Care Services Efficiency Delivery

Anticipating Future Needs

August 2007

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## Introduction

Background

During 2006/07 IPC was commissioned by the Care Services Improvement Partnership (CSIP) to engage in a project working with three contrasting local authorities in order to develop a model approach to commissioning social care services. The first report from that work was published by CSIP in November 2006 and entitled "Key Activities in Commissioning Social Care". This document has subsequently been revised with a new edition being published in the summer of 2007. "Key Activities in Commissioning Social Care" outlines the demand forecasting process as containing the following four elements:

Fig 1. Demand Forecasting
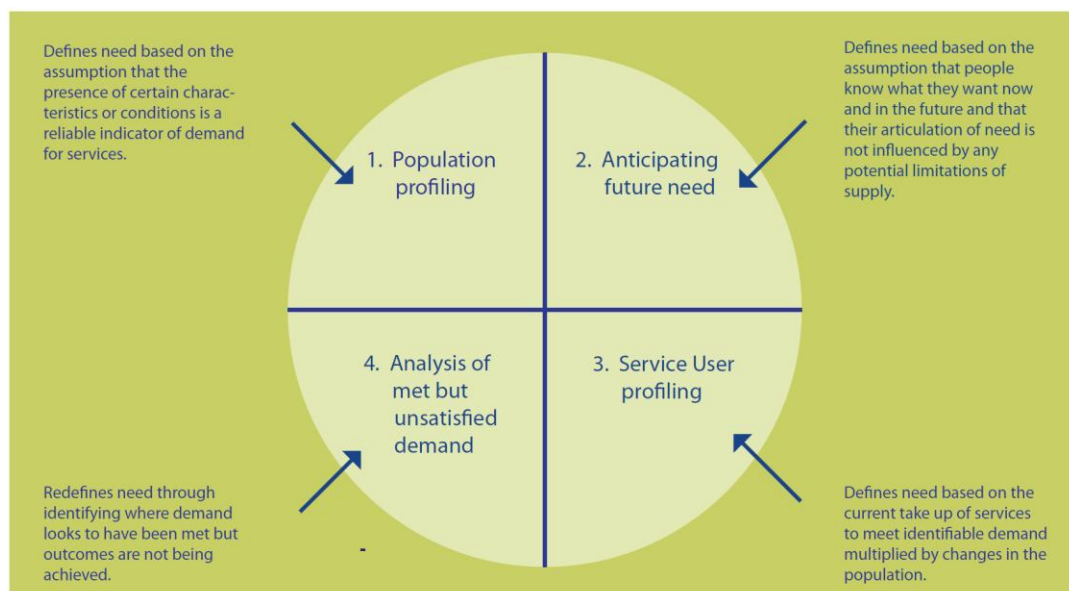
Following a number of discussions between IPC and the Care Services Efficiency Delivery Programme (CSED) three projects were devised to help develop tools and approaches to support activities 1, 2, and 4 (as described above).

The first of these, concerning population profiling, has produced the 'Projecting Older People Population Information' (POPPI) system, released in March 2007[1]. This system (which is freely available to all local authorities and PCTs) brings together a range of existing published information concerning current and future populations of older people, some of the characteristics of those populations and linking that material to existing local authority performance data.

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[1] See http://www.poppi.org.uk/index.php

The second two projects focus on Anticipating Future Needs (this report) and arrangements for Configuring Future Services at the health and social care interface.

The case for change

In recent years there has been a recognition that consultation and involvement of older people in planning provision is increasingly important and in contrast that existing consultation mechanisms do not necessarily work well.

The Joseph Rowntree Foundation Older People Shaping Policy and Practice Project (2004) and The Help the Aged, Quality of Life in Older Age (2001) project involved older people as commissioners of research, researchers, interviewers, reference group members, advisory groups and users of research findings. Older people were involved in the whole process from the start to the finish, ie, agenda setting, implementation and review. This type of consultation is different from traditional research and policy consultation, where emphasis has largely been on discussion of *existing* services.

The Kings Fund, Care Services Inquiry, Looking Forward to Care in Old Age, took a different approach. Their study set out to explore what *younger* older people saw as important for quality of life and asked them how they perceived this would be affected as they aged.

In general many existing approaches to public and service user consultation tend to become self fulfilling prophecies. For example, in conducting surveys local authorities often ask questions which lead to a service focussed response rather than deducing what service provision might be required based on the outcomes and quality of life that older people wish to enjoy. In contrast the resulting information from the Joseph Rowntree Foundation work revealed interesting insights into what older people regard as important to them as they age and how services could be shaped better to support their needs. Often there are complaints that consultation exercises tend to target 'the usual suspects' either through consulting with organisations that may or may not be representative or by having standing reference groups. Therefore, asking the future generation of older people and current older people about the quality of life they *aspire* to and thinking how service provision might deliver on that, breaks this dead-lock. Useful approaches are those that:

- Focus on quality of life.
- Ensure the involvement of older people is on-going throughout the consultation process.

Previously little work has been completed which bring these approaches together in a format that could help to influence local authority commissioning strategies for older people. The aim of this project was to test a methodology that does just that.

The Anticipating Future Needs Project

The Anticipating Future Needs project has attempted to combat these problems by developing a simple structured methodology for engaging pre-retirement older age groups and current service users in a way that allows them to express their views about their life situation now and in the future around themes that may be incorporated into Local Area Agreements (LAAs) and local commissioning strategies. An early version of this approach was piloted as a part of the Exemplar Project and the lessons then applied to this more extensive process.

The following report comprises four main sections:

- Section A offers a brief review of the existing published literature, identifies key themes in relation to older people's attitudes to ageing, health, well being, quality of life, accommodation and funding and looks at some issues that local commissioners may wish to take forward from this work in developing their Strategic Needs Assessments.

- Section B describes the development of the approach to be used by the Anticipating Future Needs Project

- Section C reports the application of this methodology in the two test local authorities.

- Section D describes the approach that was used in more detail and provides tools and materials for others to use.

Section A - The Background to Consulting Older People

Introduction

The purpose of this section is:

- To provide an overview of the main findings from recently published studies that have asked people in late middle age and older people, what their needs and expectations are in respect to ageing.
- To enable commissioners to build on work already published by identifying potential additional projects that may address gaps in the literature.

As has been widely publicised the older person's population in the UK is growing. This means for example that:

- 85 year olds are the fastest growing population segment[2].
- By 2015 the number of people aged over 85 will increase by 27% and by 2025 over a fifth of the population will be aged over 65[3].
- By 2040 there will be 5 million more people aged over 65 than there were at the turn of the millennium. [4]
- The proportion of people aged over 65 affected by a stroke will increase by 40,000 over the next twenty years[5].
- By 2025 just under a million people aged over 65 will have a dementia[6].
- It is likely that the proportion of older people owning their own home will grow from two thirds to four fifths over the next twenty years[7].

However, whilst population based data sets the framework within which overall demand for health and social care can be estimated, it is still not a predictor of who will, or who will not, require or expect services. This can be influenced by a wide range of additional factors. For example, any of the following may have a substantial impact on the demand for health and care services:

- Affluence.
- Changes in available drug treatments or general health.
- Accessibility of services, eg, from information, to volume of service provision, to public perceptions, to physical access.

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[2] POPPI – Data extracted from the CSED system Projecting Older People's Population Information System.
[3] POPPI - ibid
[4] Huber, J. Skidmore, P, The New Old – Why baby boomers won't be pensioned off, (2003) DEMOS
[5] POPPI – op cit
[6] POPPI – ibid
[7] POPPI – ibid

- Migration.
- Capacity and desire of carers to support family members.
- Changes in public attitude to services in terms of cost appropriateness and relevance to the individual.

It is the last of these points that Anticipating Future Needs is attempting to address – how might future demand be influenced by older people's attitudes.

Below is a summary of some of the common findings from the recent consultation exercises with older people. What is known about the attitudes of those entering older age, and those already there, in regard to well-being, health and ageing, support and care, accommodation and finances.[8]

Well-being

Well-being is not an easy concept to define. To use the longstanding World Health Organisation definition it is *a state of complete physical, mental, and social well-being and not merely the absence of disease and infirmity* (WHO, 1946)[9].

Therefore, although linked to health it means more than simply whether someone is healthy or not. Steverink et al (1998)[10] contend that there is a need to maintain both physical and social well-being in order to age successfully. They suggest that physical well-being involves two components, firstly satisfying basic needs including an absence of fear, fatigue and pain and secondly stimulation through engaging in new challenging and interesting activities.

Well-being is also closely related to quality of life. There is broad agreement within the recent literature that 'quality of life' can be seen or measured as a complex inter-play between:

- Subjective interpretations of the world (individual older person/ the self).
- Objective conditions of the individual older person (housing, income, social network, health).
- Social structural and demographic variables (age, gender, marital status).

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[8] As this section pulls out the common findings from the literature reviewed, the individual findings are not separately referenced. The full bibliography can be found on page 12.
[9] Constitution of the World Health Organisation, Geneva, (1946), World health Organisation
[10] Steverink, N., Lindenberg, S., Ormel, J, Ageing and Society, Towards understanding successful ageing: patterned change in resources and goals, (1988), Cambridge University

Common findings

- The critical role of good relationships with family and friends.
- The importance of being able to socialise and enjoy company outside the home.
- The 'preventative' value of keeping the mind active and challenged, whether through formal learning or hobbies.
- The 'vicious circle' of disability reducing the ability to get out and about, which in itself then reduces mobility.
- That activity has to be meaningful to have positive effects.
- The importance of feeling respected and valued by society, which people experience as lessening as they enter old age.
- For those in early old age, the importance of being able to continue, or develop, work based or civic roles and responsibilities.

What local commissioners might additionally wish to know

Clearly the literature provides an overview of what is important to older people in regard to well-being, and in terms of potential services covers a wide range of health and local authority functions. It could be of benefit to commissioners to explore across the health and local authority communities what would be good indicators of well being amongst its older person's population and how this might be influenced by inter-agency and inter-departmental activity. Normally this kind of review is explored for wide ranging populations, eg, all over 50 year olds or all over 65's. There may also be a value in examining the impact of the range of well being services (library services, leisure services, transport) on much more acute or at risk populations. The test here is to try and discover what impact well being services might have on populations that are most at risk and what form they should best take.

At a national level it would be worth trying to identify distinctions in communities that have well integrated populations, ie shire county small towns and villages, as compared to communities where this is not the case and then exploring the impact in terms of health and social care provision.

Health and ageing

The results from the General Household Survey 2003 found that 60% of elderly people said that they had a longstanding illness, 41% said this limited their activities in some way[11]. It is managing these limitations that most older people seem to define as 'health'. For example, the Joseph Rowntree Foundation 'Getting Old is not for Cowards' (2003) research study found that health was seen by older people as adapting to physical

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[11] People aged 64 and over, Results from the General household survey, (2003), Office for National Statistics

illness and to the changes this incurs. The success of this is dependent on many other interrelated factors…*physical condition, adapting to continuous physical change, functional abilities, relationship', maintaining independence, financial satisfaction, fulfilling personal objectives, pursuing interests and taking part in meaningful activity'*[12].

Common findings

- Health is not necessarily seen as 'recovery' from illness, but being supported to get back to a point of optimum independence.
- Health and social care professionals should listen and respond to each individual older person's own definition of the required outcomes of any intervention.
- When people are ill, they want to get treatment in the home backed up by reliable medication delivery service and domiciliary care rather than go to hospital.
- People feel they could maintain their own health more effectively with regular GP check-ups and advice.
- A positive outlook is seen as promoting health and this could be promoted by therapeutic interventions to assist positive coping.
- Despite physical or mental health disabilities, many older people want to, and feel they have a right to, take risks within their lives.
- Most of those in younger old age were particularly concerned about the loss of control associated with dementia, and wanted to retain a 'say' over their future in these circumstances.

What local commissioners might additionally wish to know

One of the big unknowns for most local service commissioners is what impact does one part of the system have on another? For example, does a failure to detect continence as an issue for many older people have an adverse effect on care home admissions and if so in what proportion? Does a lack of early intervention designed to improve older people's mobility lead to later hospital admissions? Would increased health care expenditure on stroke recovery have a greater impact on older people's take up of social care services?

However, not all problems with health may be attributable to service gaps or failures; some may be attributable to earlier lifestyle choices made by older people. For example not only may smoking have an impact on people's health in old age but also diet, past drug and alcohol use, and environment. There is little information to help define how these issues may impact in later life at a local level.

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[12] Reed, J Cook, G et al, Getting Old is not for Cowards, (2003), Joseph Roundtree Foundation

Finally, whilst it may be possible to identify problems, developing appropriate solutions and approaches may not be easy. For example, there is limited information on what services could be developed by commissioners to improve people's' individual coping strategies regarding the multiple losses older people often experience.

Support and Care

The message about older people wishing to remain in their own homes has been well voiced by a wide range of studies over the years. Equally clear is that many people do not wish to rely on their own family members for care and support. Yet nonetheless many people end up doing the opposite of their stated wishes, ie, rely on family members to support them and end up in care homes when death is near. For example as a recent National Audit Office report illustrated, two thirds of people with dementia are cared for in their own homes with some 476,000 unpaid carers, normally family members, involved in providing support[13].

Common findings

- Support and care is seen as needing to encompass both practical help and social support.
- People do not want care to be restricted to their home, but to have support to do things themselves, eg being accompanied shopping.
- Consistency of carer is usually identified as the most important element of a quality service.
- People look for reliability of visits, people arriving when expected, but that the actual care given can be flexible.
- People want support with practical domestic tasks, DIY, gardening, which have often been lost in the tightening of eligibility criteria.
- Younger older people have expectations that their preferred patterns of bathing, hair washing etc, should be maintained by care services.
- While friends and family are important sources of support, people do not want to 'be a burden' to them.

What local commissioners might additionally wish to know

There are a wide number of further issues that may be looked at concerning the provision of support and care. For example:

- What impact might self directed care, either via direct payments or individual budgets, have on preventing people from coming into care homes? There is much discussion about improved preventative care

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[13] Improving Services and Support for People with Dementia, p5, (2007) National Audit Office

services yet often little capacity to effectively target where that preventative intervention can create the biggest impact.

- Similarly what is the cost benefit analysis of increasing services to carers in terms of increasing their capacity to care for longer?

- Do we potentially offer too much care at the cost of rehabilitation and recovery and how do we assess the capacity of people to recover given variable inputs?

- Do people's perceptions of public services improve if they have greater choice of care and support workers and more flexibility over the hours of availability?

- The move to maintaining more older people within the community means potentially both higher risk and people with higher needs being sustained by community services. What are people's perceptions of how well those services work as compared to the wider feedback on the range of services.

Accommodation

Currently, as older people age they are less likely to move house, although given greater mobility in general by the 'new' old population it remains to be seen whether this trend continues. In addition some of this immobility may have been caused by a lack of alternatives, ie sheltered housing, residential care or staying put. It is reasonable to expect that given the increased equity of the older population then greater diversity in the types of accommodation suitable for older people will be generated by the market.

- The majority of older people want to stay in their own homes. For example Boaz study[14] found that four fifths of older people did not want to move to another setting at all and that three quarters of those interviewed would rather have their home adapted to suit their disabilities than move elsewhere.

- However, people entering old age are more inclined to accept that a move into housing with care may well become an appropriate option if they acquire disabilities in older age.

- If older people do make a move then having sufficient space for family or friends to stay is seen as important.

- Older people express anxiety about the ability to maintain their homes into old age, and people look for reliable support to achieve this.

- People are positive about equipment and assistive technology and see this as offering real opportunities for them to stay in their own homes comfortably and safely.

- People do not want to move into a care home.

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14 Boaz A., Hayden C., Bernard M., Attitudes and Aspirations of older people: a review of the literature, (1999), DSS Research Report 101, Leeds CDS

What local commissioners might additionally wish to know

In capital terms, a large proportion of LA equity is tied up in the provision of sheltered housing. What is the potential market for re-designed premises and redeveloped sites to make better use of this capital in terms of offering accommodation that helps facilitate a wider population of older people to remain within the community? How should LA's facilitate discussions between older people and the wider housing market about their future needs?

Particularly in terms of care homes, local commissioners need to be able to gain a much better understanding of the causal factors and the care pathway that leads to residential care if a greater proportion of people are not to take that route. What are the differences between those who fund their own placement in a care home and those who are funded by the LA, in terms of longevity, knowledge of alternatives, etc?

Finances

Given increased longevity amongst older people (in 1911 average life expectancy was around age 50, by 2011 it is estimated at being just under 80 years of age[15]) and increased early retirement, it is possible that old age will divide into two parts for many people. A more prosperous early old age followed by a poorer older old age as savings and assets diminish and potential life style costs start to increase again. Nonetheless, despite increased equity and a wider prevalence of employment based pension schemes old age is still a time of comparative poverty for many. As recently as 2005/06 the Department for Work and Pensions estimated that some 45% of pensioners depended on state benefit for at least 50% of their income[16].

Common findings

- Among younger people there are many concerns about the affordability of care.
- Current older people see their pensions as falling behind earnings and financial dissatisfaction is often reported when thinking of the future.
- Older people want the option to be able to work. However, those that felt compelled to work because they had to top up meagre pensions, reported as having a low quality of life.

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[15] See Expectation of life at selected ages by gender, 1911 to 2021 (Selected years): Social trends 30 by Office of National Statistics at http://www.statistics.gov.uk/STATBASE/xsdataset.asp?More=Y
[16] Pensioners incomes series 2005/06, (2004), Department for Work and Pensions.

- Those in older age, who have limited finances, are quite frugal and those that have saved are, likewise, careful with their finances and use such savings for household emergencies and as a '*general buffer'.* [17]

- Many older people are not necessarily concerned about saving money for their children. Their own needs, as they age, are a priority over their children's inheritance. Those over 80 years old are more concerned with leaving loved ones an inheritance but the majority still consider their own needs first.

- Equity release schemes are seen by some older people as an option to improve their accommodation; however there is scepticism about financial products offered.

What local commissioners might additionally wish to know

To plan accordingly, commissioners might wish to know what older people *can* and *are* willing to pay for in terms of public care services. By the same token they also need to know what they *are not* willing or *able* to pay for. This is a crucial part of any demand analysis and discussions in relation to this are missing in previous studies. Conclusions can only be drawn by effective dialogue and consultation with the local older populace.

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[17] Older people's views and experiences of resources in Later life, (2007), Joseph Roundtree Foundation

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Section B - Developing the Approach

Overview

As described in the Introduction, the aim of this project was to develop and test a simple approach to consulting with pre-retirement older people and current service users in such a way that they could contribute to the thinking behind public service commissioning strategies for older people.

The intentions were fivefold; namely to test whether:

- This was an appropriate approach to use with older people.
- It helped to deliver a wider debate and discussion rather than a focus on existing services.
- The information gained could build at a local level on the national literature available.
- The information gained genuinely contributed to commissioning strategies.
- The interview process could help to inform potential changes that may be made to joint assessments.

The approach focused on using two methods:

- Conducting focus groups with people aged between 60 and 65.
- Interviewing a sample of current service users.

The content of the focus groups in particular built on work already conducted with the commissioning exemplar authorities but on this occasion involved two (rather than one) local authorities. Both authorities selected were small unitaries covering mainly urban populations.

Focus Groups

In total 13 focus groups were run for two hours each. The group size ranged from 6 to 14 and averaged 8 giving a total of 103 participants. All participants were aged between 60 and 65. The vast majority were already retired, even towards the younger end of the range. Each local authority constructed representative focus group samples based around social class, age, ethnicity, and gender.

Prior to commencing the focus groups, each participant was asked to complete a short questionnaire intended to identify how representative the sample of people available actually was. The main difference is the under representation of males in the groups.

Table 1 Characteristics of the Focus Group Sample

Focus Group Participant data[18]				
	Number	%	Number	%
	Male		Female	
Gender	30	34	58	66
	Partnered		Not partnered	
Partnered	53	60	35	40
	Had been carer in last 2 years		Had not been a carer in last 2 years	
Caring	26	30	62	70
	Home owning		Not home owning	
Tenure	65	74	23	26
	Over 20K		Under 20K	
Savings	20	23	68	77
	Had		Had not	
Private pensions	26	30	62	70
	Had		Had not	
Employment pensions	40	45	48	55
There was no specific question about ethnicity although in both groups an appropriate to the population ethnic balance was achieved.				

Each group was led by a member of IPC staff with a note taker also being present. The groups were structured into four time slots.

- Slot 1 - To ask people to think fifteen to twenty years ahead and consider where they might be living, what financial resources they might have and what contact they may have with family, friends and neighbours.
- Slot 2 – To ask the same questions but after people had been read a description of physical incapacity that might happen to them.
- Slot 3 - To ask the same questions but after people had been read a description of moderate dementia that might happen to them.

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[18] Some data is missing due to individuals either not completing the full questionnaire or it not being completed at all. Total no of returns = 88 out of 103.

- Slot 4 – Finally to ask people to reflect on the different perspectives of their future lives that have been talked about and consider what kinds of services they might need to assist them in the above situations regardless of who paid for that provision.

The questions were chosen to elicit a better understand of:

- What people anticipate for their old age.
- How people might respond to incapacity.
- How much people may be willing to pay and are able to pay for in their older age.

Interviews

A total of 16 interviews were conducted across the two local authorities. Each interview lasted between one and two hours depending on the health, communication ability and willingness to disclose of the service user. The majority of interviews were on a one to one basis between the interviewer and the service user, but there were occasions when the main carer (usually the service user's long-term partner) was also present. All of the service users interviewed were in receipt of some form of domiciliary care and were either still living in their own home, or in some form of sheltered accommodation. None of the people interviewed were living in a residential care home. Efforts were made to ensure that the interview sample were representative of their local authority area in terms of ethnicity, level of disability, social class, age and gender.

The questions were planned around seven quality of life domains. They were a combination of the domains identified in Gabriel Z & Bowling A (2004) 'Quality of Life from the perspectives of older people', *Ageing and Society*, 24, 675-691 and Bajekal M, Blane D, Grewal I, Karlsen S & Nazroo J (2004) 'Ethnic differences in influences on quality of life at older ages: a quantitative analysis', *Ageing and Society*, 24, 709-728. The domains are: Health and Functional Ability, Home and Neighbourhood, Social Relationships, Activities and Hobbies, Social Roles and Responsibilities, Finances, Psychological Wellbeing and Outlook. These domains do not cover cultural and/or religious issues; consequently it may be important for an interviewer to keep these in mind during the interview.

The focus of the questioning was based around four themes as follows:

- What did you used to do in your life?
- What do you do now?
- Why did you change?
- What impact has that had?

The thinking behind this approach was to try and move away from an assessment and care planning structure and into one where an estimate could be made of the impact of limiting aspects of people's individual lifestyles. If quality of life and well being are important factors in maintaining people within the community then this approach tries to estimate what has been lost and from that develop a commissioning approach that looks at how such losses may be limited.

Section C - Applying the Approach

Introduction

Although neither the interviews nor the focus groups were designed around the themes in the earlier literature review the outcomes from the two processes have been grouped under those headings. This is designed to help in making comparisons between the national and the local perspective and to identify how far the local discussions can take the commissioning agenda forward.

Focus Groups

Well-being

All the groups were very vocal on this issue, and it was clear that enjoying a good quality of life was important to people. General well-being was a theme that ran through all the discussions.

In line with the findings in the literature review, family and friendships were seen as important to people's sense of well-being.

Leisure pursuits were often mentioned as key to well-being and positive self-esteem. Most wanted to continue these, as they aged, for as long as possible. The vast majority of the participants in the focus groups were able to 'get out and about'. They all felt they would deteriorate physically and mentally without these opportunities. The experiences of current service users showed these concerns to be well grounded.

Most people in the focus groups were retired. Although this was associated with loss of income it was also associated with loss of social links. Some had gone back to work primarily for the companionship. Many felt that they would like the choice to become involved in paid work but did not want to feel compelled to work because of financial hardship. Having enough money to enjoy a quality of life was important to well-being which we will come back to in the finance materials below.

There was a general consensus that people would want influence and bearing in regard to civic responsibility. A majority of people already felt as if they had become invisible.

Health and Ageing

Many of the participants initially had a positive attitude to health and ageing. Although disconcerted at the prospect of a physical disability, people felt that this could be adapted to with support. Maintaining independence was paramount and people expected services that facilitated this. Many felt it was their own definitions of independence and goals that should be

adhered to by professionals, as it was their life. All wished to remain in control of their lives and after an illness get 'back to normal' as much as possible.

Linked to this, people felt that there needed to be specialist knowledge and treatment of specific health conditions. Many wanted information, guidance and support to live as independently as possible within their limitations.

Many participants wanted six monthly/ annual health checks. Some thought this could be at their GP's or an Occupational Health Clinic in specific areas. The link was made that workers have access to an Occupational health department at work to ensure a healthy work force – why should this not continue when retired to be healthy citizens? People also thought comprehensive information should be provided at these check-ups not just about their health conditions and the usual care path-ways and referrals, but information about other interventions such as alternative therapy or other related treatments.

In contrast to people's expectation that they could live within the limitations of a physical illness or disability, there was huge concern regarding dementia. People had very negative images of this and felt that 'nothing could be done for you when you're like that' or 'it wouldn't matter when you're like that because you wouldn't know what was going on'. There was little recognition of the stages of dementia. Despite the facilitators making a clear distinction between moderate and severe dementia, for the groups it was one and the same thing. Participants were very concerned about risks such as wandering in the community, and felt that they could not be successfully managed in their own homes. The vast majority were adamant that they would need to be looked after in an institution if they developed dementia.

Support & care

All participants recognised that care and support would come from many sources – family, friends, neighbours, social services and the NHS. However, participants were clear that they did not want their grown up children looking after their personal care needs. They were happy to let them manage finances on their behalf, or 'pop-in' or do the shopping, if needed, but little else. They did not want to be considered a burden and thought their children should be left to get on with their own lives. There was agreement on this matter across all the ethnic groups.

Some agreed that if they had a temporary illness they would call upon family if necessary but this would not be a long term arrangement. However the vast majority did not even like this idea.

There was agreement that friends and neighbours would be helpful in terms of 'keeping an eye out for you', perhaps do your shopping but it was considered unfair to expect them to do anything else.

The majority thought they would not mind their partner caring for them and providing personal care if they had a disability. However they wanted good services to be available to support them in this.

The weight of opinion was that the bulk of care should be provided by professionals as opposed to family, friends and neighbours. This was keenly felt by those who were currently living on their own. This group also highlighted the need for care to be available in night time hours.

Accommodation

Most people envisaged staying in their own homes as they aged, and would prefer this. To achieve this objective people were prepared to make adaptations to their lifestyle and environment. At the very minimum it was considered that their houses needed to have fully adapted shower/bathing facilities downstairs and/or a stair-lift. People were not willing to consider moving their bed downstairs.
For those living on their own, housing was a preoccupation and many had started to think ahead to more suitable alternative accommodation. Some wanted to move near families, but nobody wanted to move in with their adult children although a few considered a 'granny annexe'.

Women, in particular, who were living on their own found it problematic managing gardens and general maintenance in terms of cost and the dangers of rogue tradesmen.

Some participants had already planned ahead and downsized their accommodation. Many had thought of downsizing but there was concern that they could not afford a decent small property or bungalow. However, moving to a *smaller* property did not equate with moving to a *small* property. Many participants mentioned that they did not want to drastically downsize and did not want to be 'living in a box'. They wanted space to entertain family and friends. For many a second bedroom was important, especially if their partner were to become disabled or ill.

All groups stressed the importance of being near hospitals, shops, post office and bus stops. They also wanted their communities to be safe.

There were mixed responses regarding housing types such as Extra Care Housing and Retirement Villages. In general, participants liked concepts of 'home for life' and housing that allowed for the spectrum of independent living through to nursing care. There was a significant minority who did not like the idea of living with just other older people and felt that this would depress them, especially if their neighbours had dementia or challenging

behaviour. Some reflected that this would make them 'go downhill'. They preferred mixed communities and did not like the idea of what they saw as 'segregation'. They concluded that it was nice to be around younger people and one lady said 'it would be awful not to hear the sound of children's laughter'.

The vast majority were very concerned that they would not be able to manage in their own homes with dementia, even with a high level care package and significant risk control measures in place via Assistive Technology (AT). Their general knowledge of AT and how risks can be managed within an individual's home was, at best, limited. Therefore, participants believed that if they developed dementia they would need to move to a care home. They would not want this but did not see that they had an alternative choice. They were very pessimistic about care homes and considered care standards poor. They thought it was important to build small scale specialist therapeutic environments where they could be 'looked after properly'.

Finances

People who had assets felt they would use them to maintain a basic quality of life and for some to enjoy luxuries. Some thought they would do this by releasing equity. Some participants were much more positive about equity release products than others, who thought they were a 'con'. All thought independent financial advice was very important as you aged.

The general consensus was that it was unlikely that their children would inherit. They felt that their children were understanding and didn't expect substantial inheritances. A small number said they had no money to bequeath so it was not an issue. Only one person said they would live austerely so that their children could receive an inheritance and did not want a care home for this reason. This gentleman was from a BME group. However, the other BME participants shared the consensus that assets and money should be used to look after yourself and not your children.

Nobody wanted to leave debt to their families and this did worry some people. Participants were asked whether they could envisage a time where they may need financial help from their children. Some reflected that they may ask as a last resort but that this would affect their pride and self esteem (particularly true of male participants).

The groups were clear that their pensions were not in line with the cost of living. A significant minority were worried about meeting basic financial demands such as running a car, the cost of food, bills and council tax - which they saw as ever increasing. Some felt it was very difficult to imagine financial planning as they were unable to judge future rises in utilities bills and taxes. Most imagined that bills would increase at a greater rate than pensions and they would financially struggle.

Those who were on benefits did not feel these were sufficient. People also mentioned that they felt penalised if they had saved up moderate sums as they were in the 'middle bracket' and because of this did not get any financial help. They saw this as unfair. Many felt that they needed to be more aware of the state benefits which may help towards the cost of their care.

There was resentment of, and anger about, having to pay for care. They felt that they had paid taxes all their lives and now were not reaping the dividends. Some suggested there was benefit in spending their money early, thus having their care paid for when required. There was little distinction made by participants between central and local government, between central and local taxation, or between the NHS and social care as providers of support.

People particularly felt that they should not have to pay for nursing care (the details of the Registered Nursing Care Contribution were not known) and that any care needs arising from dementia should be considered health related and therefore met without contribution or charge.

There was some debate around what people would and would not be willing to pay for, in regard to community facilities. They felt that their taxes were not wisely spent by their Council, but they would be willing to pay if the services were of a good quality and affordable.

Most people felt that equipment and adaptations for daily living should be funded publicly and that this would be less expensive for the public purse in the long run.

In general the majority of group participants were pragmatic about spending money on care in old age and conceded that they would have no choice but to use assets to support their personal/social care costs (most saw it as appropriate to fund their own 'well-being' services). Ideas on how to do this covered low risk equity release schemes, selling their home and dipping into savings. They also expected 'the government' to meet them half way through, for example, further investment in preventative community and leisure facilities and higher thresholds for financial support, so that people in a 'middle bracket' were not penalised.

Messages from the focus groups for local commissioners

The focus groups contain a number of messages for local commissioners over and above the national material. We would identify these as:

- As mentioned in the literature review there may be benefit in discriminating between wider leisure opportunities available to the whole community, those specifically targeted at older people and those leisure activities targeted at particular groups of older people without

whom the loss of such activities may seriously diminish their desire to remain within the community.

- In those instances where older people have a disabling illness or condition, health and social care professionals need to focus on what goals are important to the individual and are most likely to maintain their independence.

- Overall, Commissioners need to place emphasis on improving and building communities, possibly through anchoring Local Strategic Partnerships and Local Authority Agreement in a clear outcomes framework based on effective consultation with the population. In developing commissioning strategies, all key players need to be involved, to share information, agendas, obstacles and resources (including for example, Future Builders, Change Up fund) to effectively plan forward. Key players would include health, the wider council such as planning and leisure, fire, police, the independent and voluntary sector.

- If people's response to dementia is one that it automatically requires residential nursing care then LA's and health bodies need to far more actively promote community alternatives and support to carers if people are going to see these alternatives as acceptable.

- There appears to be a change in attitude to the responsibility of families to care for older relatives. Some of this is based on older people's personal experience of caring for their parents, some because of a desire to be self sufficient. Changes in people's capacity to care could have major financial implications for local government and clearly suggests that increasing support to carers needs to be a higher priority.

- Participants in the focus groups see there being a need for diversity in housing provision suitable for older people. Their views suggest to commissioners that properties need to be of a variable size, some in specialist settings, some not, but all with a diminution in labelling such housing 'older people's accommodation'. Care and repair and the capacity to adapt existing property should remain high priorities in a strategic approach that cuts across tenure types.

- The strength of feeling from focus groups around the need for decent bathroom/shower facilities needs to be taken into account by commissioners. The coming generation of service users will not be willing to accept a bed downstairs and a wash in a bowl.

- Commissioners need to give support to accessible and reliable information on personal finance and particularly equity release, such as the House Proud scheme.

- Where older people fund services and make a contribution there needs to be a greater recognition of that contribution and the impact it has on people's sense of fairness and that increased volumes of provision in the future will require a greater partnership approach to funding.

- Involving older people in helping to make and critique local policy decisions may have wider implications than simply consultation. Such

discussions for a number of people may also be a way of making people feel valued and hence improve their sense of well being.

Interviews

Well Being

For the interviewees, friends did not have so much of a role within their lives because many friends were frail themselves and a number had died. However the importance of a good neighbour was mentioned often. Older service users saw family as important, but these relationships were defined more by care as opposed to social reciprocal exchanges.

Many service users mourned their loss of independence and ability to 'get out and about'. All but a very small minority of service users had stopped going out and doing things such as shopping for pleasure, theatre, cinema, and the pub. Many hardly ever left their home except for necessary medical appointments or allotted day care. They clearly expressed how devastating this was and how it impacted on their general well-being.

A significant number of service users had learnt new skills such as handicraft and painting to pass the boredom of being in their home for very many hours. However actually going out was fraught with difficulties for the following reasons:

- Lack of confidence to leave their homes
- Lack of safe communities; from infrastructural gaps such as transport, and level roads, to 'gangs of youths'.
- No equipment to be able to go out - most had manual wheelchairs and those who could self propel could only do so for short distances.
- No-one to take them out – even those with family nearby very rarely went out.

Health and Ageing

Service users who were still mobile and especially those who were active in their local community considered this vitally important and were worried that if their mobility got worse they may not be able to be as active. Service users that had the highest quality of life had made adaptations to their health limitations successfully. These were often those who had had thirty or forty years of a disability. They had had longer to get used to, and adapt to, their disability, emotionally and practically, than those recently affected. They had much more sophisticated equipment that enabled them to get 'out and about', such as motorised wheelchairs, and they had appropriate housing that met their mobility needs. The contrast with older people who had become recently disabled was considerable.

A specific concern for the older group, particularly those who had suffered strokes, was their experience of lack of rehabilitation within hospital and community settings. Many interviewed felt that their 'rehabilitation potential' had been arbitrarily set by clinicians without honest discussion with them as patients. Many were very cynical about this and had felt that they were given up on due to their age. Many felt that this was worse in the community and that physiotherapy had not followed them home from hospital. Also when they needed it at home, it was non-existent. All of them believed that their mobility could have been improved if they had had more rehabilitation input.

The majority, who had significant loss of mobility, found this devastating and that it had impacted so severely on their lives that at some points they had wanted to die. Some described how they had been given anti-depressants. One felt that she had lost her role of 'head of the family' and now felt 'useless' and described her loss of independence as 'unbearable'. It appeared nobody had been offered counselling.
It was clear that this group of people had to deal with multiple losses concerning their health and were particularly vulnerable to depression which, in turn, further affected their well-being and physical health.

Podiatry, opticians and dentistry services were all used by group participants although for a significant number this had to be facilitated by a family member. This suggests that for those who don't have such support then accessing these services may prove difficult. The feeling was that access to these services was often over-looked by statutory organisations placing the responsibility on the individual and their family.

Associated with this, many older people reported how they got confused with the plethora of hospital out-patients' appointments. They found getting there frustrating, were often expected in different hospitals and there was a lot of waiting around, both to be seen and for transport – although all interviewed considered these appointments important and endeavoured to attend.

Support and Care

As discussed in the literature review, interviewees wanted to enjoy reciprocal relationships with family, friends and neighbours. What these interviews revealed is that although many were grateful to those who provided care and support they did feel that they were a burden and this bothered them. As a consequence relationships with family members get defined by care which both upsets service users and family dynamics. For example there were those that were still married and their spouse was their main carer. Some were being looked after full-time by other family members (all of these were daughters). One lady was worried that her daughter didn't get to lead her own life because she was too busy looking after her even though she stated she could not get on without her. Finally,

neighbours were seen as important and were involved in the whole spectrum of care from personal care to 'popping in' or holding keys.

Compared with the more 'consumer' type of expectation about future service use in the focus groups, those actually in receipt of formal care were grateful for the services they received. They felt that equipment improved their quality of life and many were very pleased with the standard of the care they were given. They felt that the visits were timely and carers knowledgeable and caring. Although there were some discussions that sometimes there were too many agencies and it was disconcerting to see new faces. Amongst this small sample, there was a much more positive picture of domiciliary care than other studies have found.

Accommodation

The participants in the focus groups wanted always to be in the position to be in control of their lives and to be the key person in making decisions. However, current service users, at some point along the 'care pathway' had had decisions made for them. Many of the interviews revealed that life changing decisions, such as a housing move, had been a reaction to an emergency rather than planned.

Others, despite trying to stay in their own homes, were persuaded by family and professionals that a move was in their 'best interest' and had made such a move. For some this had worked well but for others there was resentment. The latter seemed more so when people had moved to a new place straight from hospital – many people found this very difficult to adapt to and seemed to have a poor sense of well-being and were not as positive as their peers. For example one lady had been moved into new housing from hospital and felt that the decisions were led by the professionals and family as opposed to her. Another had not been allowed to return home and had to live with her family which was not what she wanted. Both had a very poor self image and very poor outlook on life at the time of the interviews. They attributed their negative outlook to their lack of control and involvement in the decision making process.

Finances

Interviewees generally fell into two categories; those that still managed their own finances and those that had handed this over to relatives. The former group lived relatively frugal lives. They felt that they could not afford luxuries. The expression 'you live within your means' was common. Those who had handed their finances over to their relatives felt relief at having done this and expressed that it was 'one less worry'.

Those interviewed were less concerned with finances and were more concerned in talking about health and their support networks.

Notably they were not as open or free talking about their finances as their younger counterparts were. Some also expressed distress about having to reveal their finances to the council by way of means-testing. Linked to this was the stress of financial forms such as benefit applications.

Messages from the interviews for local commissioners

- Clearly for this more fragile group of service users, as compared to the focus group population, then mobility and independence are key definers of well being. Assessments need to be reviewed as to how far they take these factors into account and promote as normal a life as possible. Isolation is inevitably going to promote a feeling that a care home may be a preferable option.

- It was noticeable that although for some people major life changing events had occurred there were little or no opportunities to discuss the impact of these and to develop strategies to combat their effects. Events that for a younger age group would almost certainly produce an offer of counselling rarely seem to occur for older people suffering similar loss and trauma. Not only has this the potential to improve people's lives again it could be cost effective in terms of preventing acute admissions.

- The emphasis placed by both age groups on 'getting back to normal' requires a focus for commissioners on rehabilitation. This may be specific to particular conditions, such as stroke, or a wider need to ensure sufficient therapies, or services (such as intermediate care) to give older people the opportunity to regain optimum functioning.

- Sufficient support needs to be in place to be able to respond to AT calls or information. If not, this could actually hasten an admission to a care home. For example if an older service user with dementia is wandering continually at night and the key holders are the family this could put them under even more pressure. Therefore practicalities of AT within the complex community care matrix need to be given further thought.

- Preventative services such as podiatry need to be developed in greater proportion than the increasing numbers of older people, to take into account the current gaps and the future demand.

- Although only mentioned by a minority of interviewees, consistency of care staff is perceived as important, particularly where care staff conduct intimate tasks such as bathing or shaving etc. Consideration needs to be given by commissioners and providers as to how consistency over these tasks can best be achieved.

- With older people possessing increasing volumes of equity and wealth consideration needs to be given to how on the one hand people can best receive impartial and quality advice and on the other hand also be protected either from unscrupulous trades people, care agencies or relatives.

- Overall, for commissioners the message from this group is that assessment, primary care and care planning may deal with the capacity

to remain alive, fed and bathed but if a lack of attention is paid to quality of life issues it may not be a life worth leading.

Section D - Taking the approach forward

Introduction

Although only based on a relatively small sample this type of approach to consultation has now been trialled across three local authorities (one in the exemplar project and two in this piece of work) and with in excess of 200 people. The feeling was that:

- The focus group and the interview format made people think about what was important for their quality of life rather than just focusing on the services available.
- The focus groups and the interviews seemed to result in people feeling listened to and therefore appeared to be a good way of improving the relationships between the local authority and the local population.
- Both forms of data collection produced information that confirmed and added to the published literature and could beneficially contribute to commissioning strategies for older people.

This section aims to provide a step by step guide to the process of recruiting participants, conducting the interviews and focus groups and analysing the data. It divides into five sections:

- Identifying the sample
- Constructing and planning the interviews and focus groups
- Analysing the data

Identifying the Sample

Focus Groups

Whilst the number of participants and hence the number of focus groups to be run can be flexible, eight to ten groups involving between 80 and 100 participants seems a reasonable number for commissioners to aim for. In general groups below eight in number can tend to not have sufficient diversity to promote good discussion. Any more than twelve and some participants may feel intimidated from speaking in public.

It is important to recruit a range of participants that are representative of the local population aged 60 to 65 years old in terms of gender, socioeconomic status, tenure and ethnicity. Each set of commissioners will have different approaches to recruiting such participants. This may range from getting the cooperation of local offices of the Department for Work and Pensions, using bus pass lists, local libraries, shops and newspapers for recruitment.

Venues need to have good transport links, provide easy access for those with disabilities and appear agency neutral and not old age biased, ie not part of the local authority, health service or voluntary sector working with people in old age. Whilst some groups can be in the day time, some should be in the evening to allow people in work to participate. Finally it might be important to consider arrangements for those who are also full time carers to make certain that they too can participate.

At the venue it may be necessary to provide level space for wheelchairs and walking frames, a loop system and microphone amplification (one in three older people will have hearing difficulties), comfortable facilities with accessible toilets and adequate breaks. Plans should be made for how people will be welcomed on arrival, how refreshments will be served and how late arrivals will be managed.

It is better to have refreshments before the session begins. A break in the middle means the discussion loses momentum and at the end it may cause confusion over when the discussion terminates and may get in the way of the next group coming in.

Interviews

Interviews should be conducted with people who are current recipients of care at home. In terms of numbers interviews should probably cover a fixed percentage of the service user population. To maximise representation it may also be helpful to exclude people who regularly take part in consultations or lead for voluntary organisations that contribute to strategic thinking.

The interview process may require clearance from local ethics committees (this could take time) and independent facilitators for both the focus groups and the interviews should have had police checks and offer guarantees of confidentiality.

Constructing and planning the activity

Focus Groups

The aim of the focus groups is to understand from amongst the immediate pre-retirement age population their plans and thoughts about care and support in their old age. The information needs to be detailed enough for commissioners to use in planning what provision may need to be available for this group and on what kind of funding basis.

The focus group should be semi-structured and designed to run for approximately two hours. One facilitator should probably not aim to conduct more than two focus groups in one day. The focus groups need to be facilitated by a person independent from commissioners, to give confidence

to participants. The facilitators' task is to pose questions, seek clarification and promote dialogue between participants. An experienced note taker who is responsible for summarising the main themes should also be present. Tapes can be used although often a note taker seems less obtrusive and can act as a useful sounding block in testing results with the facilitator.

It is important to at least reimburse participants any expenses they may have incurred in attending and most focus group approaches would expect to give people some form of honorarium, commonly in the form of shopping vouchers. Some people who are disabled or who have personal assistants may need the authority to make alternative care arrangements in order for them to attend.

Table 1 gives a step by step account of the format for the focus groups. A full script can be found in Appendix Two.

Table 1 Stages of Focus Group Activity

Stage	Activity
Stage 1	Offer a general introduction saying that the discussion will be based around planning for older old age and the resources that people may bring to help them at various stages of their lives.
Stage 2	Ask participants to think fifteen to twenty years ahead and consider where they might be living, what financial resources they might have and what contact they may have with family, friends and neighbours.
Stage 3	Ask participants to read a description of physical incapacity. Now ask participants to imagine themselves in this situation and ask them to answer the same questions.
Stage 4	Ask participants to read a description of moderate dementia. Now ask participants to imagine themselves in this situation and ask them to answer the same questions.
Stage 5	Next ask participants to reflect on the different perspectives of their future lives that have been talked about and consider what kinds of services they might need or require to assist them in the above situations regardless of who paid for that provision.
Stage 6	Having identified the types of services people feel they might need ask participants which of these services they are willing to pay for.
Stage 6	At the end of the discussion thank participants for their involvement and ask them to complete a brief anonymous

Stage	Activity
	questionnaire which identifies their age, gender, whether living with a partner or not, their assets and whether they have cared for an older friend or relative for more than 5 hours per week in the last 2 years (Appendix Three).
Stage 7	Finally participants might receive some payment for participating depending upon the usual practice of the local authority.

Interviews

The interviews should be conducted with existing service users and can take anything from thirty minutes to one hour and thirty minutes depending on the health, communication ability and how much information the interviewee wishes to share. It is unlikely that the interviewer will be able to complete more than four interviews in one day.

The interview format is designed to tease out information about changes to the person's quality of life as they have aged. Appendix One outlines a question and discussion framework template designed to facilitate the interviews. However, the template is to be used only as a framework, to understand how people lived their lives before, how they have changed, why and how this has affected quality of life and well-being. It is not an exhaustive list and the interviewer should use it simply as a guide and draw on the appropriate sections taking lead from the older person's answers. It may be important that carers (paid or otherwise) are present when the interviewer arrives to make sure that the interviewee is still happy to participate in the interview. However, it is preferable if the interviews are conducted without the carer present. This is because those being cared for may not always be honest in their answers for fear of offending those caring for them and this can therefore have an impact on the quality of information collected.

Analysing the Data

In analysing the data it is important to remember that the aim of engaging in this approach is that the collated information will feed into the design of local commissioning strategies.

Focus Groups

The information collected from a focus group via the note taker should provide a comprehensive record of the discussion. The aim of the analysis is to look for trends and patterns that reappear among various focus groups. Themes can be identified by paraphrasing common ideas or comments*.*

Interviews

The initial task in analysing the interview data is to find overarching concepts that help make sense of what is going on in the scenarios documented by the individual interviewees. From the interviews' notes, patterns of experiences can be listed. Themes can be identified by bringing together components or fragments of ideas or experiences, which often are meaningless when viewed alone. Themes that emerge from the interviewees' stories can be pieced together to form a comprehensive picture of their collective experience.

The interviews may offer two sorts of material:

- Reviewing responses in terms of the actual provision a person receives as compared to what provision could have been offered or developed that would more effectively have met that person's needs. This may have an impact on reconfiguration of the actual care package offered to that person.
- A range of wider themes which can offer a view as to how the needs of individuals may be better captured and from which improved or different service provision can be developed.

Appendix One

Interview Question and Discussion Template for Individuals in Receipt of Care at Home

Notes for the interviewer

Introduce yourself and explain that the interview will take approximately 1 hour 30 mins.

Explain that questions will be asked about different areas of their life including friendships, activities and health.

Reassure them that if they do not want to answer a question(s) that you will honour this and likewise if they want to terminate their interview you will respect their wishes.

1   Can you tell me a bit about yourself / background?

2   Health and Functional Ability

2.1. Mobility

What is your mobility like?
Has it changed? Why do you think this has this changed?
What impact has this had?

2.2. Daily Living

What tasks did you use to do?

- Food shopping
- Cleaning
- Washing up
- Cooking
- Laundry
- Personal care (bathing, haircuts etc)

What do you do now?
Why has this changed?
Who was the decision maker and were the change(s) desired?
What impact has this had?

2.3. Health

What did you use to do re:

- Toenails
- Exercise
- Medication
- Teeth
- Other health issues

What do you do now?
Why has this changed?
Who was the decision maker and were the change(s) desired?
What impact has this had?

3   Home and Neighbourhood

3.1. Housing

(The past tense is relevant if the older person has had a recent move if not the present tense will apply - enquire as to changes within their current set-up that may have happened due to ageing)

Where did you live? What was the accommodation like? How did you manage the maintenance of the home / garden? DIY? Did you feel safe in your home? What made you feel safe / unsafe?

Where do you live now?
Why did this change?
Who was the decision maker and were the change(s) desired?
What impact has this had?

3.2. Neighbourhood

(The above past tense is relevant if the older person has had a recent move if not the present tense will apply - enquire as to changes within their current home/ environment that may have had an impact on their lives)

What was the neighbourhood like?
Did you feel safe in the neighbourhood?
What made you feel safe / unsafe?
What is your current neighbourhood like?
Why did this change?
Who was the decision maker and were the change(s) desired?
What impact has this had?

4   Social relationships

4.1. Family

What family relationships did you have (long-term partner, children, grandchildren). How often did you see them? What sort of things did you do with them?
What do you do / who do you see now?
Why has this changed?
Who was the decision maker and were the change(s) desired?
What impact has this had?

4.2. Friends

What friends did you have? Where did you meet them?
Social groups? Neighbours? Religious Centre?
How often did you see them? What did you do with them?
What do you do / who do you see now?
Why has this changed?
Who was the decision maker and were the change(s) desired?
What impact has this had?

5   Activities and hobbies

5.1. Hobbies and Personal Development

Were you involved in social groups/ educational courses?
Did you go on holiday? Where to? Who with?
Weekends away? Day trips? Meals out? Shopping? Theatre? Etc.
What things do you do now?
Why did these things change?
Who was the decision maker and were the change(s) desired?
What impact has this had?

5.2. Transport

How did you use to get out and about? Car? Bus? Taxi? Etc
What do you do now?
Why did this change?
Who was the decision maker and were the change(s) desired?
What impact has this had?

6   Social roles and responsibilities

6.1. Work (paid or unpaid)

Did you work?
What do you do now?
Why did this change?
Who was the decision maker and were the change(s) desired?
What impact has this had?

6.2. Caring Roles

Did you previously have any carer roles / responsibilities? Children?
Grandchildren? Partner?
What do you do now?
Why did this change?
Who was the decision maker and were the change(s) desired?
What impact has this had?

6.3. Community / Civic roles

Did you previously have any community / civic roles? Run a social / support
group? Involved in a community scheme? Part of a local organisation?

What do you do now?
Why did this change?
Who was the decision maker and were the change(s) desired?
What impact has this had?

7   Finances

How did you manage your finances?

- Paying bills
- Paying mortgage/ rent?
- Income?

How do you manage them now?
Why did this change?
Who was the decision maker and were the change(s) desired?
What impact has this had?

8   Psychological wellbeing and outlook

8.1. Self-esteem

How did you feel about yourself? What words would you have used to describe yourself?
How do you feel now? What words would you use to describe yourself now?
Why has this changed?
What impact has this had?

8.2. Outlook

How did you feel about life? What words would you have used to describe life?
How do you feel about life now?
Why has this changed?
What impact has this had?

Appendix Two

Focus Group Script

(2 hours)

INTRODUCTION (10 mins)

Hello my name is ……………. and thank-you very much for attending today. Before we move on it is important just to go over some house-keeping arrangements:

We have up to 2 hours for this discussion.
The toilets are….
Fire alarms
Mobile phones please turn off/ or on to silent

Individual introductions – first name only please

Thank you for agreeing to participate in this discussion.

The local authority/ PCT are interested in forming a picture of what services and support older people in ………… will want in 15-20 years time to ensure that their health housing and social care needs can be met.

We hope that you can help us today by talking about what you think your life may be like in 15 to 20 years time. You may have already thought about this and have a very good idea about where you think you may want to live or who will support you as you get older – it would be really helpful if you could share this with us.

We hope that you will find the questions we pose interesting and help you to think what you may need as you get older. If at any time during the session you feel affected by the discussion and would like to take a break from the conversation, please feel free to leave the room and one of us will make sure that you are ok.

We will be noting down your comments and we may also record some of the discussion today so that we can develop our findings into a report. The council will happily provide you with a copy of the report if you so wish. You will not be identified by name in the report.

30 mins	**General Views About Old Age**
	The following should be written on page 1 of the Flip Chart :
	We would like you to think about your life in 15/20 years time, for example:
	■ Where will you live?
	■ What kind of social life do you think you might have, what type of hobbies and leisure activities will you be pursuing?
	■ Who do you see yourself having regular contact with, family, friends etc.
	■ Will you be financially healthy?
	(Some groups at this stage will move straight into discussion. If the facilitator feels the groups need prompting the following scenario may be used).
	I am going to read you a short description of someone's life at this stage – We can then reflect again on the questions.
	Read ….
	Louis and Margaret are looking forward to their retirement and old age. They both feel that they have got over the difficult periods of their lives – the work, the children, the house etc. – it's now time to enjoy themselves. "We are not going to be like the grumpy old men and women we see on television – we are going to remain open minded, free spirits and welcome what life throws at us with open arms"
	They are both in reasonably good health, they have had their fair share of ups and downs but nothing too serious – keep fit and healthy a motto they hope will stay with them.
	They have seen their children through university and have paid off their mortgage, good albeit small pensions and some savings, it will be sufficient to give themselves and their children the occasional treat. Louis says "I've worked hard for this, I'm going to enjoy spending it, maybe a few small holidays and a few changes to the house, nothing too fancy or extravagant"
	"We have made some good friends over the years, a few close friends from church and the usual acquaintances – we tend to rely more on each other, we've had to and now that the children have left home we need to even more"
	So looking at the questions (on page 1 of the flip chart) again ....

20 mins	**Physical Incapacity** So we now have a general picture of your life. What we would like to think about now is how would a change in your physical health affect you? I will again read you a short case study and ask you to reflect back on our earlier discussion of your life in 15- 20 years time. **Read ….** Kalia and Aysen are in their mid-seventies, they have lived in their 3 bedroom family home for the last 40 years. Recently Aysen suffered a stroke and after a spell in a Stroke Unit returned home. The Doctors said Aysen has reached her 'rehabilitation potential' and there is little rehabilitative input now she is back home. Whilst she does not need a wheelchair, she now relies heavily on a walking stick and now can just about manage the stairs and has obviously noticed a considerable change in her mobility. She tires very easily and is now unable to do the shopping and cooking. **Change the flip chart to page 2** **The following information should be written on page 2 of the flip chart :** Given this scenario: ▪ Where you live and the type of house you live in? ▪ Your support network – family, friends and possible carers? ▪ Any possible changes to how you may spend and save your money or how you may use your assets?
15 mins	We would like to consider the same questions in another scenario. What changes do you think may be needed if your partner were to become similarly incapacitated or if you were now living alone. **Read ….** Louis and Margaret have not been so fortunate with their health of late. Margaret has been suffering with severe arthritis in her legs and hands. She has difficulty getting out of bed and has not left the house in months. Louis though in slightly better health has found looking after his wife a strain and has not got a good night's sleep for weeks because of Margaret's care needs. Because of all the effort he is putting into looking after his wife, his own health is starting to suffer. **(Again use the questions on page 2 of the flip chart 2)**

15 mins	**Mental Health**
	We have considered physical changes and how these may impact on your life, we would now like to move to possible changes to your mental health and in particular for you to consider how you may need to deal with dementia.
	When we talk about dementia, we normally say that there are three types – mild, moderate and severe.
	First of all, let me give you some details about dementia.
	With moderate dementia, it's slightly more obvious than mild dementia and the problems are more apparent and disabling.
	■ Be confused regarding time and place. May go out shopping at night
	■ Become very clinging
	■ Forget names of friends or family, or confuse one family member with another
	■ Forget saucepans, kettle. May leave gas unlit
	■ Wander around the streets, perhaps at night, sometimes becoming completely lost
	■ Be neglectful of hygiene or eating, perhaps saying they have had a bath or a meal when they have not
	■ Become angry, upset or distressed very rapidly.
	Now I will read you a case example:
	Mrs Patterson who is now 82 recounts a recent trip into the town centre. She says "I had been looking forward to meeting my friend for coffee at that smart new coffee bar all week and had managed to sort out all the bus times, when I find myself in an unfamiliar part of town. I was not sure of how I got there and even more worrying where I was supposed to be going. I felt all panicky and worried about what was happening to me. I was fortunate that a young lady asked me if I was okay before ringing my Les to get my son to pick me up"
	So again. I would like you to discuss how you feel your life will change
	Gesture again to the questions on page 2 of the flip chart

10 mins	**Next, we need to consider severe dementia.**
	With severe dementia the person is severely disabled and needs a great deal of help. They may:
	■ Be unable to find their way around
	■ Be unable to remember for even a few minutes that they have, for example, just had a meal
	■ Be incontinent of urine and/or faeces
	■ Show no recognition of friends and relatives
	■ Need help or supervision with dressing, feeding, washing, bathing and using the toilet
	■ Fail to recognise everyday objects
	■ Have difficulty walking, perhaps eventually becoming confined to a wheelchair.
	So how do you think these may impact on your life?
	Again relate to the questions on page 2 of the flip chart

15 mins	**Service Needs**
	So we have looked at the possible physical and mental changes that may occur in older old age. We would now like to talk about what kinds of help and support you might need.
	Write the following questions on page 3 of the flip chart. Use these questions to facilitate the discussion about services.
	Think of the kinds of problems you have talked about and the resources you have to tackle those problems. What are the gaps?
	When do you think you might need help from health and social care or from other sources.
	What things do you feel would be most important to you to maintain?
	Which services would be so important that you would be prepared to pay for them?
5 mins	Before you go we would like you to provide some very basic information anonymously about yourself, this will be used to build a simple profile of the people we are seeing from the four groups today. **(Hand out questionnaire)** Please fill these out and hand them to me as you leave.
	Thank you very much for attending / and goodbyes.

Appendix Three

Focus Group Questionnaire

Please provide the following details				
Age				
Gender				
Ethnicity / Religion				
With partner (whether married or not)	**Yes**		**No**	
Assets (please indicate yes or no)	**Own Home**	**Private Pension**	**Employment Pension**	**Savings over £20,000**
Have you cared for an older friend or relative for more than 5 hours per week in the last 2 years	**Yes**		**No**	

This information will be used only for the purpose of describing the general characteristics of the focus group. Individuals will not be referred to in the report.

Thank you