntary sector locally, or were reluctant to cross boundaries in order to facilitate access.

Amongst the carers interviewed, there was some awareness of the local voluntary sector organisations and the services that they offered, but in the main, participants and carers were not accessing the support services. This may stem from a belief that it was the carers' duty to provide this kind of help and that additional support should not be necessary. In some cases it did reflect carers' assessment that what was on offer was not suitable for them or their loved one.

7.2.5 What should good support for self management look like?

From our participants' accounts of accessing support, or deciding not to access support, it is possible to outline some recommendations of what useful support might look like.

In general terms it seems clear that service providers should work with those requiring support to assess their needs and expectations regarding the type and level of support that would be regarded as appropriate and helpful. Although among older people chronological age is not always the deciding factor, the older old are less likely to be ready to access formal or physically demanding self management activities. Those with spouses or partners, as we have seen, require family level support rather than an individual orientation. Whilst our respondents, overall, were keen to present themselves as good self managers, service providers need to be able to help older people raise their confidence and help them to set realistic goals. If services are to become more personalised then such support will need to come through core professional activities rather than courses such as that offered by the EPP.

Our findings reinforce the point that suggestions of support should, wherever possible, come from a service provider who is trusted by the older person. Much self care, rather than specific LTC management, is and should be focused on helping people to maintain their independence for as long as they want to.

The implications of these observations for 'integrated' or 'holistic' models of care are considerable. Whilst improving the coordination of care and communication between professionals are certainly important, older people's preferences with respect to support suggest caution. Our data show that the GP remains the central figure for many in support self management of LTCs in daily life. Community pharmacists are also providing continuity of care, and increasingly regular support, in the important area of medicines management. Other sources of support such as that offered by nursing, social services

or voluntary organisations may be positively valued by older people- and, we have seen, often are – the acceptability and legitimacy of such support is variable. Formal courses in self management are of relevance only to a small minority of older people – in one of our areas such courses were unknown. The GP clinic and the authoritative figure of the GP continue to offer perceived practical advice and referral in which context older people can express their vulnerabilities, fears and wishes with confidence. Policy and service development related to self management needs to consider these implications if initiatives in the future are to remain relevant to older people in their everyday environments.

7.3 Qualitative study: service providers and commissioners

7.3.1 Beliefs about self management

Service providers and commissioners held positive views about self management and self care and recognised that they had a role in supporting and encouraging it. However, as with the interviews with older people, the interpretations of self management and self care varied across the sample of interviewees.

Some spoke specifically about self care and self management being about taking responsibility for your health, feeling empowered to make decisions and to maintain your independence. Whereas others focused more on the specific aspects of managing LTCs, for example recognising trigger factors for exacerbation.

In some respects, as with older people, this may represent service providers and commissioners making a distinction between self care and self management, with self care being more about the things that people do generally to maintain their health and their independence, and self management being more about the technical management of symptoms. Service providers and commissioners interpretations of self care and self management may have been influenced by their professional background. For example, those working in social services may be likely to be less concerned about specific self management techniques and more concerned about promoting overall independence and personal care.

On the whole, both service providers and commissioners seemed to have well rehearsed the benefits of self management and self-care. The benefits were seen to be helping people to maintain control over their lives, preserve their independence and to reduce fear and doubt about their conditions which would decrease unnecessary use of health services. Even so, few service providers or commissioners were convinced that this was a likely outcome.

Moreover, providers and commissioners were concerned that older people might regard an over emphasis on self management as a substitute for formal care. This view is supported by our data from the interviews with older people who suggested that some were concerned that they were being ‘fobbed off’ with self management advice instead

of receiving the health care they needed. In these circumstances older people might continue to use formal health care as an entitlement, regardless of self management messages. The task facing providers and commissioners here is in showing how self management can complement formal management of LTCs, or that not using services is warranted and appropriate.

Although many of the commissioners and service providers interviewed appeared to be confident of the benefits of self management, they were concerned that they were perhaps not accessing the groups who were most likely to benefit. This may therefore decrease the overall population level usefulness of their self management activities.

It may therefore be important for service providers and commissioners to look at developing ways of accessing the hard to reach groups, and to increase their understanding of why certain groups might be hard to reach. We have also seen that self management is often seen to be less relevant to the oldest age group. There is clearly an important debate to be held here, among providers and commissioners, as to the relevance of self management messages across the age range in later life. As has often been pointed out, a 'one size fits all' approach is not helpful in service development in the area of self management, especially among older people.

7.3.2 Beliefs about useful self management support and advice for older people

Service providers and commissioners gave several examples of self management techniques and devices that they had found to be useful to older people with LTCs. Medicines management advice was perhaps considered to be one of the most useful self management strategies. This again is reflected in our accounts from older people, where medicines use figured largely in the everyday management of LTCs.

Medicines management advice may be particularly useful for this age group, as the majority of older people that we interviewed were on multiple medications for multiple LTCs, and therefore the management of their medicines may have been one of the most tangible aspects of self management that they felt they could cope with. Clearly medicines management advice may be difficult to implement amongst some groups of older people, especially among the frail and cognitively impaired.

In addition, other self management techniques might not be seen as suitable for all older people. For example, telecare was considered to be particularly difficult for those who did not have a great deal of cognitive function and manual dexterity. This is again echoed in the data from older people and carers who saw the benefit of certain self management techniques but believed that it might be difficult for them to be used. This suggests that some of the existing self management techniques and approaches may need to be redesigned and tailored to the needs and capacities of older people, or may simply not be relevant.

As is to be expected in a study of self management, there was much discussion amongst service providers regarding the Expert Patients Programme (EPP) which has been one of the most high profile self management interventions in recent years.

In some of the case study areas there was a certain degree of scepticism about the likely benefits of the EPP. In the North West case study area, the EPP had been abandoned as providers were uncertain as to its benefits. They believed that its benefits were more about combating isolation rather than the actual course content. In the London case study area, service providers described their uncertainty about the likely benefits of the course, whether individual attendees were followed up and what they actually got out of the course.

In the areas where the EPP was running, many of those attending appeared to be middle aged and working, although some older people did attend. There were no courses we could see that were specifically aimed at older people, which may in some cases have acted as a barrier to older people attending, in that they may not have felt that it was relevant to them. There were also reported difficulties in keeping courses running in some areas due to the ill health of participants and lay tutors, as well as transport difficulties, a problem that beset service delivery other than the EPP.

One of the implications of this situation is the need to consider the benefits and drawbacks of designing and running an EPP style course particularly for groups within the older population.

Local health professionals seemed to be particularly uncertain and sceptical about the EPP, in part perhaps because the courses were not meant to involve any medical input. There was evidence that some professionals also had difficulty in referring people to the course (either perceived or real) and were unsure who the courses were aimed at. They were also concerned about how beneficial such courses might be and how the advice given might fit in with the more formal healthcare management of LTCs.

The EPP coordinators who were interviewed also reflected on how the jargon used within the courses might act as a barrier to some people attending, for example it may be important to talk about 'looking after yourself' rather than self management.

Our evidence suggests a gap may be opening up in the development of self care and self management support; between the overall commitments to such approaches to older people among professionals, but scepticism about the value of specific techniques or course based approaches such as the EPP. There is a need therefore for those concerned with service development to find ways of communicating more effectively how self management activities they are undertaking fit in with, or can appropriately be substituted for, the formal care that they are receiving. The aim here would be to offset the tendency that older people may feel that they are being given self management advice as a substitute for formal care.

7.3.3 Beliefs about older people's willingness to get involved in self management

Service providers may also need to tailor the degree to which older people become involved in self management according to their perceptions of older people's confidence and willingness to self manage. It will be important for service providers to recognise the degree to which their patients are willing to self manage, i.e. to identify those who might just be under confident but not unwilling to self manage; versus those who are likely always to be unwilling or unable to self manage. However, this assessment of needs, wants and expectations is likely to take time which in turn has resource implications.

Providers and commissioners views of older people's expectations about care in general and self management support were considered to be variable and complex. Part of the reason for this complexity and variability was the wide range of age ranges that service providers were being asked to provide services for. Service providers commented on the problem of grouping all older people together, in particular, the younger and older age groups.

Finally, we have discussed in some detail the important role the voluntary sector plays in supporting self care. This line between health and social care on the one hand, and voluntary sector bodies such as Age Concern on the other, is frequently blurred. The campaigning and challenging role of the voluntary sector is not always easily reconciled with a growing incorporation of their activities into formal provision. Likewise the tendency of voluntary bodies to be increasingly caught up with commissioning and competitive tendering has emerged as an issue from our interviews. The role of the voluntary sector in supporting self care and self management, together with issues such as cross boundary working remain important topics for future service and policy development.

7.4 *Methodological discussion*

The study contained three elements, mapping work; questionnaire and qualitative work. We believed that our research design was appropriate to answer the research question but that despite this that there were some limitations to our approach.

Overall, for this research we undertook a case study approach. On the whole we were very satisfied with the case studies that we selected in terms of allowing us to capture a range and diversity of experience. However, we were disappointed with the selection of case study areas in one aspect, as only one of the case study areas was ethnically diverse, when originally we had planned to select two.

7.4.1 Mapping work

In terms of the mapping work, we identified the majority of the services available within each case study area via Internet searches and by undertaking follow up telephone calls. However, using these approaches we may not have identified all of the services within each area, especially if the services were new, short-lived or were not advertised on the Internet. It may also have been difficult for us to identify all of the available services because, as our interviews with service providers and commissioners demonstrated,

there was some concern that too much advertising and promotion of their services could create an unmanageable demand.

A different or complementary approach to the mapping work might have been to use a short online or postal questionnaire for commissioners and service providers within each area to identify, in order to capture information about all of the available services, some of which may not have been in the public domain.

7.4.2 Questionnaire survey

On the whole we feel that undertaking a questionnaire survey was the most appropriate and cost effective method of collecting the data that we required. However, as our questionnaire collected self report of LTCs rather than doctor confirmed diagnosis from medical records, some misclassification of LTCs may have occurred. In some of the interviews with older people LTCs were revealed which they did not report experiencing when they completed the questionnaire. However, the degree to which this is a limitation is debatable as we were concerned with older people's beliefs and experiences of the LTCs that they were experiencing and how they affected them, rather than medically defined conditions.

We achieved a relatively low response rate of 40% which may reflect our sampling strategy and our method of survey administration. As we selected a random sample of older people registered with a number of GP practices in each area, we therefore included a relatively high percentage of older people living in residential and nursing care in our sample who were less likely to be able to complete a questionnaire without assistance. This was evidenced by the number of potential participants living in residential and nursing care who opted out of the study. A different method of survey administration may have increased the response rate, such as interviewed administered questionnaires.

In addition we may have achieved a relatively low response rate as we used NHAIS data to select our sample from which, despite being one of the most useful and accurate ways of accessing patients' names and address, has a 7% error rate. Arguably, a higher response rate could have been reached if we had asked individual practices to select samples and check them in order to ensure that the selected names and addresses were correct.

We found that our respondents were most likely to be younger, female and living in less socially deprived area than those who did not respond, and this needs to be taken into account when interpreting our results.

We may have been able to obtain the experiences of those who were older and who had moderate or severe dementia if we had used proxy interviewees such as relatives, spouses or friends. We may have also obtained a greater response to our questionnaire from the London case study area if we had had more funding to translate the questionnaire into the range of languages spoken in the area. We found that the language line translation service that we had available was very poorly used, which further demonstrates the need for translations or other methods of questionnaire administration with this group.

Finally, using these methods may have increased the sensitivity of our questionnaire in tapping into the experiences of those with a wider range of characteristics.

7.4.3 Qualitative interview studies

Recruitment and sampling

We recruited older people for interview from those who replied to the questionnaire survey. We had a large number of questionnaire respondents who agreed to be interviewed which provided us with a sufficient and varied sampling frame for our qualitative studies of older people and carers. Therefore, we can say that this is a feasible approach to identifying participants for qualitative studies. There were some limitations though, as using this method of identifying interviewees may have meant that there were certain groups within the population whom we were unable to access and gain their accounts of self management and self management support. For example, we did not achieve a good response to the questionnaire survey from those who were in the poorest health, and from those for whom English was not their first language. However, wherever possible we made every effort to approach these groups for interview if they had replied to the questionnaire and had agreed to be interviewed.

In future studies, we would perhaps use different methods to survey and interview hard to reach groups. For example, this might include undertaking interviewer administered surveys with those living in residential and nursing care. Undertaking surveys in residential care may be both ethically and logistically challenging as the majority of residential homes are privately owned, and many residents may require a proxy to give consent to them participating in the study.

We also recruited carers from our questionnaire respondents; that is, we asked older people to nominate their carer to be approached for interview, or interviewed older people who identified themselves as a carer when they completed the questionnaire.

We had varying success in using this method of identifying carers across the case study areas. Where questionnaire respondents did not perceive the support that they were providing to their spouses, friends or relatives as 'caring', they were unlikely to self identify as carers. Those who were 'carers' also provided varying levels of support to older people, and therefore did not necessarily identify themselves as carers, partly because they did not believe that the support that they provided was intensive enough to be classified as 'formal caring'.

For some of the reasons detailed above we were unable to identify the numbers of carers for interview that we had originally planned to recruit. We chose not to use other methods of identifying carers as we considered that those participants whom we might be able to recruit from carers' organisations and support groups may not be particularly representative of carers in general. Some evidence was provided for this by the fact that the carers whom we did interview were very unlikely to have been in contact with carers' organisations or support groups.

As we had so few carers volunteer to be interviewed we were unable to use a comprehensive sampling strategy. We attempted to select a maximum variety purposive sample of carers across all four case study areas, rather than selecting a maximum variety purposive sample of carers within each of the case study areas. By a maximum

variety purposive sample we mean that carers were selected to represent as much variety as possible within the sampling frame.

We identified commissioners and service providers to be interviewed as part of this study from the mapping work undertaken within each case study area. On the whole, we were able to identify a good range of service providers and commissioners within each area via our internet searches and follow up telephone calls.

However, given the transient and fast moving nature of service development and provision we were just able to obtain a broad snapshot of service provision within each care, and may also not have identified all of the available services, particularly as many were not heavily promoted.

Given the plethora of services available within each case study area we were also unable to interview all service providers within each case study area due to resource constraints. Therefore we attempted to interview a broad range of service providers both within and across all case study areas, with the broad aim of enabling us to encompass the full range of available support but also to enable us to compare service provision across all four areas.

In some areas we were unable to gain the consent of all of those whom we would have liked to have interviewed. For example the EPP coordinator in the South West Case study area did not agree to be interviewed, but on the whole we feel that we have obtained valuable accounts from the majority of relevant participants and services.

Interview process

Interviews were undertaken face to face and in service providers' and commissioners' workplaces and in older peoples' homes. The interviews were undertaken by three interviewers (SP, HM and SC) who as far as possible worked together to ensure that they used standard approaches to the interviewing process. For example, joint topic guides were developed collaboratively, and the interviewers met regularly to review their findings and their approach to the interviews. Despite the efforts to standardise the interview process, there may have been some differences in the approaches of the interviewers and in the accounts obtained by them due to their different characteristics, interviewing styles, levels of experience with the interview process and the case study areas in which they were interviewing. As far as possible we tried to take this into account during the data analysis process. For example, we discussed how and why the accounts from older people in the more socially deprived areas differed from those in the more affluent areas.

8. Conclusions and recommendations

8.1 Self care versus self management

Self care can be defined as something that healthy adults living in modern societies do for themselves. Even as people age and acquire disabilities most remain independent and care for themselves, with intermittent informal and professional help in crises and with particular problems that may emerge. Maintaining independence may depend on timely intervention as and when the latter arise, coupled with appropriate rehabilitative support after events such as operations or other potentially disruptive hospital admissions.

It is possible, therefore, to consider most care provided outside of residential institutions as supported self care. This may help to explain the positive preference of many of our participants for GP based care and medically based approaches which aim to identify and treat temporary illnesses, rather than to provide long term social care to an individual. For many of our participants the latter carried stigmatising connotations of being unable to cope. By contrast, using health care – as a universally available service which is required by everyone from time to time – was regarded as ‘normal’.

Many professionals providing support to older people in community settings recognise and respect such considerations. However, this is not always so, and at a formal/institutional level there appears to be frequent confusion regarding the goals of such initiatives as EPP courses which aim primarily at promoting ‘self efficacy’ (and which may have a relatively simple content, because they focus on enabling participants to experience ‘mastery’ and build confidence) as opposed to those aiming to teach specific competencies (like how and when to inject insulin) or services intended simply to enable people to ‘cope’ with daily life.

Ageing typically involves a gradual loss of physical or mental abilities, alongside a sometimes more traumatic loss of work role, income, valued personal relationships and/or life partners. These may be offset by gains such as having grandchildren and/or – for those able to afford them – extended holidays, and more time for pursuits such as golf or walking. But the long term trend is normally towards a narrowing of opportunities and activities. The ultimate end point can be individuals becoming effectively confined to living alone in premises they rarely if ever leave.

If those at risk can be helped to approach life with self confidence and retaining a positive outlook, it is possible they may be enabled to live longer in an independent setting. That is, self care support might delay or prevent the decline of some individuals into ‘old’ old age. The hope is that this will reduce residential care costs, although it is uncertain whether or not total health and social care costs would decline as a result, or indeed how realistic such thinking is ‘real world’ everyday settings.

It is likewise possible that self care support provided in late middle life and early old age could help to prevent the development of subsequent problems requiring more costly

forms of community or hospital provision. Yet this has not been demonstrated in practice. It is also worth noting that if members of the public (and indeed health and social service staff) feel that self care support is primarily aimed at cost cutting rather than improving health and other welfare outcomes, this could have negative consequences in terms of service quality and service user satisfaction.

A key theme throughout all the research data collected in this study was the explicit or implicit distinction that older people and service providers made between self care and self management. Differing definitions of these terms influenced expectations of services offered and provided.

Older people generally appeared to view self care as being the ability to look after themselves by living a healthy lifestyle and maintaining their independence by taking advantage of aids and adaptations where appropriate. In some cases, these activities were directly related to their LTCs, for example keeping to a particular diet. However, self management tended to be seen as encompassing those activities that were directly designed to help manage or monitor specific symptoms, for example, measuring blood sugar levels or checking blood pressure.

As mentioned above, the extent to which older people are willing to take responsibility for their health varied. Those who considered the technical management of their condition to be the service providers' responsibility were unlikely to take a self management approach to their LTCs.

Commissioners and service providers appeared to make similar distinctions between self care and self management. Their professional backgrounds and beliefs about the scope of their practice may have had an impact on whether they felt they were providing self care support, self management support or both. Social services professionals appeared to be more likely to believe that they provided self care support, i.e. support to help older people maintain their independence rather than to manage particular symptoms related to their LTCs. Health professionals were more likely to believe that they provided both self care and self management support. Representatives from the voluntary sector also seemed to believe that they provided both self care and self management support.

Thus, the picture regarding self care and self management currently appears somewhat confused from both service providers' and service users' perspectives.

8.1.1 Recommendations

Policy

Policy makers and researchers should consider further research to explore, among a wider sample of older people, the distinctions made between self-care and self-management.

Informed by older people's perceptions, **policy makers and health service managers** should review and standardise definitions of self-care and self-management in order to reduce confusion. Standardisation is likely to aid the move towards joint working and joint commissioning between health and social care.

Needs assessment and service planning

Commissioners and service providers, when assessing the needs of older people both when assessing the needs of older people both collectively and individually, should investigate and take into account the **expressed needs** of older people for self-care support, self-management support, or both.

Commissioners and service providers, when assessing the needs of older people collectively and individually, should investigate and take into account the **perceptions** held by older people about the support options that may be made available.

Commissioners and service providers should use this information from needs assessment in their planning and redesign of services, in line with the World Class Commissioning framework's Competency 3 – that the needs and wishes of patients and the public should drive commissioning decisions.

Strategies for service delivery

Service providers will need to develop strategies to communicate to older people that self management support is not being offered to them as a substitute for formal care entitlements, and that self management support can complement existing formal care.

8.2 Influences of the characteristics of older people on their expectations of health and of care and support

We included a wide variety of older people in our study in terms of age, health status, socio-demographic factors and expectations of health and of health and social services. This highlighted the need for both commissioners and service providers to recognise the heterogeneity of the population of older people they are providing and developing services for rather than relying on "one size fits all" options.

Across all of the case study areas we had several examples of how age may affect people's expectations of their health and of health and social services. Perhaps unsurprisingly in a society where people generally expect to live active and healthy lives well into their retirement, those in the younger age groups also appeared to have higher expectations of the services they felt should be available to them. Easier access to information about LTCs and potential support options together with a lower level of deference to health professionals within the younger old may increase demands upon health and social care.

However, age is not the only determinant, and expectations of health and of healthcare services do not necessarily fall simply because people become older. In some cases we found that socioeconomic factors could influence expectations. Thus people living in one of the more deprived areas in our study appeared to make fewer demands on health and social services because their expectations were lower. Many of their contemporaries had already died and to be coping relatively successfully with LTCs was considered an

achievement in itself. Regardless of age, participants' with poor experiences of care in the past also had lower expectations of their local services.

Older people's willingness to take responsibility for their own health was also likely to have an impact on their expectations of their health and of services. Although the majority of our participants believed that their health was a shared responsibility, there were different interpretations of what this meant. For example, some participants accepted responsibility for avoiding an unhealthy lifestyle, by eating well and stopping smoking, but still felt that they should be able to seek medical care promptly for their symptoms. Others felt that they should share responsibility with their GPs and wanted a more active role in the management of their LTCs.

Our research did not generate statistically significant quantitative information demonstrating differences in self care related competencies and outcomes between identifiable population groups. However, the social and material capital available in richer as opposed to poorer communities is likely to differ in its nature as well as its scale, and this may influence individual and group experiences of living with LTCs.

It should not be simplistically assumed that less affluent or otherwise less advantaged people are automatically less likely to be psychologically confident or less able to live independently in their social and physical environments than are members of more advantaged groups. Nevertheless, financial, educational and other assets are potentially significant variables in enabling individuals to cope as well as possible with the challenges of 'young old age', at least up until the point when physical or other challenges force a loss of independence and/or demand extensive care provision.

Given such realities the capacity of programmes such as the EPP (or related self care interventions) to reduce health and social care demand at a population level should not be overstated. They might, for instance, encourage higher expectations in high need communities, while having relatively little impact in other areas.

8.2.1 Recommendations

Policy

Policymakers and health service planners should not overestimate the capacity of specific interventions (such as the Expert Patients Programme) to reduce the population's demands on health and social care services

Policymakers and health service planners should recognise that interventions such as the Expert Patients Programme may need to be tailored to the needs of specific populations, e.g. the population of older people.

Policymakers and health service planners should be aware that interventions in health literacy and patient education can potentially widen health inequalities if they are disproportionately taken up in more affluent areas; and should plan steps to mitigate this.

Needs assessment and service planning

Commissioners should ensure that local needs assessment takes into account three critical 'perceptual' issues in the way older people in their area approach accessing health and social care:

- Belief systems regarding health in one's older years
- Prior experiences of healthcare
- Perceptions of local service availability

Commissioners and local service providers should use these assessments to ensure services are designed to be acceptable to various groups of older people with long term conditions.

8.3 Applicability of existing self care / self management support to older people with LTCs

We interviewed a wide range of service providers offering a variety of support for older people with LTCs in all four case study areas. However, the older people interviewed did not seem to be accessing support from the full range of support options available. Most interviewees appeared to rely primarily on support from their general practice, community pharmacy and local hospital. By contrast, support from social services, the voluntary sector and self help programmes seemed under-utilised, for example, just two of the older people had attended Expert Patients courses.

Although providers discussed the new roles, such as health coaches and medicines managers that have been created in recent years, few older people appeared to be aware of them. This raises questions about the promotion and applicability of these support options.

Many of our questionnaire non responders and opt outs were at the frailer end of the population. Those who did respond to the questionnaire and agreed to be interviewed may have been in better health and consequently less likely to feel the need to seek support from social services or the voluntary sector. There appeared to be a certain stigma attached to accessing social services support and some of our interviewees expressed a reluctance to join self help groups that they felt were provided for those in greater need. Indeed, there was a general aversion to group activities. Many people did not consider themselves "joiners", suggesting that alternatives to group-based support need to be developed or that people's confidence in joining groups could be enhanced.

8.3.1 Recommendations

Integration of services

Commissioners from both the NHS and local authorities who are planning to integrate health and social care services for older people with long term conditions will require

active strategies to overcome many older people's negative perceptions of using social care.

Service planning and design

Commissioners, using needs assessment that includes an investigation of older people's beliefs, experiences and preferences, should commission a greater variety of support options specially for older people's self-care such as support to navigate the health and social care system, and support to monitor symptoms.

Commissioners should involve older service users and potential users in reviewing existing services and developing new forms of self-care and self-management support.

Commissioners should, in particular, ensure that:

- A range of support options are available to ensure that for example, there is individualised support available to people for whom group activities are unattractive or unacceptable
- If group interventions are commissioned, that account is taken of the diversity of older people in relation to age, culture and beliefs about health, so that older people feel that comfortable taking part in group interventions'

Service delivery

Health and social care staff who wish to recommend a group-based support service to an older person will need active confidence-building strategies to support older people 'across the threshold' and induct them into the group.

8.4 Role of the GP in providing self care and self management support

The GP was considered by many to play a key role in providing general care and, to a lesser extent, support for self care and self management. Continuity of care was highly valued and in some cases people were willing to travel considerable distances to see the GP they had known for many years. However, although GPs played an important role for the majority of older people, it is important to say that not all our interviewees were satisfied with the care they provided, some felt that their needs were being dismissed by their GPs and that in some cases their GPs displayed 'ageist' attitudes.

Moreover, some service providers interviewed felt that GPs were ill-informed about the potential support options available within a particular area and were reluctant to engage with the voluntary sector. Paternalistic attitudes appear to persist and some GPs appeared to question the willingness and capacity of older people to manage their LTCs. This is likely to affect efforts to engage patients in self management activities.

8.5 The interface between GP and allied primary health care services and other forms of LA and PCT funded care

General practice and community pharmacy services are relatively uniform across the country, in large part because they are mainly funded on a secure national contract basis and are consistently available to older people free of charge. They are illness treatment and end of life care centred, although the support gained by many service users from professionals like GPs may be more significant than is often appreciated. For a proportion of older people their doctor or on occasions their pharmacist can be the highest value personal 'human social capital' asset they possess.

By contrast, PCT/LA self care support services are more likely to be locally unique and to exist for limited periods before being replaced by alternative initiatives. Services available from the voluntary sector also vary as local funding becomes more or less available. Both social service and voluntary sector provided support can be charged for as and when it is judged necessary. Compared to the widely understood, stable, pattern of primary health care services available, PCT/LA funded self care support and allied provisions like self management courses are more of a fragmented patchwork. The resultant uncertainties affect service users as well as GPs.

Our research shows that seen from the perspective of PCT/LA and voluntary service providers, conventional GP led care may appear isolated and 'unfairly' well funded. Practitioners' lack of awareness of local services might also seem arrogant and uncaring. However, from the GPs' perspective LAs and PCT funded self care initiatives can be experienced as a confusing amalgam of constantly altering provision, which lacks an easy to use 'front door' through which to refer patients in need of support to appropriate forms of local help.

8.6 The development of PCTs and LAs as integrated service commissioners

Our evidence suggests that there is typically only very limited high level interest in and understanding of self care support service development for older people in PCTs/LAs. For many local politicians, for instance, people who are over retirement age and in poor health are not seen as an attractive group (see London case study). But at the same time there is policy pressure for an interest in integrated service commissioning and better co-ordinated service provision. There is a logical case for both of these last, although there is also a danger that the main drivers for such developments relate more to organisational survival and leadership level interests than they do to genuinely well informed (and welfare improvement oriented) service user preferences. This suggests that there will be an ongoing need for robust local performance monitoring by external agencies.

8.7 Self care and medicines taking in later life

People are living longer today, in part because of the ability of modern medicines to control cardiovascular and other disease risks, symptoms and progression rates. But the price paid for such benefits includes older people having to take complex treatment regimens. Complying with these can become a dominant task in their lives. Our research data reflects this situation, and the extent of difficulties encountered by a number of respondents as they try to take their medicines correctly with only limited help from any professional source.

8.7.1 Recommendations

Policy

In designing guidance, support and incentives for better support to older people's self-care – for example, care planning, personal budgets and integrated services -- policymakers **and health service planners** should take full account of the need to:

- recognise and develop the central role of the GP, and
- encourage the integration of GP and support services, and the engagement of GPs with the wider patchwork of health, social care and voluntary sector provision for their patients

Because of the central role of the GP, **policymakers, health service planners and GP professional bodies** should consider further research into:

- GPs' perceptions of their role in relation to supporting self-care and self-management
- GPs' perceptions of older people's capacity and willingness to self manage

Any such studies should include consideration of what would be required successfully to encourage primary care practices to engage in care planning across boundaries with a wider range of services, and to be a key partner in helping people to navigate those services.

Professional education and training

Professional bodies such as the Royal College of GPs and the General Medical Council may need to review the extent to which medical education, training and development equip GPs (and associated primary care professionals such as practice nurses) to work in partnership with older patients to formulate self management strategies.

Medicines management

Since managing medications can become a dominant and even overwhelming factor in older people's self-management, **local service providers** including GPs, pharmacies, and other organisations whose care staff directly interact with patients need to agree clear protocols and processes to ensure there is consistent, proactive advice and support for older people to manage their prescriptions and take their medicines correctly at home.

Commissioners, together with their local pharmacists, should actively review any policies that have the potential to make it either easier or more difficult for older people to manage their prescriptions and take their medicines correctly. These might include policies that affect:

- Access to pharmacist advice and services
- Length of prescription available (e.g. 28-day limits cause considerable difficulties to people)
- Patient information services
- Availability of coaching and back-up support for people taking multiple medications

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Appendix one Report of questionnaire development

Background

This report details the development of a questionnaire to be used within the postal survey of older people undertaken as part of this study. A draft of the questionnaire was sent to the ethics committee with the original ethical committee application for the study. Ethical approval was granted for the study, but the research team were requested to submit the final version of the questionnaire as a substantial amendment to the ethics committee.

From the outset of the study, several key domains were identified within which the research team considered it was important to collect data. These domains were as follows;

Domains of interest	Source of questions
General health	Health Survey for England (Becker & Choudhury 2005)
Prevalence and nature of long term conditions	Health Survey for England (Becker & Choudhury 2005)
Quality of life	EQ 5D (EuroQol group 2009)
Patient activation	Patient Activation Measure (Hibbard, Stockard, Mahoney, & Tusler 2004; Hibbard, Mahoney, Stockard, & Tusler 2005)
Knowledge, education and training for self management for long term conditions	Developed by research team
Use and beliefs about medicines	Developed by research team
Use of health and social services	Developed by research team
Social capital	Health Survey for England (Becker & Choudhury 2005)
Whether older person has a carer or acts as a carer	Census 2001/ Methodological work for Census 2011 (Office for National Statistics 2009a)
Demographic questions	Census 2001 / Methodological work for Census 2011 (Office for National Statistics 2009a)
Interest in further research	Developed by research team

We developed a draft questionnaire which was sent as part of the ethics committee application for the study (Draft one), but this questionnaire required significant development work so that it would be clear and easy to answer without an interviewer present. We also needed to ensure that our initial choice of outcome measures were appropriate.

Aim

To develop a questionnaire for a postal survey to be administered to older people to measure their general health, prevalence of LTCs, attitudes towards managing their health, service use and experiences of using services.

Method

A cognitive interviewing approach was used to develop the questionnaire (Willis G 2005). Using this approach, participants, who are similar to those to be included in the study, are asked to complete the questionnaire in the presence of a researcher. The participant is asked to read each question aloud prior to completing it, and to verbalise their thoughts about the question in general and their response to the question. In particular, respondents are asked to highlight any areas of the questionnaire which are unclear, inappropriate or repetitive. The participants' thoughts about the questionnaire are recorded by the researcher either in note form or on audiotape. This approach enables the researcher to determine whether the questionnaire is being interpreted in the way that they intended it to be. It also helps to identify any changes that need to be made to the questionnaire to increase its ease of completion and intelligibility.

Questionnaire development using cognitive interviewing is an iterative process, with changes being made to the questionnaire following each set of cognitive interviews and the new draft of the questionnaire then being tested.

Cognitive interviews were undertaken in two Age Concern day centres in London, with the first two stages being undertaken in one centre, and the final stage being undertaken at a second day centre. The first two stages were undertaken in November 2007 and the final stage was undertaken in January 2008. Participants were given a copy of the study information sheet, consent form and questionnaire and sat with a researcher to complete the questionnaire using the 'think aloud' technique, where they were asked to think aloud regarding their responses to each question.

All participants were given a thank you of £20 gift vouchers. The interviews were conducted by SP and SC.

Results

Characteristics of interviewees

We interviewed 16 people in total (four males and twelve females). Five were interviewed at stage one, six were interviewed at stage two and five were interviewed at stage three.

Table two – Characteristics of interviewees

Interviewee	Age	Gender	Ethnicity	Stage
One	80	Female	White Irish	One
Two	67	Female	White British	One
Three	64	Male	White British	One
Four	77	Female	White British	One
Five	74	Female	White British	One
Six	73	Male	White British	Two
Seven	80	Female	White British	Two
Eight	90	Male	Portuguese	Two
Nine	79	Male	White British	Two
Ten	82	Female	White British	Two
Eleven	69	Female	White British	Two
Twelve	86	Female	White British	Three
Thirteen	80	Female	White British	Three
Fourteen	82	Female	White British	Three
Fifteen	89	Female	Black Caribbean	Three
Sixteen	77	Female	Black African	Three

Questionnaire drafts

1. Draft one was the original questionnaire draft.
2. Draft two was the questionnaire draft which was used in the first set of cognitive interviews. This draft was produced following discussions within the research team.
3. Draft three was developed following the first set of cognitive interviews and was tested in the second set of cognitive interviews.
4. Draft four was developed following the second set of cognitive interviews and was tested in the third set of cognitive interviews.
5. Final version of questionnaire. This was developed using the findings from the third set of cognitive interviews and following discussions with the research team

Changes to questionnaire draft one to produce draft two

The following changes were made to the questionnaire prior to the first set of cognitive interviews;

1. Age Concern, School of Pharmacy, Picker Institute Europe and NHS SDO logos were added to the front of the questionnaire
2. The font size of the questionnaire was increased from font size 12 to font size fourteen.
3. Section headings were removed from the questionnaire and all questions were labelled sequentially throughout.
4. Some changes were made to the items in the use of medicines section with the phrase, "in the prescribed way" being added to both items b and d.
 - a. Three questions were added to explore patients' perceptions of health services. These questions were all answered on Likert scales ranging from strongly disagree to strongly agree and make up question 21 in draft two.

Changes to questionnaire draft two to produce draft three

1. All Likert scales were reordered so that they ranged from strongly agree to strongly disagree. This was because even if participants agreed with a statement, they began to circle "strongly disagree" if it was on the left hand side of the response options. We were unable to alter the order of the response options for the Patient Activation Measure as it has been validated to have the response options running from strongly disagree to disagree
2. All questions have been formatted in tables to improve the questionnaire layout.
3. A more prominent filter for those with or without LTCs was added to the questionnaire after question three. This helped to decrease the questionnaire burden for people without LTCs, and helped to ensure that those with LTCs completed all relevant questions.
4. The majority of open ended questions were removed, as participants reported some difficulty in being able to answer them within a postal questionnaire. Most participants said that they would not complete the open-ended questions if they received it through the post.
5. Question 20 was cut down to the following two questions "I regard having my own doctor as essential, even if this means waiting some time to see him or her" and "I would be happy to receive more of my healthcare and advice from any conveniently located pharmacy."
6. The instructions regarding recruitment of potential interviews on the final pages of the questionnaire were condensed into one page, to help to decrease the overall length of the questionnaire.

Changes to questionnaire draft three to produce draft four

1. The Patient Activation Measure was moved to after the general questions about people's health to increase the face validity of these questions to participants.
2. The 13 item Patient Activation Measure was replaced with the nine-item version to decrease the length of the questionnaire.
3. The five item EQ 5D was removed and replaced with a single item quality of life question, as many of the participants found the EQ 5D difficult to answer, or considered that some elements of it were inappropriate.
4. Question 15 was reworded to make it slightly less definite and prone to social desirability bias. For example "I am confident that I understand what my medicines are for" was reworded to "I sometimes wonder what my medicines are for".
5. The "About your local area" questions were reworded using the validated self-completion wording. This helped to increase the overall simplicity of the questions. For example the questionnaire item, "Would you say that you enjoy living in your local area?" was reworded to "This area is a place I enjoy living in"
6. The questions about being a carer or being cared for, were reworded to ensure that the wording was identical to that used within the census questionnaire.
7. The instructions on how to complete the questionnaire were emboldened along with all of the questions. This was to ensure that the questions and the instructions stood out from the response options.
8. A photograph was placed on the front of the questionnaire to improve the overall appearance of the front page. The wording on the front of the questionnaire was also simplified from "Self-management of long term health problems questionnaire" to "Managing long term health conditions: A survey of adults in four areas".
9. The language was checked throughout the questionnaire to ensure that it was consistent, for example in questions 7-10, ensuring that we had referred to a course or class throughout, rather than a session.

Changes to questionnaire draft four to produce final questionnaire

1. Question nine, the word individual was replaced with one-to-one as participants felt that individual was a little unclear
2. Item " I sometimes miss taking my medicines" was removed as participants felt that this was inappropriate and blaming them for their health problems
3. 15 f and g, the word doctor was replaced with general practitioner
4. Two photographs to be included on the front page of the questionnaire were identified, one showing those of black or minority ethnic origin, and one showing those of white origin.
5. All statements written completely in capitals were removed and replaced with emboldened text following the RNIB guidance on producing printed materials.
6. All major headings were left aligned following the RNIB guidance on producing printed materials
7. Problems with eyesight and hearing were added into question three

Questionnaire draft one

Picker Institute, NHS SDO, School of Pharmacy and Age Concern Logos

SELF MANAGEMENT OF LONG TERM HEALTH PROBLEMS QUESTIONNAIRE

What is the survey about?

This survey is about what older people do to look after themselves and their health, and about what you believe are the best ways of looking after yourself. We are interested not just in the health professionals whom you go to see, but also in all of the other things you do to look after yourself, for example the medication you take or any information that you might read.

Who should complete the questionnaire?

The questions should be answered by the person named on the front of the envelope. If that person needs help to complete the questionnaire, the answers should be given from his or her point of view – not the point of view of the person helping.

Completing the questionnaire

For each question please tick the relevant box for all of your answers unless otherwise indicated.

Sometimes you will find the box you have ticked has an instruction to go to another question. By following the instructions carefully you will answer all the questions relevant to you.

Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box.

Questions or help?

If you have any queries about the questionnaire, please call the helpline number 0800 197 5273

Please return to: Picker Institute Europe
FREEPOST (SCE10829)
Oxford
OX1 1YE
CODE NUMBER

Your participation in this survey is voluntary and your answers will be treated in confidence

SECTION ONE - YOUR HEALTH

1. How is your health in general?

Very good

☐

Good

☐

Fair

☐

Poor

☐

Very poor

☐

2. Do you have any long standing illness, disability or infirmity? By long-standing, we mean anything that has troubled you over a period of time, or that is likely to affect you over a period of time?

☐ Yes

☐ No

If yes, go to Question 3

If no, go to Section two

3. Has a health professional told you that you have any of the following long standing health problems? (Please tick all of the relevant options)

☐ High blood pressure / hypertension?

☐ Angina, which is chest pain, or chest tightness, or heart problems?

☐ Chronic pain, including chronic back pain?

☐ Bowel problems,

☐ Arthritis or rheumatism

☐ Digestive or stomach problems

☐ Depression / Anxiety

☐ Stroke

☐ Diabetes

☐ High cholesterol

☐ Lung problems

☐ Ongoing bladder problems

☐ Cancer

☐ Any other conditions that require ongoing medical care (please specify.....)

4. Do your illnesses or disabilities limit your day to day activities?

All of the time

Sometimes

A little

Not at all

5. Now we would like to know how your health is today. Please answer ALL of the questions, by ticking one box for each question below. Please indicate which statements best describe your health state today.

Mobility

- ☐ I have no problems in walking about
- ☐ I have some problems in walking about
- ☐ I am confined to bed

Self care

- ☐ I have no problems with self care
- ☐ I have some problems washing or dressing myself
- ☐ I am unable to wash or dress myself

Usual activities

- ☐ I have no problems with performing my usual activities (e.g. work, study, housework, family or leisure activities)
- ☐ I have some problems with performing my usual activities
- ☐ I am unable to perform my usual activities

Pain / Discomfort

- ☐ I have no pain or discomfort
- ☐ I have moderate pain or discomfort
- ☐ I have extreme pain or discomfort

Anxiety / Depression

- ☐ I am not anxious or depressed
- ☐ I am moderately anxious or depressed
- ☐ I am extremely anxious or depressed

SECTION TWO - BELIEFS ABOUT TAKING CARE OF YOURSELF

1. How much do you think you know about managing your illness? Do you know...?

Just about everything I need to know	Most of what I need to know	Some of what I need to know	A little of what I need to know	None of what I need to know
--------------------------------------------	--------------------------------	--------------------------------	------------------------------------	--------------------------------

2. Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally **by circling your answer**. If the statement does not apply to you, please circle non applicable

a. When all is said and done, I am the person who is responsible for managing my health

Disagree strongly	Disagree	Agree	Agree strongly	Not applicable
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b. Taking an active role in my own health care is the most important factor in determining my health and ability to function

Disagree strongly	Disagree	Agree	Agree strongly	Not applicable
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c. I am confident that I can take action that will help prevent or minimise some symptoms or problems with my health

Disagree strongly	Disagree	Agree	Agree strongly	Not applicable
-------------------	----------	-------	----------------	----------------

d. I know what each of my prescribed medications does

Disagree strongly	Disagree	Agree	Agree strongly	Not applicable
-------------------	----------	-------	----------------	----------------

e. I am confident that I can tell when I need to obtain medical care and when I can handle a health problem myself

Disagree strongly	Disagree	Agree	Agree strongly	Not applicable
-------------------	----------	-------	----------------	----------------

f. I am confident that I can tell the doctors concerns I have even when he or she does not ask

Disagree strongly	Disagree	Agree	Agree strongly	Not applicable
-------------------	----------	-------	----------------	----------------

g. I am confident that I can follow through on medical recommendations my doctor makes

Disagree strongly Disagree Agree Agree strongly Not applicable

h. I understand the nature and causes of my health problems

Disagree strongly Disagree Agree Agree strongly Not applicable

i. I know the different medical treatment options available for my health condition

Disagree strongly Disagree Agree Agree strongly Not applicable

j. I have been able to maintain the lifestyle changes for my health that I have made

Disagree strongly Disagree Agree Agree strongly Not applicable

k. I know how to prevent problems with my health

Disagree strongly Disagree Agree Agree strongly Not applicable

l. I am confident I can work out solutions when new situations or problems arise with my health

Disagree strongly Disagree Agree Agree strongly Not applicable

m. I am confident that I can maintain lifestyle changes, like diet and exercise, even during times of stress

Disagree strongly Disagree Agree Agree strongly Not applicable

Some people receive training to manage their long term health problems through a government programme called The Expert Patient Programme, and sometimes GPs also run similar classes.

4. Have you ever taken part in a course or class about your illness?

☐ Yes

☐ No

5. If yes, was it an individual session, or a group session?

☐ Individual

☐ Group

If yes

6. Who provided that training?

☐ Social worker

☐ Practice nurse

☐ GP

☐ Voluntary organisation (e.g. arthritis care)

☐ Other (Please specify).....

7. What did you think of the training?

Very good

Good

Fair

Poor

Very poor

8. Would you like more help, advice or support to help you manage your health condition?

☐ Yes

☐ No

9. If yes, what type of support would you like?

.....

...

.....

...

.....

...

SECTION THREE - USE OF MEDICINES

1. Do you take any medicine, tablets or pills for your illness / disability?

☐ Yes

☐ No

If yes, how many different medicines do you regularly take? (Please state an approximate number).....

2. To what extent do you agree or disagree with the following statements: (Please circle your response)

a. I am confident that I understand what my medicines are for

Strongly agree

Agree

Disagree

Strongly disagree

b. I am confident that I take my medicines correctly

Strongly agree

Agree

Disagree

Strongly disagree

c. I very rarely miss taking my medicines

Strongly agree

Agree

Disagree

Strongly disagree

d. I need help taking my medicines

Strongly agree

Agree

Disagree

Strongly disagree

e. I believe that the medicines I am prescribed are beneficial to my health

Strongly agree

Agree

Disagree

Strongly disagree

f. I believe that the medicines I take do me more good than harm

Strongly agree

Agree

Disagree

Strongly disagree

g. I believe that doctors prescribe medicines too readily

Strongly agree

Agree

Disagree

Strongly disagree

h. I worry about the side effects of the medicines I take

Strongly agree

Agree

Disagree

Strongly disagree

g. I trust pharmacists (chemists) advice more than my GP about my medications

Strongly agree

Agree

Disagree

Strongly disagree

SECTION FOUR - USE OF HEALTH AND SOCIAL SERVICES

1. During the last twelve months have you attended / used any of the following services?
(Please tick all that apply)

- | | |
|----------------------------------------------------------------------------------------------------|------------------------------------------|
| <input type="checkbox"/> GP | <input type="checkbox"/> Home help |
| <input type="checkbox"/> District nurse | <input type="checkbox"/> Care worker |
| <input type="checkbox"/> Hospital (out patient) | <input type="checkbox"/> Meals on wheels |
| <input type="checkbox"/> Hospital (inpatient) | <input type="checkbox"/> Lunch club |
| <input type="checkbox"/> Hospital (A&E) | <input type="checkbox"/> Day centre |
| <input type="checkbox"/> Complementary therapist (e.g. osteopath, chiropractor, massage therapist) | <input type="checkbox"/> Social worker |

Any other services (please specify)

.....

2. How satisfied are you with the current level of support you have?

Very satisfied

Satisfied

Neither satisfied
or dissatisfied

Dissatisfied

Very dissatisfied

3. Are you getting the support you need?

☐ Yes

☐ No

4. If no, what other support would you like?

.....

...

.....

...

.....

SECTION FIVE - ABOUT YOU

1. What is your sex?

☐ Male

☐ Female

2. What is your date of birth? (Please write in the boxes provided)

Day

Month

Year

3. What is your occupation?

.....

4. If you are retired, what was your main occupation when you were working?

.....

5. If you have never worked, what is the main occupation of your spouse?

.....

4. What is your ethnic group?

a. White

- ☐ British
- ☐ Irish
- ☐ Any other white background

b. Mixed

- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other mixed background

c. Asian or Asian British

- ☐ Indian
- ☐ Pakistani
- ☐ Any other Asian background.....

d. Black or Black British

- ☐ Caribbean
- ☐ African
- ☐ Any other Black background.....

e. Chinese or other ethnic group

- ☐ Chinese
- Any other ethnic group

SECTION SIX - ABOUT YOUR LOCAL AREA

1. How long have you lived in your local area?

- ☐ More than 20 years
- ☐ Between 10 and 20 years
- ☐ Between five and 10 years
- ☐ Between one and five years
- ☐ Less than a year

2. Would you say you enjoy living in your local area?

Strongly agree Agree Disagree Strongly disagree

3. Would you say your local area is a place where neighbours look after each other?

Strongly agree Agree Disagree Strongly disagree

4. Would you say your local area has good local public transport?

Strongly agree Agree Disagree Strongly disagree

5. Would you say that your area is a safe place to live?

Strongly agree Agree Disagree Strongly disagree

6. Would you say your local area has good leisure facilities for people like yourself – leisure centres or community centres, for example?

Strongly agree Agree Disagree Strongly disagree

7. How often do you speak to relatives or friends on the phone?

On most days Once or twice a week Once or twice a month Less often than once a month Never

8. How often do you speak to neighbours?

On most days Once or twice a week Once or twice a month Less often than once a month Never

9. How often do you meet up with friends or relatives?

On most days	Once or twice a week	Once or twice a month	Less often than once a month	Never
--------------	----------------------	-----------------------	------------------------------	-------

9. Do you look after anyone who is sick, disabled, or elderly, other than in a professional capacity?

☐Yes

☐No

If yes,

10. Does anyone look after you because of sickness, disability or old age other than in a professional capacity?

☐Yes

☐No

11. Are you prepared to ask the person who looks after you if they are willing to be interviewed as part of this study?

☐Yes

☐No

If yes, they can telephone us on our Freephone number 0800 197 5273.

SECTION SEVEN - INTEREST IN FURTHER RESEARCH

We would like to know if you would be willing to be interviewed about how you take care of your long term condition.

We would like to interview a few people with long term health problems to find out their views on the reasons for their problem and how they go about looking after themselves.

Whether or not you decide to be interviewed will not affect the care that you receive from any health or social care professional in any way.

A trained researcher will do the interviews. They will last for about an hour, and will take place at a time and place to suit you. This could be in your own home, or if you prefer another place, such as your GP's surgery. We will refund any travel expenses.

These interviews will be taped recorded and then typed out. The information you give in these interviews will be kept confidential.

I am interested in being interviewed about my long term health problem

☐ Yes

☐ No

If yes: please can you tell us where to contact you

Please use block capitals

Family name: Given name.....

Address:

.....
.....

Postcode.....

Telephone (including STD code)

Daytime..... Evening.....

Appendix two: Questionnaire administration

2a. Questionnaire survey covering letter

Dear [Insert participant's name]

Re: Questionnaire survey exploring support for older people with long term health problems

TO BE INCLUDED AT THE BEGINNING OF THE FIRST REMINDER LETTER [We recently sent you a letter asking whether you would be willing to help us with our research by completing a questionnaire. We are investigating the support available for older people to self-manage their long term health problems within their local community. If you have already replied to the questionnaire, please ignore this letter and we will not contact you again.

If you have not responded yet, and would like to help us, we would be grateful if you could complete the questionnaire that we sent you two weeks ago, and return it in the FREEPOST envelope at no cost to yourself. If you would like to help, but need another copy of the questionnaire, please contact Suzanne Parsons or Helen Magee on our FREEPHONE number 0800 197 5273.]

TO BE INCLUDED AT THE BEGINNING OF THE SECOND REMINDER LETTER [We recently sent you a letter asking whether you would be willing to help us with our research by completing a questionnaire. We are investigating the support available for older people to self-manage their long term health problems within their local community. If you have already replied to the questionnaire, please ignore this letter and we will not contact you again. If you have not responded yet, and would like to help us, we would be grateful if you could complete and return the enclosed questionnaire in the FREEPOST envelope at no cost to yourself]

BEGINNING OF FIRST MAILING LETTER

The Picker Institute Europe (an independent research organisation), the School of Pharmacy (University of London), and the charity Age Concern, have received funding to conduct a research project in your area.

The project has been funded by the NHS Service Delivery and Organisation Research programme and aims to explore the support available for older people to self-manage their long term health problems within their local community. The project's findings will be fed back locally and nationally, with a view to improving the support available within the community for self managing long term health problems.

A key part of this project is a postal questionnaire which we would like to invite you to take part in.

What is the purpose of the survey? The survey is about how you look after your health and what you think are the best ways of keeping healthy. We are interested to hear about the health professionals you see, the services you use, and all the other things you do to look after yourself.

Why have I been chosen? You have been invited to take part in this survey because you live in [XX], which is one of the areas in which we are conducting the research. Your name was selected at random from XXX Primary Care Trust's records.

Do I have to take part? No. Taking part is voluntary. If you choose not to take part it will not affect your care in any way. If you do not want to take part, or you don't want to answer some of the questions, you do not need to give us a reason.

What if I decide to take part? If you decide to take part, please complete the questionnaire and return it in the FREEPOST envelope. No stamp is needed. The questionnaire should take about 20 minutes to complete. If you do not wish to take part, please could you return the blank questionnaire in the FREEPOST envelope. If we do not hear from you in two weeks, we will send you a reminder letter.

Will my response be kept confidential? Yes. You have been given a unique number so that your name and address are not on the questionnaire, and will never be linked to your responses. The last page of the questionnaire asks if you would be interested in taking part in further research. If you are, you can enter your contact details. We will detach this page from the rest of the questionnaire so that your contact details will not be stored with your responses.

Your personal data are held in accordance with the Data Protection Act 1998. Your contact details have been passed to Greens Digital, a mailing house responsible for sending out the questionnaires and processing the responses. Greens Digital will process your answers in confidence and keep them separate from your contact details.

Contact for further information - If you would like more information about the survey, or have any questions on how to complete it, you can call our FREEPHONE number **0800 197 5273**, at no cost to yourself and we will do our best to help. The line is open between 9am and 5pm, Monday to Friday. Please ask for Suzanne Parsons or Helen Magee.

Thank you.

Yours faithfully

Suzanne Parsons
Senior Research Associate
Picker Institute Europe

2b. Final study questionnaire

Managing Long Term Health Conditions



Image courtesy of Age Concern England

A survey of adults in four areas of England

What is the questionnaire about?

This questionnaire is about your health, the things you do to look after yourself and what you think about the area you live in. For example, we are interested in the health professionals you see, the medication you take, the services you use, and any information that you might read about health.

Completing the questionnaire

The questionnaire should be completed by the person named on the envelope. If someone is helping you to fill it in, it is important that the answers are given from **your** point of view.

Some questions won't be relevant to you. If this is the case, please follow the instructions carefully and just answer the questions relevant to you.

Don't worry if you make a mistake; simply cross it out and put a tick in the correct box.

Do you have any questions or need help?

If you have any queries about the questionnaire, please call the helpline number **0800 197 5273**. You do not need a stamp to return the completed questionnaire to us, simply use the Freepost envelope provided.

Your participation in this survey is of course entirely voluntary and your answers are confidential.

Your Health

Please tick the relevant answer unless otherwise indicated.

1. How is your health in general?

Very good	Good	Fair	Poor	Very poor
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. Do you have any long standing illness, disability or infirmity?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

2a. If YES how much does your health problem limit your day to day activities?

A lot	Moderately	A little	Not at all
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. Has a health professional told you that you have any of the following long standing health conditions? (Please tick all that apply)

- | | | | |
|--------------------------------------------|--------------------------|--------------------------------------|--------------------------|
| a. High blood pressure/hypertension | <input type="checkbox"/> | i. Angina or heart problems | <input type="checkbox"/> |
| b. Persistent pain | <input type="checkbox"/> | j. Bowel problems | <input type="checkbox"/> |
| c. Arthritis or rheumatism | <input type="checkbox"/> | k. Digestive/stomach problems | <input type="checkbox"/> |
| d. Depression or anxiety | <input type="checkbox"/> | l. Stroke | <input type="checkbox"/> |
| e. Diabetes | <input type="checkbox"/> | m. High cholesterol | <input type="checkbox"/> |
| f. Eyesight problems | <input type="checkbox"/> | n. Hearing problems | <input type="checkbox"/> |
| g. Asthma or bronchitis | <input type="checkbox"/> | o. Bladder problems | <input type="checkbox"/> |
| h. Cancer (please specify) | <input type="checkbox"/> | p. Any other conditions | <input type="checkbox"/> |
-
- (please specify)
-

4. In general my present quality of life is ...? (Please circle your response)

Excellent	Very good	Good	Neither good nor bad	Bad	Very bad	Extremely bad
-----------	-----------	------	----------------------	-----	----------	---------------

5. Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by circling your answer

If the statement does not apply to you, circle "Non applicable"

a. When all is said and done, I am the person who is responsible for managing my health condition

Strongly disagree	Disagree	Agree	Strongly Agree	Not applicable
-------------------	----------	-------	----------------	----------------

b. Taking an active role in my own health care is the most important factor in determining my health and ability to function

Strongly disagree	Disagree	Agree	Strongly Agree	Not applicable
-------------------	----------	-------	----------------	----------------

c. I am confident that I can tell when I need to obtain medical care and when I can handle a health problem myself

Strongly disagree	Disagree	Agree	Strongly Agree	Not applicable
-------------------	----------	-------	----------------	----------------

d. I am confident that I can follow through on medical treatments I need to do at home

Strongly disagree	Disagree	Agree	Strongly Agree	Not applicable
-------------------	----------	-------	----------------	----------------

e. I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health condition

Strongly disagree

Disagree

Agree

Strongly Agree

Not applicable

f. I have been able to maintain the lifestyle changes for my health that I have made

Strongly disagree

Disagree

Agree

Strongly Agree

Not applicable

g. I know how to prevent further problems with my health condition

Strongly disagree

Disagree

Agree

Strongly Agree

Not applicable

h. I am confident I can figure out solutions when new situations or problems arise with my health condition

Strongly disagree

Disagree

Agree

Strongly Agree

Not applicable

i. I am confident that I can maintain lifestyle changes like diet and exercise even during times of stress

Strongly disagree

Disagree

Agree

Strongly Agree

Not applicable

6. How many long standing health problems do you have?

None (if none, go to Question 16)	<input type="checkbox"/>
One	<input type="checkbox"/>
Two	<input type="checkbox"/>
Three or more	<input type="checkbox"/>

Looking after yourself

7. Thinking about your long term health problems, how much do you think you know about managing your illness?

Just about everything	Most of what I need	Some of what I need	A little of what I need	None of what I need
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. Have you ever taken part in a course or class about managing your illness?

Yes	<input type="checkbox"/>
No If no, go to Question 13	<input type="checkbox"/>

9. Was it a one-to-one or a group course or class?

One-to-one	<input type="checkbox"/>
Group	<input type="checkbox"/>

10. What did you think of the course or class?

Very useful

☐

Useful

☐No
opinion☐

Not very useful

☐

Not at all useful

☐**11. Who provided that course or training? (Please tick all that apply)****a.** Social worker☐**b.** Practice nurse☐**c.** General practitioner☐**d.** Expert patient programme☐**e.** Other (Please specify)☐

.....

...

.....

.

12. Would you like more help, advice or support to manage your health?

Yes

☐

No

☐**Use of Medicines****13. For your illness or disability, do you take any prescribed medicines or tablets?**

Yes

☐

No

☐

If YES, how many different types of medicine do you regularly take?

14. For your illness or disability, do you buy any medicine or tablets from the chemist or pharmacist, (medicines or tablets not on prescription from your doctor)?

Yes

☐

No

☐

If YES, how many different types of medicine do you regularly take?

.....

15. Below are statements that people sometimes make when they talk about their medicines. Please indicate how much you agree or disagree with each statement as it applies to you personally. Please circle your response

a. I sometimes wonder what my medicines are for

Strongly agree

Agree

Disagree

Strongly disagree

b. I take my medicines in the prescribed way, most of the time

Strongly agree

Agree

Disagree

Strongly disagree

c. I sometimes wonder whether the medicines I am prescribed are doing me any good

Strongly agree

Agree

Disagree

Strongly disagree

d. I think that some doctors prescribe medicines too readily

Strongly agree

Agree

Disagree

Strongly disagree

e. I sometimes worry about the side effects of my medicines

Strongly agree

Agree

Disagree

Strongly disagree

f. I trust the pharmacist's advice about my medicines more than that of my general practitioner

Strongly agree

Agree

Disagree

Strongly disagree

g. I trust that my general practitioner prescribes the best treatment for my health problems

Strongly agree

Agree

Disagree

Strongly disagree

Use of health and social services

16. Have you attended or used any of the following services during the last 3 months? (Please tick all that apply)

- | | | | |
|--------------------------------------------------------------------------|--------------------------|-----------------------------------|--------------------------|
| a. General Practitioner | <input type="checkbox"/> | h. Paid home help | <input type="checkbox"/> |
| b. Practice nurse (the nurse you see at your general practice) | <input type="checkbox"/> | i. Meals on wheels | <input type="checkbox"/> |
| c. District or community nurse (the nurse who visits you at home) | <input type="checkbox"/> | j. Lunch club / day centre | <input type="checkbox"/> |
| d. Hospital (outpatient) | <input type="checkbox"/> | k. Social worker | <input type="checkbox"/> |
| e. Hospital (inpatient) | <input type="checkbox"/> | l. Pharmacist | <input type="checkbox"/> |
| f. Hospital (Casualty/A&E) | <input type="checkbox"/> | m. Occupational therapy | <input type="checkbox"/> |
| g. Physiotherapy | <input type="checkbox"/> | n. Speech therapy | <input type="checkbox"/> |

o. Any other health or social services? (Please specify) ☐

.....

17. If possible, I prefer to see the same general practitioner all of the time, even if this means waiting some time to see him or her (Please circle your response)

Strongly
agree

Agree

Neither agree
nor disagree

Disagree

Strongly
disagree

18. I would be happy to receive more of my health care and advice from a convenient pharmacy (Please circle your response)

Never

Sometimes

Always

About your local area

The following questions are about the local area in which you live. We are interested to find out about how life in your local area is related to health.

19. How long have you lived in your local area? (Please write the number of years)

Please indicate whether you agree or disagree with the following statements.

20. This area is a place I enjoy living in

Strongly agree

Agree

Disagree

Strongly disagree

21. This area is a place where neighbours look after one another

Strongly agree

Agree

Disagree

Strongly disagree

22. This area has good local transport

Strongly agree

Agree

Disagree

Strongly disagree

23. This area is a safe place to live

Strongly agree

Agree

Disagree

Strongly disagree

4. This area has good leisure facilities for people like myself, for example, leisure centres or community centres

Strongly agree

Agree

Disagree

Strongly disagree

25. This area has good local healthcare services

Strongly agree

Agree

Disagree

Strongly disagree

26. How often do you speak to relatives or friends on the phone?

On most days

Once or twice
a weekOnce or twice
a monthLess often than
once a month

Never

27. How often do you speak to neighbours face-to-face?Everyday or
most daysOnce or twice
a weekOnce or twice
a monthLess often than
once a month

Never

28. How often do you meet up with friends or relatives?Everyday or
most daysOnce or twice
a weekOnce or twice
a monthLess often than
once a month

Never

29. Do you look after, or give any help or support to family members, friends, neighbours or others because of their long term health problems which you are not paid for?

Yes

☐

No

☐

29a. If yes, for how many hours do you provide unpaid care.....

30. Does anyone look after you or give you any help or support for your long term health problems which they are not paid for?

Yes

☐

No

☐

30a. If yes, for how many hours a week do they do this

About you

31. Are you?

Male

☐

Female

☐

32. What is your date of birth?

.....

33. What is your occupation, or if you are retired, what was your main occupation when you were working?

.....

34. What is your ethnic group?**White**

British

Irish

Any other white background
(Please specify)

.....

Black or Black British☐ Caribbean☐ African☐ Any other Black background
(Please specify)

.....

Mixed

White and Black Caribbean

White and Black African

White and Asian

Any other mixed background
(Please specify)

.....

Asian or Asian British☐ Indian☐ Pakistani☐ Any other Asian Background
(Please specify)

.....

Chinese or other ethnic group

Chinese

Any other ethnic group
(Please specify)

.....

Further research interview

We would like to interview some of you about how you take care of your long-term health problems or help other people to do so. These interviews would take place at a time and place convenient to you, and we would give you a small gift voucher as a thank-you.

There are three types of people we are interested in talking to. If you would like to talk to us and come into one of these categories, please tick below and write in your name and address.

I have a long-term health condition	<input type="checkbox"/>
I help a relative, friend or neighbour with things like washing, dressing, taking their medication and shopping	<input type="checkbox"/>
I am helped by a neighbour, friend or relative with things like washing, dressing, taking medication and shopping AND I have asked this person if they would be willing to talk to you AND they have said I may give you their name and address	<input type="checkbox"/>

I AM WILLING TO BE INTERVIEWED AND MY NAME, ADDRESS AND TELEPHONE NUMBER ARE:

Name:
Address:
Telephone number:

MY NEIGHBOUR. FRIEND OR RELATIVE IS WILLING TO BE INTERVIEWED AND HIS/HER NAME, ADDRESS AND TELEPHONE NUMBER ARE:

Name:
Address:
Telephone number:

Thank you very much for your help

Please check you have answered all the questions that apply to you. Please post the questionnaire back in the FREEPOST envelope provided. No stamp is needed.

Appendix three: Topic guide for qualitative study of older people

Introductions and reiteration of the study's background and purpose

1. Consent procedure – ensuring that participants are fully aware of the aims of the study and what their involvement is likely to entail, i.e. that they have received and had an opportunity to read and understand the information sheet
2. Assurances of confidentiality and that participants are free to withdraw at any time without their care being affected in any way
3. Any further questions
4. Obtain agreement to proceed or not

Background

- Background of participant – *Age, interests, general health*
- Experience of having long term conditions – ask participants to speak about their major health problems, *e.g. When diagnosed, Impact on life, for example how their problems impact on their relationships with others, their ability to do what they want to do in their lives, What they do to look after themselves - what works for them and what doesn't work for them*
- Attitudes towards taking care of their health, *e.g. Do they believe that looking after their health is their responsibility, a shared responsibility between them and the health professionals they consult, or is it something that is mainly the responsibility of health professionals?*

Accessing support in general and for self management

- Meaning of support for looking after their health in general and for caring for their long term condition in particular– *What does support mean to them? Help, advice, practical assistance, someone to talk to, care from health professionals and social services.*
- Beliefs about the support they need to look after their health and themselves in general – *What areas of your life would you like more support with? Prompt for health care, psychological and social support, help to access care, information on support services, alterations to the home.*
- Experience of support – *At the moment, who and what would you say are your main sources of support? What are the things that help you the most to look after*

yourself? Prompt for GP, practice nurse, friends and family, age concern, social workers, help when coming out of hospital (intermediate care)

- Experiences of getting help and support from health services, social services and other local services for general health and for long term conditions. *(Take health services, social services and other local services in turn and explore)*
- Ease / challenges to identifying and accessing services – including ease of access to particular services versus continuity of care with one health / social care professional. *How did you hear about these people / organisations? How easy were they to approach / access? How easy was it to get an appointment? Potential barriers to accessing services, time, location, format, availability, awareness, information, appropriateness of support to needs*
- Expectations of service – *Did you have any expectations of the help and support prior to getting it? Where your expectations met? In what ways were your expectations met and not met?*
- Acceptability and usefulness of advice given – *Was the advice suitable for your situation? Was the advice sensible? Did you get any help in putting the advice into practice?*
- Suggestions made by health and social care professionals to help participants to look after themselves
- Beliefs about and awareness of local providers of support – *Do you know of anyone else who might provide support to you locally? Reasons if any, for choosing not to approach particular health professionals or services.*

Meaning and experience of self care / looking after yourself

- Meaning of looking after yourself / self care to participants – *What sort of things does looking after yourself include?*
- Factors influencing the decision to actively look after yourself. *Can you say what has influenced your decision to look after yourself? What role has the opinions of your friends and relatives played in this decision? Has anything else influenced your decision? – prompt for magazines, TV, newspapers, internet*
- Beliefs about the support you need to help you to look after yourself, if any?
- Strategies for self care / looking after yourself – what things have you tried that work and don't work? *Can you describe to me an example of something that really helps you in looking after yourself and makes your day to day life better? (emphasize that it doesn't have to be something that a health professional has suggested)*
- Experiences of obtaining support to help you look after yourself – *Perhaps revisit their earlier descriptions of obtaining support and see if there were any suggestions of self care made*
- Who are the providers of support?

- What is the nature of the support offered if any?
- Beliefs about the appropriateness and usefulness of the support available to help you to look after yourself
- Challenges and facilitators to accessing support for looking after yourself
- *Time, Location, Format, Availability, Awareness, Information, Appropriateness of support to needs*
- Beliefs about the effectiveness of looking after yourself
- Effectiveness of management of health problems by a health professional versus looking after yourself

Appendix four: Topic guide for qualitative study of carers

Introductions and reiteration of the study's background and purpose

1. Consent procedure – ensuring that participants are fully aware of the aims of the study and what their involvement is likely to entail, i.e. that they have had the opportunity to read the information sheet and to ask any questions that they have about the study
2. Assurances of confidentiality and that participants are free to withdraw at any time without their care being affected in any way
3. Any further questions
4. Obtain agreement to proceed or not

Background

- Background of carer – *age, occupation, general health, suffering from any long term conditions*
- Beliefs about their role in managing their health problems (and their caree's health problems) and in making decisions about their health and health care – *For example, is looking after their and their caree's health problems the responsibility of health professionals, a shared responsibility between them and health professionals or is it something that they take the lead on?*

Role as a carer

- Who they provide care for and for how long?
- Circumstances which led to them taking on a caring role. *Increasing care needs of caree, previous support no longer available, no one else able to take on the role*
- Nature of the support provided. *Personal care, managing health care, medicines administration, social and emotional support, information, practical day to day support etc*
- Challenges to providing care / support. *Information needs, support from other family members, own health, time, awareness and availability of support options*
- Enabling factors to providing care / support. *Support from health and social care professionals, information needs, support from other family members, own health, time, awareness and availability of support options*
- Influence of caring role on

- General health – *influence of caring on participants' general health, and ability to look after themselves*
- Relationships with family and friends, including their caree – *Disagreements between them and their carees regarding care and advice from health professionals*

Relationships with health and social care professionals e.g. *What support is provided / available from health and social care professionals to help them to look after their caree?; Ease of carrying out health professionals suggestions / wishes etc; Agreements / disagreements with health professionals over the care suggestions made*

Accessing support for their caring role and for their general health

- Beliefs about their support needs for their caring role - *Social and emotional support, information, practical, financial and support to self care*
- Experiences of accessing support as a carer from health services, social services and other local services (e.g. respite care, carers' networks. "looking after me" style carers course)
- Appropriateness of the timing of the support – *What support is needed at particularly points in their experience of being a carer?*
- Experiences of accessing support for their caring role – *Have you accessed any support for your caring role? Who has provided you with support and can you describe what help they have given to you?*
- Ease / challenges to identifying and accessing support services – *How easy is it to identify potential support? How easy is it to access the support that you have identified? What are the challenges to accessing support services?*
- Expectations of services accessed – *Did you have any expectations of the support and help that you have had? Where your expectations met? If not, in what areas did the service / support fall short?*
- Acceptability and usefulness of advice and support given – *What sort of advice have you been given? How useful was this advice?*
- Suggestions for self management advice made for their general health?

Accessing support for their caree

- Beliefs about the support needs of the person that they look after – *What areas of your caree's life would you like them to have more support with? Prompt for health care, psychological and social support, help to access care, information on support services, alterations to the home.*
- Experiences of obtaining support for their caree - *At the moment, who and what would you say are the main sources of support for your caree? What are the things that help them the most to look after themselves? Prompt for GP, practice*

nurse, friends and family, age concern, social workers, help when coming out of hospital (intermediate care)

- Their experiences of accessing support for the person that they look after
- Ease / challenges to identifying and accessing local services and information- *Have your caree accessed any support? Who has provided this support and can you describe what help they have been given?*
- Expectations of services accessed – *Did you have any expectations of the help and support prior to getting it? Where your expectations met? In what ways were your expectations met and not met?*
- Acceptability and usefulness of advice and support given- *Was the advice suitable for your situation? Was the advice sensible? Did you get any help in putting the advice into practice?*
- Suggestion of self management made?

Self management / self care support

- Meaning of looking after yourself / self care to participants – *What sort of things does looking after yourself include?*
- Factors influencing the decision to actively look after yourself, and to help their caree to look after themselves. *Can you say what has influenced your decision to look after yourself? What role has the opinions of your friends and relatives played in this decision? Has anything else influenced your decision? – prompt for magazines, TV, newspapers, internet*
- Beliefs about the support you and your caree need to help you to look after yourself, if any?
- Strategies for self care / looking after yourself – what things have you and your caree tried that work and don't work? *Can you describe an example of something that really helps you in looking after yourself and makes your day to day life better? (emphasize that it doesn't have to be something that a health professional has suggested)*
- Experiences of obtaining support to help you and your caree look after yourself – *Perhaps revisit their earlier descriptions of obtaining support and see if there were any suggestions of self care made - Who are the providers of support?; What is the nature of the support offered if any?; Beliefs about the appropriateness and usefulness of the support available to help you to look after yourself; Challenges and facilitators to accessing support for looking after yourself?*
- Beliefs about the effectiveness of looking after yourself
- Effectiveness of management of health problems by a health professional versus looking after yourself

Appendix five: Topic guide for qualitative study of service providers and commissioners

Topic guide for service providers

1. Introductions and reiteration of the study's background and purpose
2. Consent procedure – ensuring that participants are fully aware of the aims of the study and what their involvement is likely to entail.
3. Assurances of confidentiality and that participants are free to withdraw at anytime without their care being affected in any way
4. Any further questions
5. Obtain agreement to proceed or not

Background

- Background of interviewee – *professional background, role within organisation, years working with organisation, description of their professional role*
- Description of their role in providing support for older people in general and in particularly for self management
- Relationship of their organisation to others locally, where does their organisation fit into the local landscape? *Do they refer to other organisations? From whom do they accept referrals?*

Description of the support / service they provider

- Background to service being provided – *How and why did it come into existence? Length of time that service has been in existence*
- Aims / philosophy of the service – *Overall aims of service if any, target group for service, e.g. age group and range of needs service aims to meet*
- Access to service – *when, where, frequency. Perceived barriers and facilitators to accessing the service*
- Changes to the service if any whilst it has been in existence and why? – *Changes to the target group, content. Reasons why, changing needs of the population*

Self management / self care support

- Meaning of self management / self care to them – *What does this mean to you in terms of providing services which aim to support self care*
- Beliefs about the effectiveness or not, of self care / self management – *What are the benefits of supporting self care for you as a service provider for older people?*

- Challenges to promoting self care / self management – *How does supporting and promoting self care / self management compete with other aspects of your role as a service provider?*
- Beliefs about acceptability of self care / self management - *Beliefs about the acceptability of self care / self management to older people and to different health and social care and voluntary sector professionals. Are people willing to take responsibility for self care? What role do you think that people believe you have in promoting self care?*
- Influence on the suggestion to self care / self management on consultations with patients / clients – *Have suggesting self care impacted on your consultation with patients and clients and in what way has it influenced the consultations?*

Experiences of providing the support service

- Nature of the self management advice or support provided by their service – *Description of the support offered by the service in general and of the self management aspects of the support*
- Beliefs about the extent to which support can be tailored to individuals' needs – *Challenges and facilitators to doing this*
- Beliefs about older peoples' expectations of the service – *What do you think are older people's expectations of the service*
- Own expectations about what the service can provide
- Dealing with gaps between their and older peoples' expectations
- Challenges to providing the service and ways of overcoming challenges
- Description of quality improvement process if any to ensure that the service continues to meet people's needs

Role of service in relation to other support options

- Relationships with other organisations and service providers
- Challenges / difficulties of working with other organisations

Topic guide for commissioners

Background

- Background of interviewee – *professional background, role within organisation, years working with organisation, description of their professional role*
- Description of their organisation's role / policies in terms of commissioning and providing general health and self management support to older people with long term conditions – *Does the organisation have any explicit priorities around older people's health?*
- Relationship of their organisation to others locally, how does their organisation relate to others that are involved in commissioning services locally

Description of the support / service they commission and the commissioning process

- Planning services provision - *How do they go about identifying older people's needs around self management and self care? What is the process of identifying potential providers to meet older people's needs? Can they describe how decisions are made regarding the commissioning of services*
- Background to service (s) being provided – *How and why did they come into existence?*
- Aims / philosophy behind the approach to commissioning – *Overall aims of commissioning strategy, e.g. target groups and range of needs that strategy aims to meet*
- Beliefs about ease of access to services – *when, where, frequency. Perceived barriers and facilitators to accessing services*

Self management / self care support

- Meaning of self management / self care to them – *What does this mean to you in terms of commissioning services which aim to support self care?*
- Beliefs about the effectiveness or not, of self care / self management – *What are the benefits and costs of supporting self care for you as a commissioner of older people's services?*
- Challenges to promoting self care / self management – *How does supporting and promoting self care / self management compete with other aspects of your role as a commissioner?*
- Beliefs about acceptability of self care / self management - *Beliefs about the acceptability of self care / self management to older people and to different health and social care and voluntary sector professionals*

- Influence on the suggestion to self care / self management on consultations with patients / clients

Beliefs about services to support self management / self care

- Nature of the self management advice or support provided by the services commissioned
- Beliefs about the extent to which support can be tailored to individuals' needs – *Challenges and facilitators to doing this*
- Beliefs about older peoples' expectations of self management support – *What do you think are older people's expectations of the services in relation to self management support*
- Own expectations about what the service can provide – *What do you believe that the services you are involved in commissioning can offer in terms of self management / self care support*
- Dealing with gaps between their and older peoples' expectations – *What do you believe is that most appropriate way to manage older people's expectations about what services can offer them?*
- Challenges to providing the service and ways of overcoming challenges – *What challenges do you believe that service providers face when supporting self care?*
- Description of quality improvement processes for services, and for the commissioning process itself – *How do you ensure that high quality services are commissioned that meet older people's needs?*

Appendix six: Qualitative study documentation



Support for self management of long term health problems amongst older people

We would like to invite you to take part in a research study. Before deciding whether to take part, it is important that you understand why the research is being done and what it involves for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

- Part one tells you the purpose of this study and what it involves
- Part two gives you more detailed information about the conduct of the study

If there is anything that is not clear, or if you would like more information, please contact [Insert name and telephone number of relevant researcher]. Please take time to decide whether or not you want to take part.

Part one

1. What is the purpose of the study?

The study aims to improve the support for self management of long term health problems among older people by improving our understanding of their expectations and experiences of self managing their health problems and how these relate to the availability of local services.

2. Why have I been invited?

FOR SERVICE PROVIDERS AND COMMISSIONERS [We identified you as a local service provider or commissioner from our audit of the services in your area]

FOR OLDER PEOPLE [You replied to our recent questionnaire survey and expressed interest in taking part in an interview]

FOR CARERS [You replied to our recent survey about your health and indicated that you act as a carer.] [You contacted us after the person whom you care for replied to our recent survey and asked you whether you would be interested in taking part in our study].

3. Do I have to take part?

No, it's up to you to decide whether or not to take part. We will describe the study and go through this information sheet. If you would like to take part, we will ask you to sign

a consent form to show you have agreed. If you decide not to take part, this will not affect the standard of any care that you receive.

4. What happens if I decide to take part?

A trained researcher will visit you in your home, or at another convenient location, to interview you.

FOR SERVICE PROVIDERS AND COMMISSIONERS [The researcher will discuss with you your organisation's perspective on greater responsibility for health, your experiences of developing and delivering services to support self management and working in partnership with other providers.]

FOR OLDER PEOPLE [The researcher will discuss with you your attitudes towards self care, the services available to support you and any difficulties you may have experienced in obtaining support.]

FOR CARERS [The researcher will discuss with you, your experiences of caring for someone with a long term health problem, the services available to support carers and the impact upon your own health.]

The interview will last for about one hour, and will be audio-taped and typed out, to help us to analyse the information. For taking part, we would like to offer you a £30 gift voucher to thank you for your time and co-operation.

5. What are the potential benefits of taking part?

FOR SERVICE PROVIDERS AND COMMISSIONERS [You will have the opportunity to express your views about self management amongst older people.]

FOR OLDER PEOPLE [You will have the opportunity to express your views about important aspects of managing your health]

FOR CARERS [You will have the opportunity to express your views about important aspects of caring for someone with a long term health problem.] We cannot promise the study will help you or them, but your information might help improve the management of long term health problems in the future.

6. What if there is a problem?

If you have any concern about any aspect of this study, you should speak to [Insert name of relevant researcher], who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting Caroline Powell, Picker Institute Europe, King's Mead House, Oxpens Road Oxford, OX1 1RX
Telephone: 01865 208 100

7. Will my part in this study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in part two.

This completes part one of the information sheet.

Part two

8. What happens if I don't want to carry on with the study?

If you withdraw from the study, the audiotapes and transcript of the interview will be destroyed.

9. Will my taking part in this study be kept confidential?

Yes, all of your information will be kept strictly confidential. Only the researchers working on this study will have access to your information, which will be destroyed after the research is completed. Your name will be removed from the transcript of the interview so that you cannot be recognised from it. Direct quotes used in any subsequent reports will be anonymised.

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

A report of the findings will be produced for the NHS Service Delivery and Organisation (SDO) Research and Development Programme. You will not be identified in any report or publication without your consent.

11. Who is organising and funding the research?

The study is being carried out for the NHS SDO Research and Development Programme. It is being organised by Picker Institute Europe, an independent health services research organisation, the School of Pharmacy, University of London and Age Concern.

11. Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee, to protect your rights, safety, wellbeing and dignity. This study has been reviewed and given a favourable opinion by the Oxfordshire A Research Ethics Committee.

Thank you for taking the time to read this sheet

*ii. Consent form***Consent Form****Support for self management of long term health problems amongst older people**

Please initial box

1. I confirm that I have read and understand the information sheet dated [insert date] for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected

☐

3. I understand that data collected during the study may be looked at by members of the research team from the Picker Institute Europe, School of Pharmacy, University of London. I give permission for these individuals to view my information

☐

3. I agree to the interview being recorded

☐

4. I agree to take part in the above study

☐

.....
Name of Carer

.....
Signature

.....
Date of interview

.....
Name of researcher

.....
Signature

.....
Date of interview

Disclaimer:

This report presents independent research commissioned by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the NIHR SDO programme or the Department of Health. The views and opinions expressed by the interviewees in this publication are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, the NIHR SDO programme or the Department of Health"

Addendum:

This document is an output from a research project that was commissioned by the Service Delivery and Organisation (SDO) programme whilst it was managed by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) at the London School of Hygiene & Tropical Medicine. The NIHR SDO programme is now managed by the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton.

Although NETSCC, SDO has managed the project and conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. Should you have any queries please contact sdo@southampton.ac.uk.