

Increasing the Voice, Choice and Control of Older People with High Support Needs

A Research Findings Paper from the South East Regional Initiative (SERI)

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Summary

This report shares the findings and lessons from a qualitative research study focusing on the experiences and aspirations of older people with high support needs – about their lives, their support and the choice and control they have in relation to this support.

Background

Following the launch of the Independent Living Strategy¹ in March 2008, the South East Regional Initiative (SERI) was designed to demonstrate and measure the effectiveness of investing in independent living for older people with high support needs. This work focused on increasing the voice, choice and control of older people living in care homes and those at risk of moving into care.

The Office for Disability Issues (ODI) commissioned two concurrent programmes of work to deliver this goal, which, together with the design of quantitative data collection and analysis, comprised the Regional Initiative:

- Providing change management support to local authorities, statutory and non statutory partners and local communities in 3 sites in the South East: Portsmouth, Oxfordshire and West Sussex
- Independent qualitative research to build the evidence base of what works in increasing the voice, choice and control of older people with high support needs.

This report shares the findings and conclusions drawn from the qualitative research, and builds on those shared in an interim report produced in April 2010. The interim report is summarised in an 'Insights' publication available on the [NDTi website](#). These

¹ Independent Living Strategy: a cross government strategy about independent living for disabled people, Office for Disability Issues, March 2008

findings have also informed the overarching themes and conclusions from SERI, which are published in a separate report, “The SERI Story: outcomes and lessons from increasing the voice, choice and control of older people with high support needs” (accessible through the [ODI](#) and [NDTi](#) websites).

Research aims

The overarching aim of the qualitative research was to find out and record the impact of increased voice, choice and control on individuals’ experiences and opportunities for independent living. This included finding out what changed for older people with high support needs living in care homes and those at risk of moving into a care home, as a result of the work carried out within and across the three sites. Details about those work programmes are provided in [Appendix 1](#), and in the overarching ‘SERI Story’ report referred to above.

The research focused on two main questions:

1. What are the experiences and feelings of voice, choice and control like now amongst these two populations; and what are the key influences on these experiences and feelings?
2. What is changing or has changed as a result of the mechanisms, interventions, options and opportunities for increasing the voice, choice and control of older people with high support needs? What has helped or hindered?

It built on evidence from research funded by the Joseph Rowntree Foundation² which presented older people’s vision of what a ‘good life’ looks and feels like to them. The “Keys to a good life for older people with high support needs” - as this vision is known - were used in the current research to inform the design of the methodology and to analyse the findings.

² Older people’s vision for long term care, Bowers et al, November 2009, Joseph Rowntree Foundation, www.jrf.org.uk

The six Keys are:

1. Personal identity and self esteem
2. Meaningful relationships
3. Personal control and autonomy
4. Home and personal surroundings
5. A meaningful daily and community life
6. Personalised support and care

Methods

In total, 63 older people with high support needs took part in the research. Over the research period a total of 99 research interactions were carried out, including interviews and focus groups. These interactions took place either once, twice or three times with each person. This sample of 63 people had the following characteristics:

- There was a fairly even distribution of participants across the two target populations, although more repeat interviews took place with people living in care homes; the neighbourhood workstreams took longer to get going, leading to delays in identifying and recruiting appropriate participants;
- Of the 63 participants, 40 (63 per cent) were female, and 23 (37 per cent) were male, mirroring population figures for the South East of England as a whole, where the gender proportions for a similar distribution of ages are 65 per cent and 35per cent respectively³;
- The majority (41 per cent) were aged in their 80's at the time of the research; 32 per cent were younger than 80 (the youngest was aged 60) and 27 per cent were 90 or older (the oldest being aged 100);
- 24 participants (38 per cent) had been diagnosed with dementia, or another cognitive impairment – although this

³ Based on 2001 census data for South East England, Office for National Statistics, <http://www.statistics.gov.uk/census2001/pyramids/pages/j.asp>

- proportion was much higher among female participants (48 per cent) than among male participants (22 per cent);
- A small ethnic minority was represented in the sample, with one participant being of Caribbean ethnicity, and three participants of non-British, European ethnicity.

We did not collect detailed information about participants (e.g. housing tenure, nature of funding for support received) unless participants offered this information themselves. Our focus was on their experiences, expectations and aspirations for exercising choice and control over any support they receive.

Six Core Findings

Six core findings emerged from a cross cutting analysis of the detailed findings relating to each round of fieldwork. These findings apply equally to older people with high support needs living in care homes and those living in their own homes at risk of moving into care.

1. Living a normal life

This finding links in particular to personal identity, personal authority and control, and having a meaningful life - three of the six keys to a good life identified in earlier research. Older people with high support needs participating in the research wanted the opportunity to 'live a normal life'; to be part of daily routines many of us take for granted and to contribute to the community and society they live in. Three specific features of this finding are highlighted in the main research report, including:

The importance of contact with peers and with other generations

Older people with high support needs want to have contact with people of different ages and different generations; encountering people of all ages is part of the experience of living 'a normal life' and we heard many stories from people who desperately missed having close relationships with young people.

Handling money

Living a normal life and being able to exercise voice, choice and control includes being able to handle and use money. One woman with dementia living in a care home told us how she had been out for tea with friends but felt dreadful that she had no money to pay for it, “I think someone took me out once and I felt awful – I didn’t have any money to buy them a cup of tea”.

Keeping physically fit and healthy

Some form of exercise or physical activity is a feature of normal life, which people with high support needs often lose the opportunity for, e.g. through carrying out daily chores such as housework and shopping.

2. Maintaining an individual identity

A dominant theme throughout the research was that older people with high support needs are individuals, with unique experiences and histories that have shaped their lives and affect how they respond to their current circumstances. This was central to people retaining their personal identity and autonomy, having a voice, and exercising choice and control in their lives. As a research team we found it was not difficult to find out about people’s identities - who they are and what is important to them - although there was evidence that this was not happening as a rule. One care staff member, when she heard about one woman’s love of painting, was astonished that she had not known this about her, in spite of being involved in her care for some time.

3. Belonging

A further common finding was older people’s need to belong to personal networks that are meaningful to them; to contribute to interests and activities outside their homes; and to be a part of family and community life. For people living in their own homes, the presence of informal support networks was a key factor to them remaining in their own home. Networks were also important to care home residents, particularly those in the locality closest to

their home. Many of the people we met told us they were either living in care homes away from their familiar locality, or they were no longer part of local community or family life. Loss of networks or close family and friends was a great sadness to the people we met, particularly those with dementia or memory loss. It was also a loss to the family members we met, who often felt as though their loved one was being rejected or forgotten, for example when neighbours or friends forgot to ask after them.

4. Aspirations and hopes for the future

Some participants had very clear hopes and aspirations for their current and future lives, although at times they were reticent to express them. These aspirations covered a wide spectrum of interests, activities and relationships. Many people we spoke to had wishes that they did not expect to see fulfilled, although it did not take away the desire or need to hope and look to the future; and for some of our interviewees it was painful to talk about lost dreams. We met people living in care homes whose main aspiration was to continue living where they are now, and who were fearful of change. We also heard from a number of people who were worried that if they needed more personal care then they would have to move, either from their own homes to a care home, or from a care home where they were established and happy.

5. Permission and power

This finding focuses on the question of who holds the balance of power in relationships with or involving older people with high support needs? It highlights the precariousness and uncertainties of many people's situations, including not knowing what the rules are, or who makes the rules when you live in a group situation. Examples (from people living in care homes) included not knowing if they could go into the garden, whether and how they could invite someone to lunch, or if relative could take them home for a visit. Similar feelings were shared, although less frequently, by those living at home.

One man commented ruefully on the 'inevitability' of his loss of privacy and feeling of control over his own home as "too many people have access" (he was referring to people's knowledge of his key code). One of the main issues which emerged from this analysis was the distinction people drew between being 'cared for' and being 'cared about'. We found particularly in care homes and in day centres that older people, their relatives and carers often did not feel empowered to speak up, and did not know what they could or could not ask for.

6. Choice and control over finances

The sixth finding, choice and control over personal finances, links strongly to people's feelings of personal authority and control, and whether they felt they had a voice or choice in the way their lives were run. It was a dominant theme in the care home and community interviews. The amount of control people had over their finances was very varied. We met care home residents (the majority of whom were men) who were in full control of their finances, suggesting a gender difference in roles within this particular generation. This also challenges popular stereotypes of older people with high support needs who are often considered unable to manage or control their own, often complex, financial arrangements. One man we met in a care home manages his financial affairs online and has regular visits from his accountant. Another who was caring for his partner at their home and who had significant support needs himself, was also actively managing his business involving a number of companies. All those interviewed who were living at home had access to money /funds for their own personal expenditure even if they did not directly manage them, in contrast to the experiences of participants living in care homes.

Five Key Messages

Five overarching messages have been distilled from looking across these findings and identifying the dominant, emerging themes.

Firstly, it is evident that older people with high support needs wish to live a 'normal life', including contact with friends, family members, people of all generations in local neighbourhoods, and being a part of social networks. The older people we met have aspirations, and for some people, a strong sense of longing to be a part of the everyday activities associated with having a 'normal life' with opportunities for maintaining a healthy, active lifestyle. This includes being able to manage and use money on day to day expenditure, as well as on significant decisions such as where, how and with whom to live. In spite of these clear aspirations, there is a very low set of expectations among the current generation of older people with high support needs with regards to their right to a good life with choice and control over their own personal support. This was clearly influenced by the predominantly low expectations and aspirations found amongst the different people who were in touch with or 'caring for' the people we met, including family members, care staff, neighbours.

Second, isolation and loneliness remains a significant issue⁴ for older people with high support needs - both for those living in care homes and those living at home. Loss of (and lack of contact with) peers (both relatives and friends) reduces people's social networks in later life; we met many older people whose relatives and friends

⁴ Age UK Oxfordshire (2011), Safeguarding the convoy: a call to action from the Campaign to End Loneliness; Victor, C, Bond, J, Scambler, S (2009), The Social World of Older People, Open University Press, Maidenhead; Victor, CR, Scambler, SJ, Bowling, A and Bond J. (2005), The prevalence, of, and risk factors for, loneliness in later life: a survey of older people in Great Britain, Ageing and Society, 25 (3), pp357-76; Cattán, M. (2010), Preventing Social Isolation and Loneliness among Older People, Lambert Academic Publishing Saarbrücken; Department for Communities and Local Government (2006), Sure Start to Later Life: ending inequalities for older people. A social exclusion unit final report.

had either died and/or no longer kept contact with them. There was also isolation from familiar places including people's homes, local facilities and community activities, which all added to a sense of disconnection from community and daily life. The few older people in care homes that we met who belonged to wider networks of friends and family, seemed able to retain more of their own sense of identity and have more meaning in their lives. The older people we met who were involved in the community workstreams appeared to have more extensive and stronger, informal support networks which were crucial in enabling them to remain living in their own homes.

Third, people of all ages and stages of life have different life histories and different experiences – but the importance of older people's histories and life experiences cannot be overstated for those who need a lot of support in their lives. Professionals of all backgrounds, disciplines and levels (from care worker through to consultant physicians, housing tenancy officers to commissioning leads) need to focus their support and their services on engaging and listening much more closely to older people and the people in their lives, in order to get to know and really understand what's important to individuals as well as whole communities. The role of gender and ethnicity in particular, were highlighted in relation to how voice, choice and control is exercised if support needs increase or people move to live in accommodation which is not their own. We saw examples of clear differences in the way men and women adapted to care home life, although this was rarely acknowledged. We believe a greater understanding of this is required in order to address this issue more effectively. We met people from different cultural backgrounds who told us how difficult it is for them to express and retain their sense of self and identity if their cultural heritage is not acknowledged or understood. This links to hearing people's stories and understanding the importance of life course for older people – how earlier life experiences may be impacting on people's lives, circumstances and choices now.

Fourth, knowledge and information, and support to use information tailored to individual needs and circumstances, is crucial for exercising voice, choice and control. We met a number of people

who were struggling to find out about and access information that would enable them to retain control and make informed choices. A key message was the over-riding need for personal support to make sense of the wealth of information that does exist; and the need to trust the information giver and provider of that support. Those workstreams that focused on this aspect of independent living had clearly understood the centrality of this issue in enabling older people with high support needs to exercise choice and control, and the steps they were taking to improve and adapt their provision was welcomed. The nature, style and quality of communication clearly influenced people's ability to make individual choices about how they live their lives. This includes recognising the importance of the senses; the people we met with hearing loss and sight problems demonstrated how this affects their ability to exercise voice, choice and control. It also includes the importance of carers and care staff taking time to really listen to what is being said or communicated by the person – both verbally and non verbally. This was often overlooked either because of their focus on physical tasks or belief that a person could not communicate their wants and wishes if their verbal language was minimal or non linear.

Finally, older people with high support needs feel powerless in many of the situations they find themselves, and this power differential with professionals and family often goes unrecognised and/or unacknowledged. This can be overcome by prioritising and strengthening mechanisms for older people to be equal partners in all aspects of decision making, and ensuring they are supported to find solutions to living their life in the way that makes sense to them. The focus on increasing the individual and collective voices of older people with high support needs within SERI has helped to shift attitudes at all levels of local service systems, in specific settings and within local communities, but our discussions with individuals involved in this initiative have confirmed that this is the start of a very long journey.

Lessons from Doing the Research

In addition to these five messages, a number of important lessons are highlighted in the full Findings report, sharing insights gained from the overall experience and specific aspects concerning the methodology with a view to informing both changes in practice and future research.

Clarity and familiarity with the research subject

The research team were aware from early planning stages through to interviews and conversations with research participants, that the research challenged a number of people. Specific lessons from undertaking the research include:

- The need to adapt language and provide examples in order for 'independent living' and 'voice, choice and control' to be meaningful to different participants, consultees and staff.
- The need to raise expectations about older people with high support needs (especially those living with dementia) being able to participate in research.

Focusing on unheard voices

Our commitment to communicating directly with the older person with high support needs in this study:

- Challenged some perceptions exposing embarrassment and low expectations of professionals, relatives, friends and neighbours
- Was aided and strengthened by the ethical approval processes
- Empowered older people, helping them to feel valued
- Was welcomed by families and carers, once it had been explained, who then worked with the research team to enable their friend or relative to have their voice heard

Including older people with dementia in research

We learnt a great deal about involving people living with dementia in research, including insights into how people's thoughts, views and experiences about complex issues can be gathered where communication is difficult. Whilst there is a significant body of literature about engaging with people living with dementia (see Chapter 4), we found that expectations and attitudes were still firmly of the view that people with dementia either have nothing to offer the research process or cannot be engaged in any meaningful way. We also found that participants wanted to be involved, enjoyed the process and enhanced our understanding of their situations.

The need for flexibility in the design of research over time
Specific issues that require attention in the design and implementation of future research to ensure this is productive for everyone involved, include: how to establish and track changes over time when working with people living with dementia who may be living in different places and times; and accommodating participants' changes in health and circumstances, including patterns of communication and memory recall.

Repeat interviews and continuity

Participants often remembered us between research visits, which was very encouraging. This ranged from people having "some recollection" of us from previous visits, to people becoming familiar friends and inviting us round to tea. As one team member described, "Being remembered – and trusted – felt good".

Involving consultees; families / friends / neighbours / carers

Involving a third party at times helped us to reach and hear the participant's voice, although in some situations the consultee's own voice dominated. In most cases, the role of family and friends as 'proxy' or additional voices for participants was invaluable. There were a few people where, despite our best efforts to communicate with the primary participant, the main interviewee

became the carer. However this gave those carers a rare and valued opportunity to tell their own story and know that they, also, were being listened to.

Role modelling co-production in the research team

The research team consisted of four members with a rich mix of ages, knowledge, experience and perspectives. This team approach was built into the design of the research, and enabled:

- Interviews to be carried out by sensitive, experienced peers, leading to rich, insightful data
- Interviewers to work in pairs ensuring effective use of interview and participant time, consistency of approach and reliability of findings between team members
- A learning environment where different perspectives were brought forward, providing rigorous challenge and debate.

Areas for Action

Chapter 5 of the full report outlines the potential areas for action to ensure that the findings, messages and lessons highlighted in this report are addressed – both in terms of future research in this area, and in improving the life chances and experiences of older people with high support needs.

There are three main areas for action identified from reviewing the findings, messages and lessons. These actions relate to:

- i. Specific issues identified in the findings and key messages
- ii. Lessons learnt from the design, methodology and experience of undertaking the research
- iii. The use of data, research tools and resources developed for SERI.

Chapter 1: Introduction

1.1 Purpose and Background to the Research

Following the launch of the Independent Living Strategy in March 2008, the South East Regional Initiative (SERI) was designed to demonstrate and measure the effectiveness of investing in independent living for two specific groups of older people with high support needs: older people currently living in care homes and those living at home at risk of moving into care.

The Office for Disability Issues (ODI) commissioned two concurrent programmes of work to deliver this goal, which, together with the design of quantitative data collection and analysis, comprised the Regional Initiative:

- Providing change management support to 3 sites in the South East: Portsmouth, Oxfordshire and West Sussex (see [Appendix 1](#) for details of this work)
- Independent qualitative research to build the evidence base of what works for older people with high support needs.

This report shares the findings and conclusions drawn from the qualitative research, and builds on those shared in an interim report produced in April 2010⁵.

The overarching aim of the qualitative research and analysis was to find out and record the impact of independent living (increased voice, choice and control) on softer outcomes such as individuals' experiences and feelings of choice and control, for the two target groups. This included finding out what changed for older people with high support needs living in care homes and those at risk of

⁵ Insights 3 - Increasing Voice, Choice & Control for Older People with High Support Needs, NDTi (2010), <http://www.ndti.org.uk/publications/ndti-insights/insights-3-increasing-voice-choice-control-for-older-people-with-high-suppo/>

moving into a care home, as a result of the work carried out within and across the three sites, outlined in [Appendix 1](#).

This report therefore contributes to the outcomes and overarching messages presented in the separate, final report on the South East Regional Initiative, “The SERI Story: outcomes and lessons from increasing the voice, choice and control of older people with high support needs”⁶ (ODI, 2011).

In addition to this Findings Paper and the SERI Story report, an accompanying, web based Resource Pack is also available which includes the practical details, resources and tools used during the research process. This can also be accessed at the [NDTi website](#).

The research focused on two main areas of enquiry, or primary research questions:

1. What are the experiences and feelings of voice, choice and control like now amongst these two populations; and what are the key influences on these experiences and feelings?
2. What is changing or has changed as a result of the mechanisms, interventions, options and opportunities for increasing the voice, choice and control of older people with high support needs? What has helped or hindered?

Sixteen subsidiary research questions were identified from examining these lines of enquiry, which are listed in [Appendix 2](#).

The research built on evidence from previous research funded by the Joseph Rowntree Foundation⁷. This evidence presented older people’s vision of what a ‘good life’ looks and feels like to them. The “Keys to a good life for older people with high support needs” - as this vision is known - were used in the current research to

⁶ Integrated report on South East Regional Initiative, Office for Disability Issues, 2011, <http://odi.dwp.gov.uk/odi-projects/independent-living-strategy.php>

⁷ Older people’s vision for long term care, Bowers et al, November 2009, Joseph Rowntree Foundation www.jrf.org.uk

inform the design of the methodology and detailed research questions, and to analyse the findings. The six Keys are:

1. Personal identity and self esteem
2. Meaningful relationships
3. Personal control and autonomy
4. Home and personal surroundings
5. A meaningful daily and community life
6. Personalised support and care

1.2 The Research Team: modelling co-production in research

An important feature of this research was the make up and style of the research team. There were 5 team members consisting of two older people, one of whom has high support needs, two senior researchers and one team member who focused on co-ordinating the fieldwork administration from an office base. This role was particularly important for supporting a remote team of researchers who were doing three rounds of fieldwork, across three sites and seven workstreams.

The research team demonstrated a model of co-production in research. The rich mix of ages, knowledge, experiences and perspectives generated valuable insights and enabled important learning to emerge about the lives of people whose voices are seldom heard in research. The team worked very closely together throughout the whole process including developing the research framework, designing the research tools, carrying out the interviews with older people with high support needs, analysis and report writing.

We had regular face to face and telephone team meetings and shared our experiences through the use of reflective diaries (see [Appendix 3](#)). The research team also attended regular action learning events held with the SERI sites, members of the change management team providing support to them, and representatives from the Project Board including Directors and senior leads from

the Government Office of the South East; the support of the project board and analytical advisory group was important in brokering access to different settings and sharing the emergent and final analysis of findings to key partners and stakeholders across the region beyond the three sites.

1.3 Purpose and rationale for the qualitative research design

The research was carried out in the three local authority areas participating in the Initiative - Oxfordshire, West Sussex and was designed to directly capture the experiences, feelings and perceptions of older people with high support needs who were directly involved in or affected by these developments.

It was not conceived of or designed as a service evaluation, which would have looked at a number of perspectives in order to attribute and understand the processes of change; the change management and quantitative data analysis, referred to above, focused on these aspects of the demonstration project, and the final “SERI Story” report covers these aspects of the Initiative. The focus, therefore, of the qualitative research programme was to understand and present back the direct voices and experiences of the target populations.

1.4 Linking the Research to the Changes taking place

Establishing a baseline and measuring change over time proved challenging in the research on its own, but in combination with the review of ‘what worked’ in the change management programme (see the final overarching SERI Story report) the picture does become clearer.

The qualitative research sought to identify what enabled voice, choice and control for the two target populations, and for this

learning to inform change programmes such as SERI by contributing to the evidence base of 'what works'.

The care home workstreams got going first, meaning that the research fieldwork could accommodate three time-points of qualitative data collection. The four community based areas of focus took longer to get started (leading to delays in recruiting the research sample), so the research team adapted their design and completed two cycles of fieldwork and analysis for these work streams.

In the care homes that were visited in all fieldwork rounds, we observed and heard about examples of good practice. In one care home that was visited in both round one and two, we saw (in the second visit) evidence that routines had been changed to respond to older people's preferences and priorities for support to do the things that matter to them. For example, many people wanted to get involved in and contribute to the gardening and other tasks associated with running the homes where they live.

All fieldwork across all workstreams was completed by end September 2010; the final analysis and synthesis of findings, lessons and key messages was undertaken in October and November, and shared with sites and Project Board members during December 2010.

Chapter 2: Methodology

2.1 Research Questions and Overall Design

The central question at the heart of this research programme was:

“What is different for the two target populations of older people with high support needs within and across each site, during the course of the Regional Initiative?”

Addressing this question requires a detailed understanding of the following two issues (which formed the secondary questions or key areas of enquiry):

1. What are individuals' experiences and feelings of voice, choice and control like now; and what are the key influences on these experiences and feelings?
2. What is changing or has changed as a result of the mechanisms, interventions, options and opportunities for increasing the voice, choice and control of older people with high support needs? What has helped or hindered?

Research activities to answer these questions were carried out in 5 phases spanning the period from November 2008 to December 2010, with fieldwork within sites starting in July 2009. [Appendix 4](#) contains the details of these activities by phase.

2.2 Securing Ethical Approval

Ethical approval was awarded in July 2009 by the South East Research Ethics Committee (a committee with particular expertise in issues around capacity to consent). The team were commended on the tools and protocols they had developed, and the sensitive way they were proposing to engage and communicate with participants. Although the ethical approval process was time consuming and resulted in initial delay to the fieldwork, it involved

the detailed design of processes that would have had to be developed at some stage during the research – and thus helped to ensure that these processes had been well thought through and were ethically sound.

Subsequently, gaining ethical approval had unexpected consequences. At times during the fieldwork we were challenged about our methods for ensuring older people with high support needs had a choice over whether they were involved and enabled to have their own voice heard. Having an ethically approved process to constantly refer back to enabled us to stick to these processes and maintain rigour in the face of these real life challenges, diversions and complications. Hence the ethical approval process helped us to achieve our research goals of enabling previously unheard voices to be heard.

The need for ethical rigour also threw up challenges within the research, including making recruitment processes more complex. For example, having to rely on sites to make the first contact with potential participants, along with the difficulties around balancing the need to supply people with the necessary information without swamping or confusing them. Minor changes were made to participant information sheets as a result of feedback from the sites, but the fundamental messages and details of the research remained the same. There were occasions when, due to the resource constraints and geography of the research, we weren't always able to put into practice some of the ideal measures, such as carrying out pre-interview visits with each interviewee and consultee⁸.

In summary, our overall learning regarding ethics was that the ethical approval process was a useful and constructive process that helped us achieve our research aims, but the implications of

⁸ Consultees are someone close to the research participant, for example family member, friend, carer, who we would approach to: a) help the research participant decide whether or not they want to participate in the research, b) if that person isn't able to decide for themselves, to make the decision for them in line with their best interests c) help support that person during the research (including aiding communication with researchers)

planning and carrying out the research with this high degree of ethical rigour needs to be considered at the early research planning stages in order that these methods and processes can be adequately resourced and scheduled.

2.3 Sample and Participants' Profile

There were two broad categories of research participants, namely older people with high support needs living in care homes and those at risk of moving into care, but within those categories there is a range and diversity of older people whose experiences we hoped to capture.

The team developed a sampling matrix covering a broad range of backgrounds and circumstances (see [Appendix 5](#)) covering age, gender, disability, ethnicity, sexual orientation, living arrangements etc. We were aware that we may interview only one person from a specific category; so we would not - for example - be generalising for all older people with a learning disability, but only for a particular person who has a learning disability. This process involved balancing the need to hear and learn from individual circumstances and experiences whilst also pulling out cross cutting and generalisable themes.

In total, 63 older people with high support needs took part in the research. Over the research period a total of 99 research interactions were carried out, including interviews and focus groups. These interactions took place either once, twice or three times with each person. Another way of looking at this is that 99 sets of participant data relating to 63 people were collected and analysed. The 63 people covered the 21 categories in our sampling matrix.

[Appendix 6](#), Research Sample Profile, provides a detailed breakdown of the main characteristics of the 63 people interviewed. The following summary highlights the key points from this analysis:

- There was a fairly even distribution of participants across each workstream, although more repeat interviews took place in care homes (the neighbourhood workstreams having taken longer to get going, leading to delays in identifying and recruiting participants)
- Of the 63 participants, 40 (63 per cent) were female, and 23 (37 per cent) were male. This split closely matches population figures for the South East of England as a whole, where the gender proportions for a similar distribution of ages are 65 per cent and 35 per cent respectively⁹.
- The majority (41 per cent) of our sample were aged in their 80's at the time of the research; 32 per cent were younger than 80 (youngest was aged 60) and 27 per cent were 90 or older (the oldest being aged 100).
- 24 participants (38 per cent of the total sample) had been diagnosed with dementia or other cognitive impairment – although this proportion was much higher among female participants (48 per cent) than among male participants (22 per cent). We also suspected that some participants were living with an undiagnosed dementia or impairment.
- Finally, a small ethnic minority was represented in the sample, with 1 participant being of Caribbean ethnicity, and 3 participants of non-British, European ethnicity.

We did not collect detailed information about or from participants (e.g. housing tenure, nature of funding for support received) unless the participants offered this information themselves. Our focus was on their experiences, expectations and aspirations for exercising choice and control over any support they receive.

⁹ Based on 2001 census data for South East England, Office for National Statistics, <http://www.statistics.gov.uk/census2001/pyramids/pages/j.asp>

2.4 Participant Recruitment

The research team worked with the change management leads in each demonstration site to identify key liaison people for supporting the recruitment of the research sample. This was essential for ensuring as much synergy as possible with the change management activities.

A detailed process took place under the ethical guidelines to set up research visits: an excel template was provided to each site, for them to complete with anonymous sampling details in order to invite and recruit people to participate in the first round of fieldwork activities (see [Appendix 7](#)). Participant information packs were provided to the sites with clear explanations about how this information should be disseminated, including contact details for the research team.

This recruitment method worked well in some areas, and less well in others. For example, local leads were very hands on in one site, proactively promoting the research, including visiting and encouraging relevant individuals to participate. Although to some degree this takes the recruitment out of the research team's control, this local commitment to the research was much appreciated and highlighted the advantages of local, face-to-face recruitment (i.e. rather than relying on an invitation letter). Predictably, repeat invites to second and third time participants were much easier and quicker in all three sites, although with some workstreams we were still recruiting new participants in phase 3 (due to delays with the site support and change management interventions getting started). This meant that the sample of participants included people with a mix of experiences and levels of engagement with the change management activities underway in the three sites.

2.5 Research Tools and Methods

Mixed, qualitative methods were used in each of the sites, the principal method being one to one, in-depth semi structured interviews (70 interviews were carried out in total over the three rounds). Five discussion groups involving small numbers of older people involved in the same workstreams were also held across the three sites. Observation visits were also carried out at each site in specific settings such as day centres and participating care homes, to observe how older people with high support needs were enabled to and actually did exercise voice, choice and control.

Researchers carried out visits and interviews in pairs, with one person taking a lead role in note taking whilst the other concentrated on engagement with the interviewee. This allowed us to get more from interviews, especially where communication was not straightforward, and particularly when a consultee was involved. This approach enabled the researchers to focus on different individuals within the interview/discussion, capturing responses and body language, which might otherwise have been missed. These records were shared amongst team members, ensuring a thorough debriefing and comparing of notes following each fieldwork visit. For example, after each fieldwork visit, team members involved wrote reflective diaries on the process to capture and share key issues and learning arising from each visit; these were circulated to all members of the team (see [Appendix 3](#)). All sources of data were recorded, and included in our initial analysis and subsequent synthesis of findings from different data sources.

The interviews were intense and required considerable concentration and commitment to enable the voice of the older person with high support needs to be heard; we believe the 'paired researchers' approach was necessary in order for this to happen.

Topic guides for the interviews and discussion groups, and a detailed schedule for undertaking the direct observations, were based on the Keys to a Good Life Framework and developed by

the team as a whole, to test and refine the phrasing of questions/headings to avoid jargon and ensure accessibility (see [Appendix 8](#) and the accompanying resource pack for examples). Simple, interactive and illustrated templates were also developed, based on these guides, to help communication and encourage engagement from as wide a range of participants as possible. All of the research tools, protocols and information were produced as a handbook for each team member, ensuring that everyone was equipped with the full set of tools, instruments and guides.

2.6 Fieldwork Reports and Analysis

Each team member analysed their own fieldwork using an analytical framework based on the six 'keys to a good life' domains, including a breakdown of the indicators relating to each domain, and space to record 'unintended consequences' and 'learning points'. One member of the team brought all of these analyses together at the end of each round of fieldwork. The collated data was then interrogated and refined at team meetings, and a further thematic analysis undertaken. Following the final round of fieldwork, a cross cutting analysis was undertaken to identify the dominant messages and themes from across all the phases and workstreams involved.

At the end of each fieldwork round, a data-sampling sheet was produced along with the collated analysis reports relating to all workstreams, and a Fieldwork Report prepared on the emergent themes, messages and lessons learnt. These reports were fed into the interim report produced in April 2010, and were also used to inform the basis of this Findings Paper, which focuses on the cross cutting analysis.

Chapter 3: Findings and Key Messages

Chapter 3 begins with a detailed account of the core findings arising from the research, identified from a cross cutting analysis of all the fieldwork phases. Specific findings relating to the care home and community workstreams are presented in Sections 3.2 and 3.3.

These findings are followed, in Section 3.4, by a synopsis of the key messages that emerged from this analysis. These messages are based on the evidence gathered during the research programme, but they also build on existing and contribute new knowledge of the needs, circumstances and aspirations of older people with high support needs¹⁰.

3.1 Six Core Findings

This section presents six core findings that emerged from the cross cutting analysis of the detailed findings from each round of fieldwork. They apply equally to older people with high support needs living in residential care and those living in their own homes at risk of entering residential care.

i. Living a normal life

This finding links in particular to three of the six keys to a good life identified in earlier research¹¹: personal identity, personal authority and control, and having a meaningful life.

¹⁰ Blood, I. (2010), Older people with high support needs: how can we empower them to enjoy a better life?, Joseph Rowntree Foundation, Better Life Programme; Falkingham, J., Evandrou, M., McGowan, T., Bell, D. And Bowes (2010) A. Demographic issues, projections and trends: older people with high support needs in the UK, JRF Programme Paper: A Better Life.

¹¹ Bowers et al. (2009), Older people's vision for long term care. York Publishing, Joseph Rowntree Foundation

The older people with high support needs who participated in this research wanted the opportunity to 'live a normal life'. They wanted to be part of the usual daily routines many of us take for granted, and to contribute to the community and society they lived in. This included helping with daily chores (shopping, cooking, doing the laundry); being able to continue with hobbies and interests (gardening); and having informal contact with friends and neighbours. One woman, when asked, expressed several wishes:

"I'd like to go into the garden, do shopping, get food."

The availability of gardens and easy access to outside space seemed to be particularly significant, as they related to interests and activities that people had over which they will have exercised choice and control throughout their lives. The opportunity to help with choosing plants, planting things out, and looking after the garden generally was mentioned by several men and women as something they would like to do now. One woman living with dementia explained that:

"We had a greenhouse – I didn't mind working in there. I won't mind helping if there was a greenhouse here – I'd probably need help to know what to do now though."

This was a key goal of the Person Centred Approaches and Community Inclusion development programme delivered to a number of homes in each of the SERI sites, from which small but important changes in experience and practice became evident over the course of the research programme. The full integrated "SERI Story" report covers the background to this programme, which can be accessed through: www.ndti.org.uk

When asked what would help them to exercise or experience voice, choice and control, many people including those living with dementia, said they wanted to be useful and to help others, but that the opportunities to do this appeared limited. One example was a woman who occasionally helps with routine tasks in the care home, such as folding clean towels. We were told:

“If I was asked to do things I would you know”

And:

“I would like to help the lady with things in the house and I think she would enjoy that”

And then later:

“My life seems cut so short to me and I did so want to stay”

The small number of older people from minority ethnic communities that we interviewed frequently told us that they missed preparing their own food, and valued the times that relatives were able to provide it. One man from Jamaica enjoyed and really looked forward to the food his wife brought into the care home for him.

Contact with peers and other generations

Older people with high support needs want to have contact with people of different ages and different generations; encountering people of all different ages is part of the experience of living a normal life. We heard many stories about people who missed seeing young children. We heard how much one woman missed seeing children:

“I like to see children, but I don’t see any here, though there was a baby here [visiting the home that day]”

There was a commonly expressed desire to be with people of all ages: a woman living on her own in sheltered housing commented (after referring to the fact that her great granddaughter living nearby had just started at playgroup):

“Having lots of young people around is very important and helpful”

For some it was because they did not want to be stuck in “an older people’s colony”. Day centres were also not necessarily seen as providing an adequate mix of ages or opportunities to be involved

in 'normal life'. One man demonstrated his choice and control in retaining his friends from the pub he visits. Since moving into the care home where he lives, he has continued to visit his pub weekly even though it is not the nearest, because people there have known him for 20 years.

We also observed how some people's social lives had diminished because their friends faced increased restrictions related to their impairments, for example being less able to travel long distances or get out of the house for social gatherings. Maintaining friendships was limited partly because long term friends were becoming older themselves and some were less able or willing to undertake what were often long or awkward journeys in order to retain contact with others. Access often depended on the availability of others with cars. The focus on developing a much wider range of transport options and assistance to make use of them in one SERI site, struck a chord with many people involved in this work.

Having friends of diverse ages and with varying levels of need for support themselves might help people maintain fuller social lives. However some recognised it was a challenge to get younger people engaged, with a common refrain being:

"They're all too busy with their own lives [especially work]"

This included some people living at home, such as a man who was supported by his wife. This couple had four children, and although they appreciated the fact that all of them were in constant contact, this was mainly by phone.

Case Study 1 - Mrs M: Assistance and support to stay living at home

1.Short profile

Mrs M is a widow aged 80, who lives alone in a well established and settled city area, in a 1930s house on a steep hill. She has always been a physically and socially active person who is

engaged in a range of activities and interests. Although she has had at least one recent hospital stay, her current health remains 'generally fairly good'.

So far she has been able to manage at home without significant support or assistance.

2. What took place (to increase the person's voice, choice and control)?

Mrs M points to a number of things that she feels have helped her to stay living at home in the way that she wants to:

- Limited adaptations to the house (rails etc).
- Developing a friendship with a younger neighbour, who supports her in outings and going away on holiday.
- Reminiscence work (within her own home) which increased her sense of identity and value, as well as supporting past memories
- Retaining financial control, and paying for a financial adviser
- Moving closer to family after widowhood, together with choosing a very settled area with good local facilities within walking distance
- Maintaining family contacts, including with different generations
- Long term close and trusted neighbours who can help with some of the regular care and maintenance of the house (on a paid basis)

3. Learning points (e.g. what helped/hindered across the Keys to a Good Life domains?)

Whilst the present still appears manageable (due largely to her health, finances, and all the factors in 2 above) Mrs M is anxious that her situation may change, due to a sense of increasing pressures from keeping on top of things both physically and financially. She feels her decreasing physical stamina is also beginning to limit her activity outside the home, and therefore the level and frequency of her daily neighbourhood social contacts.

She admits she is reluctant to address her fears in case this leads to leaving her much loved home. At the same time, this fear

prevents her from any pre-planning which might actively reduce the risk of her being forced into a sudden move, e.g. in an emergency.

Mrs M also commented on the inherent ageism practiced by traders; she told us the story of an older friend who needed the intervention of her son to put right a non-working major item she had bought which did not work. The trader would not exchange items without this intervention.

Mrs M's story illustrates the widely held fears of many people we met who are currently living at home, and who are anxious about the prospect of having to move, and do not want to leave their homes. It also illustrates the range of barriers as well as success factors in enabling people to stay confidently living where they want to. This in turn highlights the need for much greater attention and access to impartial help and advice in planning for the future, from and with people who are trusted by the older person involved. There is scope for applying tried and tested practical tools (e.g. person centred support and life planning) through a wide range of routes e.g. older people's organisations and networks, support services, financial advisers, solicitors and pension services.

Handling money

Living a normal life and being able to exercise voice, choice and control included being able to handle and use money. One woman with dementia living in a care home told us:

"I don't know who handles the money, someone must be able to get it"

Another woman in a care home, who was growing older with a disability, valued her independence which for her included being able to go shopping and carry out personal errands for residents. She told us how important it was for her to be able to do things for others:

“When you have a disability you feel useless, not able to do charity work, feel useless...now I can do little things that make a difference to people here and this brightens their day.”

Keeping physically fit and healthy

Exercise and physical activity is a feature of a normal life and often people who are cared for lose the opportunity to exercise through carrying out everyday activities such as gardening, housework and shopping.

There was a link, particularly with the men we interviewed, of the important connection between their identity and general health as well as being physically fit and active. One man spoke of his wish to get a new bike, and his consultee told us this related to him feeling fit and walking a lot. Another man told us he walked every morning for exercise. Several of the men living in care homes were concerned that when they had moved there they were still active and reasonably fit, even those in their 80s and 90s, but that these aspects of their health and well being were rapidly being lost.

ii. Maintaining an individual identity

A common theme throughout all the interviews in all settings was that older people with high support needs are individuals, with unique experiences and histories that have shaped their lives and affect how they respond to their current circumstances. This was central to people retaining their personal identity and autonomy, having a voice and exercising choice and control in their lives. As a research team we found it was not difficult to find out about people's identities, who they are, what is important to them, although there was evidence that this was not happening more broadly. One care staff member, when she heard about one woman's love of painting (as a result of applying the person centred approaches from the development programme), was astonished that she had not known this about her, in spite of being involved in her care for some time.

We found evidence of the resourcefulness of individuals to respond and adapt to their environment and individual circumstances, which we felt were linked to individuals' life histories and past experiences (see also Finding iv. below, Aspirations and hopes for the future). We saw examples of how small changes both in the community and in care homes, such as having the option to eat in your room or go out to a local pub for lunch (as a result of the community inclusion work in the care homes), and especially how those changes were negotiated (e.g. through the circles of support established in one neighbourhood in Portsmouth) could make a significant difference to people's ability to exercise choice and control.

In addition to these minor but extremely significant examples of what enables older people's individual identities to be recognised, understood and enhanced, there were numerous other examples about the need for and experiences of opportunities to make choices over big changes and decisions in later life such as, whether and where to move to and live. Having access to trusted sources of information and advice (as in the dementia information and advice line in Oxfordshire) was crucial in enabling choice and control.

For many people, particularly those living with dementia, the involvement of a close friend or family member who had known them throughout their lives helped people to express and reflect their individual choices. The presence or absence of these trusted and valued relationships was found to be crucially important for the older people with high support needs that we met – not least because of their knowledge of and links to their history and preferences which otherwise would be lost and remain unknown.

For example, some of the men that we interviewed who had lived through the war still held strong associations with their military life and experiences. For example, one man liked to be called by the nickname he was called in the navy and he was pleased that "everyone remembers here". Another man living with dementia always liked to wear a shirt and tie, which his consultees believed linked back to his military life. In a previous care home he had only

worn a shirt, and was now much happier wearing a tie as well. He also preferred to wear blue clothes. We were told: “He is always happy if it (clothes) are air force blue”. Another man of Jamaican heritage had served in the British Army in many parts of the world. His wife said he still responded to his army nickname; his ex army friends still used it as well as staff in the home, which pleased him very much.

Those older people who were part of a family structure with close contact with family members indicated that this gave them a sense of purpose and role. They were still a grandparent, daughter or sibling. One man told us his name but that his real identity was ‘Dad’. He and his wife had adopted four children. Another woman referred to herself as a great grandmother.

For one man who had lived abroad for a number of years, this different lifestyle in another culture appeared to play out in how he related now to the staff at the care home. He prided himself on being financially independent and the most important thing for him was being able to buy his care and comforts. To this end he exhibited a transactional relationship with staff rather than a dependency. He complained that the care home wouldn’t let him tip the staff at Christmas, for example.

Cultural and religious identity was significant: one woman with dementia from Poland spoke of the guilty feelings she has about the wartime in Poland and the mistreatment of Jewish people. Another woman with dementia, who originated from a Spanish family, emphasised the importance of her culture:

“The other night I dreamed I was there – oh it was so lovely, I was crying when I woke up.”

Religious identity was important too, although one woman, who spoke of the significance to her of being a Catholic, did not refer to attending church herself now.

Our research showed that even when staff thought they knew a resident well, there were still more details about individual lives

and identities that could be learnt through careful questioning and taking a personal interest. For example, during a focus group with people with dementia, one woman said: “I like to do fancy work – tablecloths and coarse work”, to which a staff member who was present as a consultee for another resident, replied:

“All the years I’ve known you it’s the first time I’ve known that.”

In another situation, we met a man living in a village who support his female partner who has dementia. He proudly told us that she had a very successful career and retired from fashion in the 1970s:

“She’s a bit of a celebrity, you know. Everyone here knows her. But she’s very gracious, very modest, she never made a big thing of it.”

They maintain their interests and lifestyle in the village holding regular cocktail parties, which she is very much engaged in.

We found that issues of loss of identity were stronger for people living in care home settings than for those living at home. There generally seemed more opportunity for people with high support needs living at home to maintain aspects of their identity through their ongoing roles in family and community life, maintaining personal interests and hobbies such as gardening, having access to libraries and so on. They appeared to have greater voice, choice and control over many smaller aspects of their everyday life such as dress, what they ate and when, making personal purchases and the continued reinforcement of known aspects of their histories, interests, likes and dislikes by friends and neighbours as well as families.

iii. Belonging

A further common finding across the research was people’s need to belong to personal networks that are meaningful to them, to contribute to interests and activities outside their homes, and to be a part of family and community life. This theme linked to

maintaining relationships and having a purposeful life, and is an important dimension of retaining a personal identity.

In particular it means being part of local networks in the community and outside the home, whether that person is living in their own home or in a care home. For people living in their own homes with high support needs, the presence of informal support networks was a key factor to them remaining in their own home. The focus on circles of support in Portsmouth demonstrated the need to provide support to maintain, rebuild or develop such networks in a highly individualised way. Maintaining networks were also important to care home residents, particularly those in the locality closest to their home. For many residents they were either living in care homes away from their familiar locality, or they were no longer part of the local community life.

Loss of networks or close family and friends was a great sadness to the people we met, and particularly those with dementia or memory loss. It was also a loss to their family carers who felt as though their loved one was being rejected and forgotten. One man told us how his neighbours no longer ask about his wife who lives in a care home. They talk to him but never mention his wife. Day centres were also seen as limited in terms of deeper relationships:

“We’re all friends here, but it’s not the same as having friends with similar interests.”

Being part of a family was important to the majority of people we spoke to, and people were quick to defend their families even when they did not see them as much as they would like. One woman told us how much she liked visiting her daughter or son’s home but her daughter: “has a little one and doesn’t like the distance to travel”. Another told us that:

“The best days are all the family together and we talk and laugh.”

She added later:

“I see them, but not as much as I would like.”

Another woman was grieving because her family did not visit anymore. She had recently moved into a care home and it became apparent that they had not visited because they believed it would help her to 'settle in'.

For people living in a care home environment, we found little evidence of people forming new relationships in the local neighbourhood or wider community. Any external relationships they had were highly dependent on those people they knew before they moved into the home. One woman said:

"I used to have close neighbours...I have good friends here but my relationship is really much more with (member of staff) and maybe two or three carers."

Another woman with dementia commented:

"I would like to see more friends."

People talked about the loss of their friends when they enter residential care:

"I've kind of lost them all."

People talked about their memories of friends and neighbours in the area they lived, but there was little evidence of those contacts being maintained and people felt they did not know their local area very well. One woman with dementia had occasional visitors but added: "I don't press it". Even for people living in their own homes, contact with the local community was limited:

"It would help me if I could walk better, [I] don't go to church now."

A woman attending the resource centre added:

"I have two daughters...both good daughters, [I] see them quite often – once a week at least, it depends...[I] don't know the

neighbours, I can't get out you see, only when my daughters come."

Others expressed a wish to come to a day centre more often as they met people there: "quite lonely really". Some participants suggested that the reasons for less or no contact with the wider community included the bureaucratic process for using potential volunteers of Criminal Records Bureau checks; lack of transport and support to get out and about; and being unable to visit friends and other residents when those people are admitted to hospital. One home had been pro-active in this and obtained bus passes for residents – something which (currently) all people over 60 are entitled to receive and use.

iv. Aspirations and hopes for the future

Some participants had very clear hopes and aspirations for their current and future lives, although at times there appeared a reticence to express them. For some of our interviewees it was painful to talk about lost dreams. This important finding related in particular to meaningful relationships and future concerns about personalised support and care. It shows that older people with high support needs want to be involved with all parts of human life, although at times they were unsure if they could be. This theme connects with earlier findings about the life course and the significance of continuity in a person's life; aspirations and dreams were linked to previous experiences or lost opportunities at an earlier age.

We met people living in care homes whose aspirations were to be able to continue to live where they are and were fearful of change. We heard from a number of people that they were increasingly worried that if they needed more personal care then they would have to move, either from their own homes to a care home, or from a care home where they were established and happy.

Linked to the above theme were people's wishes to have good health and to remain active. The wishes of one man who had been

a cyclist all his life was to have a new bike. One man we met had adjusted his daily walk to take account of his failing sight. He now followed a route that did not involve crossing main roads but still allowed him to go out.

Aspirations covered a wide spectrum of interests, activities and relationships. One woman told us: "My wish is that the Lord grants me the time to do more". Many residents living with dementia also shared their personal wishes: "I would like to cook" (particularly dishes from her own culture); "I would like to hold a shovel" (in the garden).

Many people we spoke to had wishes that they did not expect to see fulfilled, although it did not take away the desire or need to hope and look to the future. We were struck by the aspirations of a single older man living in a care home who told us that his two main personal wishes have changed very little since he was asked when starting school, aged five. After initial hesitation he told us that what they were:

"I used to like growing things, especially vegetables, and [I] wanted to get married – so I am halfway there."

He had always enjoyed growing things but his main wish would still be:

"To get married; I appreciate, being realistic, that it would be someone older, with kids."

One woman, who had worked in a mostly male environment, still missed male company. She told us she did not expect much to change now:

"One of them (carers in the home) wants to perm my hair – I said wait until the spring. So I guess that might change in the next few months. Other than that, nothing really, I'm quite happy. I would like a boyfriend though."

There was a sense from some of the older people we met that growing older with high support needs means that it is inevitable that their aspirations would be unrealistic, but their dreams and hopes were crucially important none the less. This was expressed by one woman who was growing older with a degenerative condition and told us:

“[I] have to let go of control – I don’t know what’s happening (physically), I try not to look ahead.”

v. Permission and power

This finding focuses on the question of who holds the balance of power in relationships with or involving older people with high support needs. It forms part of our analysis relating to the Keys of personalised support, personal authority and control, and meaningful relationships. It demonstrates the precariousness and uncertainties of people’s situations, including not knowing what the rules are or indeed who makes the rules when you live in a group situation. Examples from the care home workstreams included people not knowing if they could go into the garden, whether and how they could invite someone to lunch, or if a relative could take you home for a visit.

Similar feelings also arose, although less frequently, for those living at home. One man commented ruefully on the ‘inevitability’ of his loss of privacy and feeling of control over his own home as: “too many people have access”. He was referring to people’s knowledge of his key code.

One key issue which emerged from this analysis was the distinction people drew between being ‘cared for’ and being ‘cared about’. We heard from people with high support needs and some carers that professionals could “look after her better than I can”. One man told us this and then later said he was the one who “knew what she wanted”. The former statement applied to physical care needs rather than emotional, social and spiritual needs. We heard often about how relatives and friends who care deeply about

their relatives could enhance the lives of older people because they 'knew them best'. However, in relation to this theme on power and permission the implication was that physical needs were the predominant concern of professionals, and relatives often went along with this. One woman caring for her husband with high support needs was continuing to care for him at home. Carers were coming in four or five times a day to look after his physical needs but she wanted to care for him at home because:

"I can do things that are more stimulating than what they can do [in a home] – who's got time to do all that in a [care] home? I would want to visit everyday."

We found particularly in care homes and in day centres, that older people and their families did not feel empowered to speak up or knew what they could or could not ask for. Some of this linked to information and communication issues, but also involved people needing permission or encouragement to speak up about unmet needs, such as "we're not allowed pets here" from a man who liked animals, and who used to have a dog and was also keen on horses. It could also include people feeling they needed to ask permission to do everyday activities such as going into the garden or going to their rooms. We are not suggesting this was a policy in care homes but it was a strong message from participants, reflecting their own sense and level of disempowerment.

Some residents were particularly worried about being asked to leave, and this inhibited them from speaking up or asking too many questions. One woman told us:

"Don't like to say too much in case they say 'you will have to go'. I don't want to upset the applecart."

She was quick to point out this did not come from staff but was a view shared by other residents. They all felt that it was a 'good' home, and they felt vulnerable and scared in case they had to go elsewhere:

“I am terrified of having to move from here, it’s lovely – totally independent as you want.”

Other examples from the care home workstreams include:

“Here people are nice- no-one shouts at you.”

A further comment was added about her not wanting to be laughed at.

Another woman with dementia felt that:

“Everyone is perfect strangers to me. Nobody seems to be pleased with me.”

Another resident described her relationship with staff as ‘reassuring’. She added:

“...always polite; the nicest people you could hope to meet and always hold your hand and say thank you.”

Case Study 2 - Ms T: growing older with a disability in a care home

1. Short profile

Ms T is in her early 60s. She retired early ‘from a good job’ on health grounds and has a progressive, degenerative condition. Ms T has a supportive family who help her in a number of ways, including making a decision about where she lives. She moved into a care home two years ago.

2. What took place (to increase the person’s voice, choice and control)?

Ms T told us she has found it difficult to find the right type of supported accommodation where she feels she can retain her independence. She spoke of living in residential care and having

'battles' with local authorities to find more suitable facilities. She is now happy where she is and finds it suits her needs.

Ms T takes part in the communal life of the home. She set up and runs a daily crossword group, which she finds very satisfying. She often goes shopping and does errands for other residents who are unable to go out and finds this very rewarding, because 'as a disabled woman [I have] often felt useless and worthless'.

Ms T has many other interests. She regularly meets friends in town for lunch and is an active member of various local and informal groups and clubs. She has retained her links with and supports the local branch of a charity. She is also content to spend time on her own in her room which overlooks the garden.

However, Ms T does not feel she has a strong voice, or a lot of choice and control in managing her life. Although she does speak up if she is concerned about anything, she is very wary of being too critical. She would like to stay at this home; her greatest fear is that she might have to leave, especially as her health deteriorates. Her fear is that she will be expected to make a move to a nursing home when this happens. She is also fearful that the funding arrangements will change. She says that the fear does not come from the staff, but her own feelings of vulnerability. It was not clear who is advising or reassuring her about these issues, including thinking through different options and making plans.

3. Learning points (e.g. what helped/hindered across the Keys to a Good Life domains?)

There is a lack of readily available information and advice for people about and prior to moving to a care home, and how to make this important decision in a way that means your particular circumstances and preferences are accommodated.

Ms T feels her voice and choice are restricted because of her continual fear that she may have to leave the home that she has now moved to. Through her experience of institutions, she feels that this home is good, allowing her the independence she craves.

The fear of speaking up or anyone proactively anticipating and enabling this to happen is hampering her future plans and decisions. The absence of proactive help from staff, or an independent advisor/broker who could facilitate such discussions, is a key gap; as is the lack of advice for Ms T's family who have helped her make these decisions in the past.

The apparent lack of involvement from primary health care services in Ms T's support is a concern, highlighting the need for greater, explicit involvement in the future from health service commissioners. For people in similar situations to Ms T, there is (or should be) a joint responsibility between health and social care services to provide information about the full spectrum of options and opportunities for support, including extra care housing, homeshare schemes, co-housing, and housing aids and adaptations including telecare.

vi. Choice and control over finances

The sixth core finding, choice and control over personal finances, links strongly to older people's feelings of personal authority and control and whether they feel they have a voice or a choice in their lives. It was a dominant theme both in the care home and community interviews.

The amount of control people had over their finances was very varied. We met care home residents, the majority of whom were men, who were in full charge of their finances. We would suggest that this may reflect a gender difference in roles within this particular generation. It also challenges popular stereotypes of older people with high support needs, who are thought not to manage or able to control, their own, sometimes complex, financial arrangements.

One man managed his financial affairs online and has regular visits from his accountant. He had sold his investments to finance himself at the home, but still hoped to leave money to his family.

Another man in the same care home spoke of having total control of his finances:

“I can still do that for myself and that’s what I want.”

One resident in another care home used a money management system set up by the local council to manage his affairs. Another person, with support needs himself, caring for his partner at their home continues to manage his business involving a number of companies.

One woman who was financing herself to live in a care home expressed concern at the money running out. She had a smaller room than some of the other residents because it was cheaper. The one wish of this woman was: “I just don’t want to move away from here – it’s too nice”, which suggests that her concerns about money were affecting her choices about where and how she could live. An older man living in his own home was able to use his own finances to buy in extra support and flexible care from local people who he had known for many years.

With some people we interviewed, the availability of money helped them to be more content and less anxious about the future. It enabled them to enjoy what they saw as a good standard of living free from financial concerns, and for one person, to be able to contribute to their grandchildren’s savings accounts. However, one carer, because he had sufficient money and was paying in full for his wife’s care, felt he was not able to get help to organise alternative care and therefore he felt his choices were diminished.

Some of the people we met had less control of their financial arrangements. Some of the older women participating in the research sought help from others because their husbands had always managed the money:

“There is no way I could take over.”

“This [financial matters] is something I find quite difficult as (my husband) dealt with finances, the bills, everything like that.”

“My husband always dealt with it all.”

There were also examples where women had taken over the management of finances when their husband's support needs meant they were not able to continue running the family finances. One woman told us that she knew her husband was becoming very ill when she was out shopping one day and:

“He called me and said he had to write a cheque but he didn't know how. I just told him to leave it until I got home.”

In some cases, family were helping with complex finances such as selling shares, others preferred to go to the bank directly, or employ a financial advisor. One woman had been offered a personal budget but felt: “I couldn't do that”.

These striking gender differences are important considerations in thinking through how current reforms of personal social care and other support funding arrangements, for example addressing the need to improve the confidence and skills /experiences of the current generation of older women who have not previously been responsible for or managed family finances, especially those involving large sums of money or significant financial decisions.

All those interviewed in the community workstreams had access to money /funds for their own personal expenditure even if they did not directly manage them, which was very different to the experiences of participants living in care homes. There were examples of people living in care homes who shared with the research team how losing control of their finances made them feel.

One woman with dementia recalled:

“I think someone took me out once and I felt awful – I didn't have any money to buy them a cup of tea.”

Another man told us that: “They take my money and look after it (the people here)”, and when we probed a little more about how

much he would like to be involved in decisions about how his money was spent, he replied that: “I don’t think so”. We heard similar thoughts from a woman who as far as she was concerned had no personal money: “Nothing, not even a ha’penny”, but she did not want the worry:

“I wouldn’t like to, no I don’t want that – if I want anything (my son’s wife) will get it for me.”

The lack of control over money did inevitably impinge on other aspects of day to day decisions, for example:

“I would like to get the children birthday presents.”

Case Study 3 - Mrs W: Financial choice and control

1. Short profile

Mrs W is a cheerful, spirited woman with significant health problems who lives on her own at home in a small village. She is a widow with three children and five grandchildren. One daughter and one granddaughter live close by, and she sees another daughter once a week. Mrs W has increasing memory loss and, in contrast to some of the other people we met, is very upfront about it. “You know what my memory’s like,” she said, laughing, when we asked her about changes the second time we met her. “I just haven’t got one anymore.”

2. What took place (to increase the person’s voice, choice and control)?

Mrs W vividly described her experience of choosing to go back home after an 11-week stay in hospital. She actively resisted moving to a care home, despite pressure from staff, and insisted on returning home: “I told them, ‘no I’m not going into a home, I’ve got a home of my own. Now I’m in my own home with the help of my carers.” Mrs W commented that this may have only been possible because she had two rooms downstairs, one of which was converted into a bedroom for her on the ground floor.

Mrs W now has care workers coming four times a day, every day. They help her get dressed and with things like cooking. She pays for them privately (she is not eligible for council funded care/support) and gets on well with them. She also pays privately for gardening and help with cleaning. A volunteer takes her to a local day centre once a week.

Mrs W is very clear about what independence means to her: "When I can do a job then I want to do it. Because it gives you something to do. You want to retain your independence as long as you can. It's best if people just fill in where you can't, and not take over." Her attitude is that "As long as you've got people to help you, you can live how you want to live."

Despite this, Mrs W is sometimes lonely. Her neighbours do not provide any friendship or support, other than being willing to hold an emergency key to her house. When asked what would help the most she immediately says, 'Contact. I'd like a bit of contact, an occasional visit and phone call, over and above family. A little chat now and again doesn't hurt.'

3. Learning points (e.g. what helped/hindered across the Keys to a Good Life domains?)

Mrs W is an example of an older person with high support needs who has been able to exercise voice, choice and control in deciding to remain living in her own home with support. She stood out to the research team because of her very positive attitude; she seemed more comfortable with the idea of needing support than some of the other people we met. The reason for this difference is not entirely clear.

What was clear was that she was able to articulate her preferences when leaving hospital and resist pressures to move to a care home. Having a home that could easily be adapted also clearly played a role, as did having the finances to make decisions about who provides her with the care she needs and buying that in directly. She feels she has strong family support, which is clearly important to her - although she is also sometimes lonely and would like more contact with her family, friends and neighbours.

A key point here is the importance of financial choice and control. The research team did not meet anyone with a personal budget who was making decisions about how to spend their money on care and support arrangements (which is surprising given recent trends in the take-up of personal budgets by older people¹²). The processes and practicalities involved are, however, identical to those that would be involved for someone holding a personal budget. There are important lessons and stories which need to be shared more widely to increase the opportunity for older people with high support needs to benefit from increased choice and control.

3.2 Specific Findings and Messages Relating to Care Homes

The six findings described above apply to people with high support needs living in a care home and those at risk of going into a care home. There were also specific findings or emphases that applied to each of the two target populations; this section looks in particular at the care homes work streams.

3.2.1 Fitting in

A strong and powerful need to be a person who ‘fitted in’ rather than being an individual was a strong finding in the care home workstream.

One woman said it was important to fit in with staff and follow rules and be seen as good:

“As long as I do what I’m told and behave myself – if not, I’ll have to be told off if necessary”

¹² Personal budgets and older people: making it happen, Department of Health. 2010.

A positive example of voice, choice and control was given by a man in a residential home who described himself as a loner, which he had been all his life. He felt that his wishes had been respected and that: "I have been able to work out a life for myself here". He told us he was surprised as he had not expected to be able to retain his autonomy.

One woman in the early stages of dementia was able to maintain her individuality whilst still being part of communal living: "I like to do my own thing without harming anyone". She says she is realistic in what can be done, and when she has a bad day, which she recognises are inevitable: "When you gets a bit low – then I mostly lie on the bed".

Other comments from participants on this theme included the following:

"You don't choose who comes here."

"Sometimes you've got to put up with someone else."

"You've got to take it or leave it, you've got to make your own way."

We heard other examples of people appreciating having things in common with other residents and being with people "like myself". Conversely, others resented the activities or television programmes which were not at all to their tastes.

One man told us:

"Well they have what I would call third rate entertainment in the afternoons here. [Made a face] Yuck!"

He is interested in politics, which he felt was not always shared by others in the care home and therefore preferred to watch television in his room. He could then enjoy political debates of his own choosing.

3.2.2 Recognising the personal histories

The importance of knowing and acknowledging people's personal histories was an essential, enabling factor for people living in care homes to maintain their personal identity, as discussed earlier. For example, many people we interviewed had lived and/ or worked abroad and felt now that they were at a stage of "coming home". Our observations showed that it was not at all evident or obvious in the care home environment that some residents had spent considerable time living in other parts of the world, i.e. that this aspect of their personal history was known about or valued/recognised.

The strength of identity in people who had lived and been brought up in other cultures was significant. The consultees of one man who had a strict upbringing in Scotland believed that may have influenced his approach to his own children who were now estranged. One woman with quite severe dementia was able to tell us that she had been a teacher in a senior post in India for a number of years, and she still indicated a frustrated wish to try and convey information to those around her, as well as feeling a loss of status. Several men had had long careers in the forces and still, for example, demonstrated their wish to be well turned out.

3.2.3 'Someone who knows' - the importance of family and friends

Continuity of relationships was a significant theme, which could allow people in care homes to have some voice, choice and control in their lives by helping to maintain their identity. Family remained the most meaningful relationship for people and in particular for those living with dementia. These relationships varied although spouses were highly significant. With one man, whose wife visited every day, it was observed that her touch and speech remained familiar and physically calming influences even though he was no longer able to have a verbal conversation with her.

One vivid story told by a woman with dementia demonstrated the loss she felt at not seeing her family anymore. They were clearly dominant in her thoughts although they were no longer present in

her life. She grieved for contact with her large family of 9 children who appeared to have made a decision that she would settle if they did not visit. She told us:

“My family and my children - I would like them with me.”

She displayed extreme sadness and despair when thinking about her family.

We heard about one woman who used to have lots of friends, but her husband said:

“She had lots of friends that she would see for regular get-togethers, morning coffee, evening meetings, that kind of thing. But the relationships died off.....those people are not in her life anymore. They don’t come and visit here. They’re limited by distance, plus communication (with participant) is more difficult now. She wouldn’t recognise any of them anyway.”

And from another participant:

“A lot of people I know; we used to go to the same church, but I don’t see them much now.”

There was less evidence of people making friendships inside the care home although we witnessed occasions when people waved across the room or acknowledged each other.

One man explained his lack of close friends in the care home as being due to the fact that: “I’ve not been here very long”, although staff told us he had been there about a year or more.

Some showed a tolerance to other residents such as:

“Sometimes it’s very noisy in here, and fellas bang on the door – they can be very funny”

“Sometimes you’ve got to put up with someone else”.

Others were less tolerant:

“You don’t choose who comes here”

Case Study 4 - Mr D: Maintaining relationships when you live in a care home

1. Short profile

Mr D lives in a care home for people with dementia. He grew up locally and has always had close relationships with friends and family. He has diabetes and has been diagnosed with dementia. He was an avid cyclist up until he moved into the care home at the age of 90, but he no longer cycles. His other interests include gardening, reading and music. Before moving into the care home he lived by himself in his own home and, according to his sister, ‘kept himself to himself’.

2. What took place (to increase the person’s voice, choice and control)?

Mr D’s sister plays a significant role in his life. She visits weekly and manages all of his affairs. She pays for everything he needs, brings photographs to help make his room more personalised, brings fruit to look after his diabetes, organises outings with family and recently sold his house for him. She is a regular fixture around the care home and has even started coming in to do reminiscence work with other residents. Mr D’s sister plays an important role in promoting his voice, choice and control - because she knows him so well, sees him so often and is so committed to maintaining a high quality of life for him, on his terms. Of all the relatives who were encouraged to become involved in developing personal life histories for people living in the care homes involved in the SERI programme, she was the only one who actually did get involved.

In the first of our three interviews with Mr D, he had been extremely anxious about the possibility of having to move from the home. He said it was “A nice place to live but not home”. On subsequent visits, he seemed more settled and said, ‘Yes, I look

on this as my home.’ He also seemed more socially relaxed. He said he felt comfortable and that the staff were very nice.

One disappointment has been that Mr D’s wish to get more involved in the gardening has not transpired. On earlier visits he anticipated being able to do this, and expressed the wish to be given a small plot to tend. On our third visit he pointed out that the garden had been neglected and weeds had grown up. He mentioned one time that year that he had been able to do some watering with a hose but otherwise had not been supported to get stuck in, in the way he would like.

3. Learning points (e.g. what helped/hindered across the Keys to a Good Life domains?)

Mr D’s experience illustrates the importance of family support for adjusting to a radically different way of life, for those making the huge lifestyle change of moving into a care home. The invaluable support and contribution of Mr D’s sister illustrates the potential for a wider network of people known to the person who needs support in their life, to be involved in helping to shape the individualised nature of that support. It is a salutary reminder that this example stood out from others.

Even with this support and relationship, it was clear that some of Mr D’s expressed wishes were not being addressed by staff – highlighting the importance and challenge involved in shifting the culture and practice norms of care home environments where residents are “cared for” and not enabled to participate or do the things they have always done or shown an interest in.

3.2.4 Personal possessions

We heard from consultees and observed for ourselves that people valued being able to individualise their rooms with personal possessions and have around them items of interest that were important to them, such as books, photographs, stuffed toys and pictures. This included being able to have familiar food: one example was a woman with early dementia who expressed the joy

she felt from being able still to have the fresh vegetables she enjoyed supplied from the care home garden. But the opposite view came from a woman who told us:

“My home is not here, my family did not put things in my room.”

3.2.5 Meaningful everyday activities

The need for meaningful everyday activities was highlighted in the cross cutting themes outlined earlier (Living a normal life); this was particularly significant to people in care homes who often appeared to lack purpose in their daily lives. The objectives and sense of purpose in the care homes often tended to relate more to staff concepts of 'caring for the group', rather than supporting residents individually to pursue their own way of life in what is now effectively their home.

One person (with early stage dementia) whom we met maintained a number of hobbies, helped with the gardening, and was highly valued as a volunteer in a local charity shop; but this was an unusual example in the range of individual activities and interests she was continuing to pursue.

Relatives (including those who visited daily) often did not have any significant understanding of how the rest of people's time was spent when they were not there; nor did many staff often make use of relatives' time when visiting to extend their own knowledge of individuals' histories, identities, likes and dislikes - which would have formed the foundation for more individualised, stimulating and satisfying life. One family carer described the lack of meaningful contact and flow of information, which he experienced between himself and staff as “curious”. Another carer, concerned about his wife's lengthy isolation in her room, had not realised that his wife did actually (choose to) leave her room sometimes for meals.

There was also a common issue across the participating care homes concerning the balance of group activities predominating over support for individual interests. Communal rooms dominated

by television programmes chosen by others, and often staff, were one of the more obvious examples residents commented on, but even though group activities might be appreciated they could not substitute for some of the individual interests people would have liked to be able to pursue. One man said:

“I would like to go to the theatre; I used to see everything.”

3.3 Specific Findings and Messages relating to Community Workstreams

3.3.1 Importance of locality and community

A common factor for maintaining a clear identity when living in the community with high support needs was the length of time people had lived in the neighbourhood and how well they were and felt connected to the place and other people living there. The opposite was true when people had moved, often to be near their children. One woman who had moved house to be nearer her daughter, at the daughter's request, had lost many of her contacts and indicated that some of her status and identity in the process of moving had been lost through leaving friends behind. She had lived abroad for many years and had lost touch with many friends. Another woman spoke of living in another village but: “my daughter moved me out here – I have had to start again, but it's hard”. This resulted in separating people from the locality they had known at a time when support was extremely important. This not only took people away from sources of informal support, but also meant they were unfamiliar with what was available in their new community. They had not been able to build up those important networks and relationships now that their support needs were higher.

Familiarity with the local neighbourhood played an important role in enabling choice and control for older people with high support needs. It appeared that for some people still living in their locality, this enabled them to feel less isolated and able to exercise some choices. An important dimension of the relationships with friends and neighbours was the long-standing knowledge they had of each

other's backgrounds, particularly when that related to the locality. The importance of the local network and local knowledge was repeated on many occasions. One woman living alone, for example, has regular informal gatherings in her home.

We heard from one woman who was caring for her husband with considerable support needs, who found the support of friends and neighbours essential:

"Things are going well mainly because we have such good friends and neighbours. Nothing is impossible. You can get round anything because people are so kind. It's because we are known here [and] they are our sort of people."

We met a woman who had moved out of a care home into sheltered housing in her old neighbourhood with the support of her family. She had moved into the care home after a serious fall and described how, with her family's input and reablement support spanning a number of months, she had moved back and picked up her routines and contacts – going to the same shops, hairdresser and church as when she lived in the family home.

3.3.2 Information

Information acts both as a lever for and a barrier to voice, choice and control for older people living at home with high support needs.

For some of the people we met, lack of information – about housing options, support for carers and financial benefits – was a major problem. One group we met had never heard of Attendance Allowance or Pension Credit:

"We don't know what's out there."

Information tended to be provided in the form of leaflets and written material, when in fact people wanted someone to talk to. There was also the issue of the timeliness of information, with

examples given about the experience of trying to get information once it is needed:

“You don’t think about it until you have a crisis.”

Advanced care planning and/or support planning was not a dominant feature in the conversations of most of the people we met.

Other people we met had the opposite problem of too much information. One man started his interview by dumping an enormous pile of material in front of us and exclaiming: “This is my problem!” A number of the people we met were receiving overwhelming amounts of information from different sources; and not all of it was relevant to their needs. Another man who was caring for his wife with dementia had two diaries filled with contact details for different people and organisations, but he was unclear about what their roles were. He still found it hard to find the information he wanted on respite care. What he really wanted was someone to talk to. What he was getting were piles of written information, about which he said he did not know “whether I will ever get round to reading it”.

A critical factor as to whether written information enables personal authority and control for older people with high support needs, seemed to be the ability of people to organise the information and find their way through a complex system of benefits/finances, support, help and assistance and options for future living arrangements.

For those caring for spouses with high support needs, this also included having to order complex medication and feeding fluids. One woman explained how the most useful support she had was from her daughter who spent a considerable time putting all the information and explanations into a filing system:

“This [referring to the filing system] has been the biggest challenge, the most difficult thing for me – managing everything.”

She also showed us a page-a-day diary on the table, which had been her son's idea, to help her manage the complex needs of her husband at home. Without that family support, she would have struggled to find her way through the system, despite the fact that she herself had run an information line for carers when her own mother had Alzheimer's.

None of our interviewees used the internet as a means of enabling choice and control. We met one carer of her husband with dementia who was anxious to use a computer to both deal with practical matters and to maintain her family and other contacts. She was willing to purchase one: "This is something I really, really must get" but feels it is impossible because she cannot get to classes because of her caring duties. We heard comments that automated telephone help lines were not useful and people often gained their information through word of mouth.

Two people referred very positively to using their local authority information centre, where being able to discuss, as well as access, a wide range of information was invaluable in enabling them to select what information they needed, and assisted to make sense of it and use it.

Case Study 5 - Mr and Mrs O: Information

1. Short profile

Mr and Mrs O live in their own home on a small estate on the edge of an Oxfordshire town. Mr O cares for his wife who has dementia. They have both had other health problems including cancer. They have two daughters, one of whom has a learning disability and has lived in a residential care setting for a number of years, and who visits them occasionally. The other daughter lives about two hours away by car and has five children. She visits regularly and has been involved with some of the decision-making about her mother's care arrangements.

Mr O drives and when he is not caring for his wife he goes out for meals once a week with friends. He stays in touch with his brother

by phone. He had a career as an engineer and feels he has had to adapt to 'domestic duties' and running a home.

2. What took place (to increase the person's voice, choice and control)?

Managing information is a major challenge for Mr O. He has a great deal of paper work – flyers, leaflets, letters, lists of names and details for contacts at different organisations – which he organises to the best of his ability using file folders and two different diaries. Still, there are papers all over the house and he feels overwhelmed by the volume.

Despite all this information, Mr O finds it difficult to know where to go for help with certain things, such as how to organise respite care. Mr O believes this is due to the fact that he pays for all of Mrs O's care himself.

What would help Mr O have more choice and control is to have someone to talk to, who would sit and explain things there and then, and make suggestions rather than just answer queries: "I would like someone to sit with me and explain, tell me if something is coming up, various things that we might be entitled to. All I want to do is see someone and get an answer there and then." He relies heavily on a local carers' organisation, and recently had contact with a new information service. After the meeting, he was sent more written information: "I'm not sure whether I will ever get round to reading it." When he rang the service with a query the contact person was not there and so he did not try again.

Mrs O does not seem to have voice, choice or control in any decisions about her care. According to Mr O she is unable now to make those decisions and it is his responsibility to make the best choices for her based on the information he is able to obtain.

3. Learning points (e.g. what helped/hindered across the Keys to a Good Life domains?)

Mr O's situation shows that information alone is insufficient for people to make informed choices. Information needs to be tailored to individuals' needs and circumstances, and more attention needs

to be given to how people actually make use of information to make difficult decisions involving either themselves or on behalf of someone else – the outcome of which impacts on everyone. The importance of having someone to help or facilitate/broker individual decision making, including enabling access to and making sense of appropriate information, is also highlighted by Mr and Mrs O's experiences.

This also illustrates the importance of ensuring people living with dementia are supported to be involved in decision making so that their voice is heard and preferences are known and understood. Supported decision making tools are still not commonly used or known about by/for older people with high support needs, but there is wide scope for raising awareness and spreading their use¹³ - both for the person living with dementia and for their carer(s).

Mr and Mrs O's story also illustrates the need for much greater joint working across health, social care and other services to provide wrap around support across all aspects of people lives when their needs are both complex and multiple in nature. There is relevant learning from the dementia advisor pilots and the roll out of personal budgets and support planning¹⁴ which could be applied to Mr and Mrs O's situation.

3.3.3 'Staying on top of the house'

Another key finding that emerged from the interviews and focus groups was the energy and effort people put into trying to stay, as one person put it, 'on top of the house'. The people we met spend a considerable amount of money, time and energy attending to repairs, gardening and other maintenance, in order to stay where they want to live – in their homes.

Some coped by letting standards slip:

¹³ Independence, choice and risk: a guide to best practice in supported decision making, Department of Health, 2007; www.paradigm-uk.org/articles/Supported_Decision_Making_Book/2449/43.aspx

¹⁴ Living well with dementia: A National Dementia Strategy; Good Practice Compendium - an assets approach, Department of Health. 2011.

“The curtains haven’t been washed, or the windows cleaned, for years now – although I can still look out of them.”

Others just did the best they could:

“I try to do everything for myself, but cannot lift like I used to, but always have done everything to keep the house going.”

One consequence was that for some, the lack of maintenance meant that they curtailed their own movements:

“My garden’s a jungle now; I’m afraid to go up it as it’s so overgrown.”

Another, unexpected consequence of people spending so much time trying to stay on top of their houses was that they had less time to go out and see friends, or even just go to the shops, which increased their risk of social isolation.

It was not clear to us whether information and advice about housing options and support were lacking, or whether people did not seek it out for a number of complex reasons. One older man caring for his partner told us:

“The house is too big. We thought about moving a few years ago but we decided we’re too old to move! It would take two years to find a place and settle and friends have pointed out, you may not do better in a bungalow. The thing is, I don’t know how long Alzheimers takes to get worse – or better! The worst case would be we would have to have a nurse here, or go into a home.”

3.3.4 Transport

Transport presented as a major barrier for older people with high support needs being able to fully participate in activities and opportunities of their choice, particularly when mobility is or is becoming restricted.

Those living in rural areas in particular, found they could not get to events and activities within as well as outside the village where they live, unless they had transport provided by friends, volunteers or the council. Taxis were often found to be unreliable and expensive, and community transport schemes were restricted. Car use was important to three of our interviewees because it enabled them to go out, and one man who had given up his car said it had led to lack of mobility for him. One man drove a car and liked to be able to go out 2 or 3 times a week to meet friends and have lunch. It was also something he can do with his wife who has dementia.

Other practical matters that impacted on the daily life of the people we met included: having to go in the opposite direction from all the nearby shops to get to the post office, because the closest one had closed; and negotiating busy roads when there are no pedestrian crossings or traffic lights. This was compounded if people had sensory loss such as hearing difficulties or failing sight.

3.3.5 Lack of planning for choice and control

This section demonstrates how lack of planning can inhibit voice, choice and control. Some participants had a strong sense of what it means to have choice and control over the support they need to live their everyday lives:

“It’s best if people just fill in where you can’t, and not take over. You want to do it for yourself, when you’re able to do it. When I can do a job then I want to do it. You want to retain your independence as long as you can.”

Most, however, had unclear views of the future:

“I don’t know what the future holds”

And:

“I just take things one day at a time”

The vast majority of older people who are working hard to keep on top of their houses, seemed to have plans for how they might recruit more support to enable them to stay where they want to live. None of the carers we talked with appeared to have provisions in place for what they would do if their own health problems worsened in the future and made it impossible to be a primary carer. The precariousness of many people's situations was striking.

This is a major concern since the experiences of the people confirmed that the decision to move into a care home is often made as a result of an emergency, when there is inadequate time to fully explore all options which coupled with the inadequate information and support to help older people maintain choice and control throughout the decision-making process illustrates the unravelling and fast moving situation people find themselves in once the "need to move" is mooted.

There was also a prevailing view from many staff and relatives involved as either gatekeepers or consultees, and sometimes from older people themselves, that residential care in these circumstances is the only realistic option. This has resulted, for the people we met, in decisions about care provision being made without input from the older person involved, creating a downward spiral of diminishing choice and control.

Two paradoxes about planning become evident. One is that many carers have meticulously planned daily and weekly schedules; in one case with even brief trips to the shops planned a week in advance so as to ensure that a friend or neighbour would be available to sit with her husband. The other paradox is that where we have seen examples of excellent support that enables people to maintain choice and control, it is largely due to factors such as friends and neighbours, which were largely informal and not necessarily planned.

Chapter 4: Key Messages and Lessons

This Chapter draws together the eight overarching messages we have distilled from looking across the preceding sets of findings, themes and case studies. It also highlights a number of lessons learnt from doing the research – both in terms of the methodology and how this work interfaced and interacted with the change management elements of SERI; and in terms of influencing progress towards achieving the Independent Living Vision with and for older people with high support needs.

4.1 Five Key Messages for Enabling Voice, Choice and Control

Firstly, it is evidently clear that older people with high support needs **wish to live a 'normal life'**, which includes having contact with friends, family members, people of all generations in local neighbourhoods and specific interests, and being a part of social networks. The older people we met have aspirations, for some people a strong sense of longing, to be a part of the everyday activities associated with having a 'normal life', and to have opportunities for maintaining a healthy, active lifestyle. This includes being able to manage and use money on day to day expenditure, as well as on more significant decisions such as where, how and with whom to live.

At the same time as these clear aspirations, there is a very low set of expectations among this generation of older people with high support needs with regards to the right to a good life and to have choice and control over your own personal support. This was reinforced by the impact of low expectations and aspirations found within the different people who are in touch with or 'caring for' those we met, including family members, care staff, neighbours. Ageist attitudes need to be tackled at a number of levels within society as well as within public services in order to bring about widespread change in this respect.

Second, **isolation and loneliness remains a significant issue** for older people with high support needs - both for those living in care homes and those living at home. Loss of peers (both relatives and friends) had reduced people's social networks for many of the people that we met - whose relatives and friends had either died and/or no longer kept contact with them. Participants also shared their feelings of isolation from familiar places including their homes, local facilities and community activities, which all added to a sense of disconnection from community and daily life. A particular message here is the importance of recognising the isolation and loneliness felt by older people living in care homes, as well as that felt by people living at home.

The latter is still currently more widely acknowledged than the isolation and loneliness that exists for many people living in care homes. It was frequently unrecognised by care professionals, families and wider community members that we met during the course of this study. There is a prevailing assumption that physically being with many other older people twenty four hours a day means that a person is not lonely, irrespective of individuals' personal interests and values, and the extent of their need for retaining as well as developing new friends and community links, after the move into a care home.

The few older people in care homes that we met who did belong to wider networks of friends and family, seemed able to retain more of their own sense of identity and have more meaning in their lives. The older people we met who were involved in the community workstreams appeared to have more and stronger, informal support networks which were crucial in enabling them to remain living in their own homes.

Third, people of all ages and stages of life each have different life histories and different experiences – but **the importance of older people's histories and life experiences** are particularly important for those who need a lot of support in their lives. Professionals of all backgrounds, disciplines and levels (from care worker through to consultant physicians, housing tenancy officers to commissioning leads) need to focus their support and their services on engaging

with and listening much more closely to older people and the people in their lives, in order to get to know and really understand what's important to individual older people as well as for whole communities.

Family and friends in particular can provide vast amounts of background and knowledge about an older person who has moved to live in a care home. In addition, gender and cultural difference are not always taken into account in thinking about how voice, choice and control are exercised and experienced across the life course. For example, we saw examples of clear differences in the way men and women adapted to care home life, although this was rarely acknowledged. We believe a greater understanding of this is required through further research in order to address this issue more effectively.

We met people from different cultural backgrounds who told us how difficult it was for them to express and retain their sense of self and identity if their cultural heritage was not acknowledged or understood. This links to hearing people's stories and understanding the importance of life course for older people – how earlier life experiences may be impacting on people's lives, circumstances and choices now. It is a particularly significant finding for enabling older people with dementia to have a voice.

Fourth, knowledge and information, and **support to use information tailored to individual needs and circumstances**, is crucial for exercising voice, choice and control. We met a number of people who were struggling to find out about and access information that would enable them to retain control and make informed choices. A key finding was the over-riding need for personal support to make sense of the huge amounts of information that does exist; and the need to trust the information giver and provider of that support.

Those workstreams that focused on this aspect of independent living had clearly understood the centrality of this issue in enabling older people with high support needs to exercise choice and control, and the steps they were taking to improve and adapt their

provision was welcomed. The nature, style and quality of communication also influences people's ability to make individual choices about how they live their lives, and needs to be afforded a much higher priority. This includes recognising the importance of the senses.

The people we met with hearing loss and sight problems demonstrated how this affects their ability to exercise voice, choice and control. It also includes the importance of carers and care staff taking time to really listen to what is being said or communicated by the person – verbally and non verbally. This was often overlooked either because of physical tasks or a belief that a person could not communicate their wants and wishes because their verbal language had reduced and linear interaction was difficult.

Finally, **older people with high support needs feel powerless** in many of the situations they find themselves, and this power differential with professionals and family often goes unrecognised and/or unacknowledged. This can be overcome by prioritising and strengthening mechanisms for older people to be equal partners in all aspects of decision making, and ensuring they are supported to find solutions to living their life in the way that makes sense to them. The focus on increasing the individual and collective voices of older people with high support needs within SERI has helped to shift attitudes at all levels of local service systems, in specific settings and within local communities, but our discussions with individuals involved in this initiative have confirmed that this is the start of a very long journey.

4.2 Lessons for Future Research

This section presents the significant learning from the research, sharing both insights gained from the overall experience and specific aspects concerning the methodology with a view to informing future, similar studies.

Clarity and familiarity with the research subject

The research team were aware from the early planning stages, from the ethical review process through to the interviews and conversations with research participants and their families, friends and carers, that the research was breaking new boundaries. There were regular reminders that:

- a) Both the language and concepts of ‘independent living’ and ‘voice, choice and control’ were often new to people, and needed constant explaining and reinforcing – in particular the focus on self determination regardless of severity of need or eligibility for services. Independent living is still largely interpreted as meaning the ability or capacity for people to live at home independently, rather than being about what enables individuals to express their views, preferences and priorities for support that enables them to lead their life regardless of where they live. The overarching “SERI Story” report examines issues of language and definition in greater depth.
- b) There are generally very low expectations with regard to older people with high support needs (especially those living with dementia) being able to participate in research – both from staff working in different parts of the public service system (not just health and social care) and family members.
- c) Relatively little research has been carried out directly with the two target groups in the absence of other perspectives, in order to hear and understand their views, experiences, perceptions and concerns about their lives. The majority of research undertaken with or about older

people with high support needs still tends to focus on issues relating to services, care, needs and/or funding rather than their experiences of and aspirations for voice, choice and control.

Focusing on unheard voices

Our primary aim in this research was to communicate directly with the older person with high support needs. Our commitment to this:

- Challenged some perceptions and exposed embarrassment and low expectations (including those of professionals, relatives and neighbours)
- Was aided and strengthened by the ethical approval process, which provided the levers and procedures to use and reiterate at times
- Empowered older people, helping them to feel valued
- Was generally welcomed by family and carers, once it had been explained
- Was sometimes aided by family and carers who often sought to work with the research team, to enable their friend or relative to have a voice
- Raised problems sometimes, balancing needs and the voice of consultees with the need to overcome communication barriers and focus on giving voice to the primary participant.

Including older people with dementia in research

We learnt a great deal about communicating with people living with dementia about these issues, gaining insights into how people's thoughts, views and experiences can be gathered even where straightforward communication seems unlikely. The following quotes from research team members' fieldwork diaries capture some of this learning as we directly experienced it:

"Given time to build a trusting partnership, it is possible for us to communicate with people with dementia and get opinions from them."

“It is possible to learn things about how a person feels even if their memory makes it hard for them to explain. Repeating certain phrases, attitudes and gestures tell a lot.”

“Trigger words, actions or events can suddenly unlock more of the person.”

“We managed to find out some significant views and wishes from very marginalised and disempowered individuals.”

We found that this work required knowledge of dementia combined with this central focus on independent living (as defined above) and sensitive questioning – anticipating that the flow of speech can be variable and ‘wander’ – especially in relation to the time and space that participants were talking about. Whilst there is a significant body of literature about engaging with people living with dementia, our experience in this and previous work focusing on the views and aspirations of older people with high support needs, reinforces the need for yet further work in this area. Specifically there is a gap between the existing body of knowledge and day to day experiences and practice in the ‘real world’. Many of the staff and family members we met were firmly of the view that people with dementia would either have nothing to offer the research or could not be engaged in any meaningful way.

Participants in this research were very clear that they wanted to be involved, enjoyed the process and added greatly to our understanding of their situations.

The need for flexibility in the design of research over time

There are specific issues that do require particular attention in the design and implementation of research and development work to ensure this is possible and productive for everyone involved:

- The group of people who participated in the research with dementia were often living in different times and places. This made changes over time – a very traditional, linear way to

review change – difficult but not impossible to establish and track.

- People's health varied over time and some people were more able to communicate at some times than others
- Changes during the course of the programme affected participating care homes, such as a new home being established or an existing home being closed. This made it difficult to attribute changes to more person-centred approaches or to people settling after the move in the case of the new home.
- The availability and involvement of consultees varied and affected the content of the interviews
- Changes in the pairings of the research team due to resource issues and availabilities.

Repeat interviews and continuity

Participants often remembered us between research visits which was a surprise but also very encouraging. This ranged from people having “some recollection” of us from previous visits, to people becoming familiar friends and inviting us round to tea: as one team member described “Being remembered – and trusted – felt good”. Some people who didn't want to participate in the 1st round of research visits, subsequently did choose to in future rounds.

We did sometimes reach limits in our ability to communicate, and despite our best efforts we couldn't overcome these barriers with some participants, at least not within the resources and context of this research. This was challenging for ourselves in terms of maintaining our beliefs and principles about how people can be enabled to exercise choice and control in these situations.

Involving consultees; families / friends / neighbours / carers

Involving a third party at times helped us to reach and hear the participant's voice, although in some situations the consultee's own voice dominated. In some cases the role of family and friends as 'proxy' voices for the participant was invaluable.

There were a few people where, despite our best efforts to communicate with the primary participant, the main interviewee became the carer. However this gave those carers a rare and valued opportunity to tell their own story and know that they, also, were being listened to. As most of those carers were, themselves, an older person with a need for support, their stories and experiences were powerful and highly relevant to the research questions. Wherever this was the case, we have focused in our analysis in identifying these distinct voices, ensuring they each have their own space.

Role modelling co-production in the research team

The research team consisted of 4 members with a rich mix of ages, knowledge, experiences and perspectives. We feel that this team approach, built into the design of the research, was fundamental to our ability to carry out meaningful research in a number of ways, including:

- Enabling interviews to be carried out by sensitive, experienced peers, leading to rich, insightful data
- Allowing interviewers to work in pairs ensuring effective use of interview and participant time (by enabling one person to concentrate on maintaining flow of conversation, eye contact etc., while the other focused on observing and recording the conversation, checking topic areas covered etc.) and inter-rater reliability (with post interview checks of transcripts and interpretations of interview conversations).
- Creating a learning environment that enabled different perspectives to be brought forward, aiding rigorous challenge and debate and enhancing analysis and findings
- Team members being able to learn from each other's approaches and skills, building their own confidence in communication as the research progressed
- Providing a strong, mutually supportive team spirit throughout the different research stages, helping to motivate each other when obstacles (e.g. from 'gatekeepers') and changes to planned activities (e.g. as a result of local contexts changing) occurred.

Emotional engagement of the research team

This kind of research is intensive work, and personal engagement as a researcher is high. Words frequently appearing in team members' fieldwork diaries included: "touched", "moved", "tired...but good". As well as interviews demanding high levels of concentration, the emotions of those interviewed included sadness, unfulfilled wishes, and often invoked memories and emotions for researchers. One diary mentioned the importance of "remaining open to hearing people's feelings of distress, however painful this is". Feedback from participants indicated that they valued these conversations, and felt valued as a result of them taking place. They also indicated that those close to them avoided them whenever possible. There is a need, therefore, for these findings and lessons to be shared in staff training and development as well as standard research dissemination activities.

Thorough preparation

The focus of the research was on capturing the experiences of and opportunities for a group of older people who are seldom heard. This was taking place at the same time as an innovative change programme designed to support a shift in existing cultures and beliefs as well as implement new approaches to public service delivery. Our aim was to look for any changes in older people's experiences as a result of the change programme. We were not evaluating the overall impact but exploring any subtle changes.

We approached this complex task by developing outcome indicators that were consistent and applicable across the sites and their workstreams. In addition, we produced interview tools based on a clear set of indicators developed by the team at an early stage of the process; agreeing these key domains and indicators early on was crucial for keeping us on track as the research progressed over an 18 month period.

We met regularly as a team throughout the fieldwork phases, to analyse and interpret our findings, and agree key messages and

themes. We found attending the SERI Action Learning Events enabled the research team to make links and contacts with the sites, gain inspiration from the commitment and motivation of others involved in the initiative, and as much as possible, gain understanding about the interventions taking place at each site.

One team member focused on coordinating the fieldwork administration from an office base (described as an 'anchor' role) and this proved to be essential, given the number and complexities of different workstreams and the remote working of other team members.

Chapter 5: Implications and Recommendations for Future Action

This final Chapter outlines the potential areas for action highlighted throughout the report, to ensure that the findings, messages and lessons are addressed – both in terms of any future research in this area and in improving the life chances and experiences of older people with high support needs.

There are three main areas for action identified from reviewing the findings, messages and lessons. These actions relate to:

- Specific issues identified in the findings and key messages
- Lessons learnt from the design, methodology and experience of undertaking the research
- The use of data, research tools and resources developed for SERI.

5.1 Specific issues identified from the findings and key messages

The findings and key messages highlight the need for widespread cultural and attitudinal change within services, families and wider society, including:

- The need for **cultural change within the commissioning and delivery of services/support** in order to influence and further develop the range of options and opportunities for support; improve access to those options; explore a broader range of methods for delivering and providing services/support; and to facilitate a shift in power between those delivering services and those receiving support.
- The findings and messages also highlight the need for a **shift in attitudes and assumptions about age, ageing and older people with high support needs more generally**, i.e.

within wider society, families, mainstream services and facilities, and among older people themselves.

- Specific findings and issues relating to the experiences of older people living in care homes illustrate the need for further work to **develop, implement and spread the use of person centred approaches and tools** in shifting the power imbalance referred to above, and in enabling a stronger voice and influence for care home residents and the people in their lives.
- Specific findings and issues relating to the experiences of older people at risk of moving into care emphasise the importance of visibility, and retaining / strengthening personal and social networks as people age. There is scope for further development and testing of approaches such as circles of support, time-banking, home-share and other forms of mutual support and reciprocal relationships with and for older people with high support needs. A new action research project focusing on these aspects provides an opportunity to learn and apply these methods so that they become part of the range of support options available locally .

In addition to the above, the findings have important implications for the design and delivery of future training and development programmes for staff working at all levels (from community leaders through to practitioners and volunteers) and in a variety of public services and sectors.

5.2 Applying key lessons from the research design and methodology

The following points summarise the areas where there is scope for applying the learning from delivering the qualitative research element of SERI:

- Sharing the learning from designing and undertaking complex, long term research, development and evaluation activities in one integrated programme.
- Ensuring that formal ethical approval processes take account of the need to engage and hear the direct voices of people with high support needs who are deemed to lack capacity, or whose capacity to consent may fluctuate over time. We found that using and adapting person centred approaches in the fieldwork ensured we were able to support older people with high support needs in sensitive, empowering ways to ensure their voices and experiences were brought forward in the research. The formal ethical approval process however, is currently designed in such a way to deter researchers from finding imaginative, ethical methods for ensuring diverse and unheard voices are engaged. Ongoing work with researcher funders, sponsors and research ethics committees is required to explore the issues, tensions, solutions and effective methods in greater depth.
- Working with older people as peer researchers ensured the final design and approach to undertaking the fieldwork was robust and grounded in the reality of diverse older people's lives. It also enriched the data and analysis of findings. This experience will be shared via various research forums and networks, and used to inform and support the work of various networks of experienced older people working as researchers and experts by experience across the UK (e.g. OPAN in Wales, NDTi's network of associates, Regional Older People's Forums in England and COPA in Scotland).

5.3 Future Use of the Research Data, Resources and Tools

[Section 4.2](#) outlines the lessons and experiences of undertaking the research, and specific tools and resources which aided the research process. These research tools and resources form part of the accompanying resource pack (<http://www.ndti.org.uk/>) to ensure they are available for wider use and ongoing adaptation in future research.

The Keys to a Good Life Framework used to inform the research design have been updated and refined as a result of undertaking SERI, and are included in the resource pack.

It has been suggested that the anonymised primary data bank containing all the original interview notes and primary analysis templates would provide valuable material for future, secondary and more detailed analysis. The data bank will therefore be reviewed against the terms of the formal ethical approval secured, to establish if it can be made available to researchers, including PhD students, for secondary analysis of specific research questions, for example as part of the ESRC or UK data archive.

Appendix 1: Overview of the South East Regional Initiative, the SERI Sites and Workstreams

The SERI programme involved three key elements involving specific activities and work programmes within and across the three participating sites, including:

- i. Change management support to partners and communities in Portsmouth, Oxfordshire and West Sussex, to develop and embed options that promote independent living. The primary aim of this support was to help local partners and stakeholders to identify the key priorities (areas of focus) where this work would take place. The initiative covered the spectrum of support that older disabled people need to lead their lives, regardless of their eligibility for state funded support and care. The focus of the change management support, therefore, was not just about health and social care but the widest possible range of options and opportunities for support, including (but not exclusively):
 - The role/influence of peer and user led organisations/networks
 - Increased access to a wide range of housing related advice and support
 - Access to a broader base of community support including social networks and mechanisms for participation
 - A focus on changing lives and improving services through personalised support
 - Developing accessible transport and help to get around
 - Improve access to information, advice and support to keep healthy and well
 - Improve access to leisure and learning opportunities.
- ii. A qualitative research study to track the experiences of individual older people from the target groups in these 3 sites, used the Keys to a Good Life Framework referred to

earlier to design robust research tools to answer the key question:

“What is different [as a result of the above] for the two target populations of older people with high support needs within and across each site, during the course of the Regional Initiative?”

- iii. Quantitative data collection and analysis was undertaken in partnership with the three sites, to capture impacts and develop an outcomes framework for independent living that can be used by authorities to assess the return on their local investments. This evolving element involved NDTi and ODI analysts working with the three sites, the change management team, the qualitative research team and the project’s analytical advisory group to develop a quantitative monitoring data collection and analysis grid, in order to contribute to the evidence base of “what works” and investigate the impact of independent living on the two target populations.

The change management support and qualitative research was delivered by the Older People and Ageing Programme from the National Development Team for Inclusion (NDTi, www.ndti.org.uk) working in partnership with the three sites, and the Centre for Policy on Ageing (CPA, www.cpa.org.uk). NDTi also worked with ODI and the Project Board to develop the framework for quantitative data collection and analysis.

The following introduces the three sites and their priorities for independent living agreed with local older people and local partners, which then formed the focus of the change management support and activities. These were also known as areas of focus, and also ‘workstreams’.

The SERI Sites and their Areas of Focus

Site: Portsmouth

A densely populated urban, unitary authority on the south coast with a population of 188,500 (2004 mid-year estimates) which is projected to grow to 204,500 by 2026

Area of focus / workstreams

- Adopting person centred approaches to increase choice & control of older people living in 1 care home
- Developing a neighbourhood focus to independent living, to enable older people with high support needs living in one neighbourhood to stay connected, contributing, and living at home in their community.

Site: Oxfordshire

The most rural and least densely populated of all South East county areas, with about half of the population living in areas made up of less than 10,000 people.

Area of focus / workstreams

- Adopting person centred approaches to increase choice & control of older people living in 7 care homes (2 of which are supported by 'SERI').
- Developing & delivering tailored information for older people living with dementia to increase their choice & control in living at home.
- Designing transport options to enable older people with high support needs to participate in community life, maintain networks & reduce social isolation, especially in rural areas.

Site: West Sussex

A mixed urban and rural county on the south coast, with a large and increasing population of people aged over 65 as a result of inward migration on retirement.

Area of focus / workstreams

- Adopting person centred approaches to increase choice & control of older people living in 2 care homes.
- Increasing the voice and influence of older people with high support needs in the planning and development of a new enablement service.
- Increasing the voice of older people with high support needs in their discharge from hospital, improving their access to different support options.

Appendix 2 – SERI Research Questions

Overarching Research Question:

What is different for older people living in care homes and those at risk of moving into a care home, within and across each site, during the course of the Regional initiative (the Initiative)?

Key areas of enquiry:

1. What are the individuals' experiences and feelings of voice, choice and control like now; and what are the key influences on these experiences and feelings?
2. What is changing or has changed as a result of the mechanisms, interventions, options and opportunities for increasing the voice, choice and control of older people with high support needs? What has helped or hindered?

Subsidiary research questions:

1. How has the term 'voice' been understood in the Initiative? Is there a common understanding among professionals of what it means for older people? How have people expressed their voice? Have they been able to 'ask'? Is there evidence that it is about what is not said, as well as what is said? Is body language important?
2. What is the individual's experience of 'voice' at the moment? Does it vary between individuals? What are the circumstances that enable people to feel they have a voice? Is it different for the two target populations?
3. Has the Regional Initiative enabled older people with high support needs to have a stronger voice? If so, how and to what extent, and in not, why not? Are there significant differences between the two groups? If so, how?

4. Is there evidence that the voice of older people with high support needs is listened to? What has made that happen? What has prevented it? What has changed as a result?
5. To what extent has the Regional Initiative recognised and respected difference and diversity? Has it reached a diverse range of older people? Has the programme acknowledged their different needs, and if so, how?
6. Do the older people have people in their life that really matter to them? Who are they? How much have they been able to choose those people? Has the Initiative improved or lessened this?
7. Have the older people experienced a greater connection with people around them through the Initiative? Have they developed new friendships and if so, with whom? Has there been respect shown for sexual relationships and sexual identity, and if so, how?
8. To what extent has the Initiative enabled older people to have more control over personal decisions about their lives? What are the necessary conditions required for people to feel more in charge of their lives?
9. In what ways has the Initiative given people more control over their personal finances? How much has the Initiative helped people to manage their personal finances?
10. How has the Initiative enabled people to have more choice and control over their physical environment? What is different about the use of the public and private space? Have they had more choice about the people they spend time with?
11. What activities in the Initiative have enabled people to feel safer, more secure, warm and comfortable? What have been the barriers?
12. How has the Initiative demonstrated an increase in people's feelings of being valued and belonging? What have been the necessary conditions for this to happen across the two groups? What has hindered it?
13. In what extent has the Initiative enabled people to have a sense of purpose by feeling part of the local community? Have they been able to participate and actively contribute

to activities, volunteering and so on? How has this been achieved? What have been the barriers?

14. Has the initiative been able to demonstrate increased choice and control for older people in the support they require? If so, has that support been important for, as well as important to, the older person?
15. To what extent has the Initiative been able to give older people in the two groups access to universal services as well as specialised support? Does this include prevention and health improvement services? What are the critical factors to make this happen?
16. What has been most, and least, effective in enabling support to maintain an older person's physical, emotional and mental health and wellbeing? Has there been increased availability to physical activities, and if so, for whom? What opportunities have been created to increase mental stimulation for the two groups?

Appendix 3 - Research Fieldwork Diary

Name:

Date:

What 3 things did I expect to happen?

What 3 things did happen?

What has been the most significant thing that happened during your visit?

What have I learnt?

How do I feel now?

Appendix 4 - Summary of the Qualitative Research Phases

Phase 1: Developing the Research Methods

Nov 2008 – March 2009

- Finalising research framework and methods
- Identifying current contexts & mechanisms for achieving voice, choice & control and site population profiles
- Recruiting sample of older people with high support needs in each area
- Establishing web pages and protected online discussion forum

Phase 2: Capturing Baseline experiences

April – Sept 2009

- First round of interviews, focus groups and direct observation
- Analysis of/reporting on baseline situation
- Revising research tools and protocols as necessary

Phase 3: Capturing & sharing Interim experiences

Oct 2009 – April 2010

- Second round of interviews, focus groups and direct observation
- Analysis of/reporting on interim situation

Phase 4: Capturing & reporting on Impact

May – Oct 2010

- Third round of interviews, focus groups and direct observation
- Distillation of initial messages and lessons across all phases
- Sharing initial findings

Phase 5: Analysis & Reporting on Key Findings

Oct – Dec 2010

- Final analysis, reporting & testing of findings and areas for action
- Producing, presenting & disseminating final report

Appendix 5 - Sampling Matrix

There are a number of suggested categories that we may want to cover in the sampling, but we will only be researching people who are part of the change process. We also know that the sites are concentrating on particular issues, eg Portsmouth is focusing on BME elders. We will consider which research method is suitable for different groups, and in some cases people will come into more than one category.

Sample size

There were approximately 50 - 60 people across the three sites.
Three rounds of data collection

A comment on 'tokenism/ representation': Although we may interview only one people from a category, we will be reporting on what works, for whom, in what circumstances and why. So, we would not, for example, be generalising for all people with a learning disability, but only for a particular person who also has a learning disability (although cross cutting themes may be drawn out).

Family members and support workers

We are not interviewing family member or support workers for this work, but in some circumstances they may be present to support the older person being interviewed. We feel it is very important in the analysis of the interviews that we distinguish between the two groups.

Categories

Asked to the participants at all three sites.

1. People living in residential/ nursing care
2. Non-residential care – eligible for support with large care packages
3. People living alone

4. People who are socially isolated
5. Men
6. Women
7. Ethnic group
8. Sexuality
9. People with dementia
10. Older people with a learning disability
11. A person grown old with a disability
12. Sensory impairment
13. Communication impairment
14. Over 80
15. Under 80
16. Rural area
17. Urban area
18. Multiple hospital admissions
19. Older people living with long term conditions
20. Direct payment/ individual budgets
21. Self-funders

Definitions and notes to support matrix:

1. **People living in residential/ nursing care:** People who have lived for varying periods of time in residential homes and nursing homes
2. **Non-residential care – eligible for support with large care packages:** People who are using health and social care services- may be living in their own home, in sheltered accommodation, extra care facilities, retirement communities
3. **People living alone:** People who are not sharing their home or personal space with a partner or family member/ close friend, either in their own homes, or in sheltered housing/ extra care facilities.
4. **People who are socially isolated:** People who have no family or friend support. May be living in residential/ nursing homes.
5. **Men:** May consider '20 men : 40 women' gender split, because more women over 80
6. **Women:** (As Above)

7. **Ethnic group:** Portsmouth may focus on BME elders but need to define particular communities. Aim to include a minimum of 3 BME elders from other sites to reflect the diversity of the target population.
8. **Sexuality:** Older people with high support needs from lesbian, gay, bisexual and trans people
9. **People with dementia:** Includes people with Alzheimers disease and multi-infarct dementia
10. **Older people with a learning disability:** Includes people with a learning disability who have grown older.
11. **A person grown old with a disability:** An older person who has been disabled from an earlier age
12. **Sensory impairment:** Visually impaired or severe hearing loss
13. **Communication impairment:** To include people with stroke
14. **Over 80:** Proportion as per population stats.
15. **Under 80:** Ditto
16. **Rural area:** Include extremely rural, geographically isolated and rural deprived communities
17. **Urban area:** Include inner city areas, and deprivation
18. **Multiple hospital admissions:** As defined by number / frequency of admissions.
19. **Older people living with long term conditions:** Includes people with diabetes, chronic obstructive pulmonary disease, hypertension, heart disease, mental illness.
20. **Personal budget:** People in receipt of a personal budget
21. **Self-funders:** Both in care homes and those living at home

Appendix 6 - Seri Qualitative Research Sample - Profile

Part 1: Overview of numbers participating over whole research period

- Round A (Sep-Nov 2009): 20 interviews and 1 group discussion (with 6 people) were conducted = 26 people
- Round B (Mar-Apr 2010): 23 interviews and 2 group discussions (with 10 people) were conducted, involving 33 'primary' participants and 3 'secondary' participants who were carers = 36 people
- Round C (Jul-Sept 2010): 27 interviews and 2 group discussions (with a total of 6 people) were conducted, involving 33 'primary' participants and 4 'secondary' participants who were carers = 37 people

Over the whole research period, a total of 99 interactions were carried out with 63 people (research interactions having taken place either once, twice or three times with each person). Another way of looking at this is that 99 sets of participant data were collected / analysed, relating to 63 people.

The following table gives a summary of the number of people who took part in each round of the research, broken down by workstream type:

Number of people engaged, via interview or discussion group	Round A	Round B	Round C
Care homes	20	17	16
Neighbourhood	6	19	21
Overall	26	36	37

The following table shows the different combinations of rounds in which people participated, again broken down by workstream:

The different combinations of rounds that people participated in	Workstream type: Care Homes	Workstream type: Neighbourhood	Grand Total
People who took part in only 1 round:			
	13	20	33
A only	10	6	16
B only	1	6	7
C only	2	8	10
People who took part in 2 rounds:			
	11	13	24
A and B	3	0	3
B and C	7	13	20
A and C	1	0	1
People who took part in all 3 rounds (A,B and C):			
	6	0	6
Grand total of older people engaged at least once over the research period	30	33	63

N.B. the above tables do not include the following people:

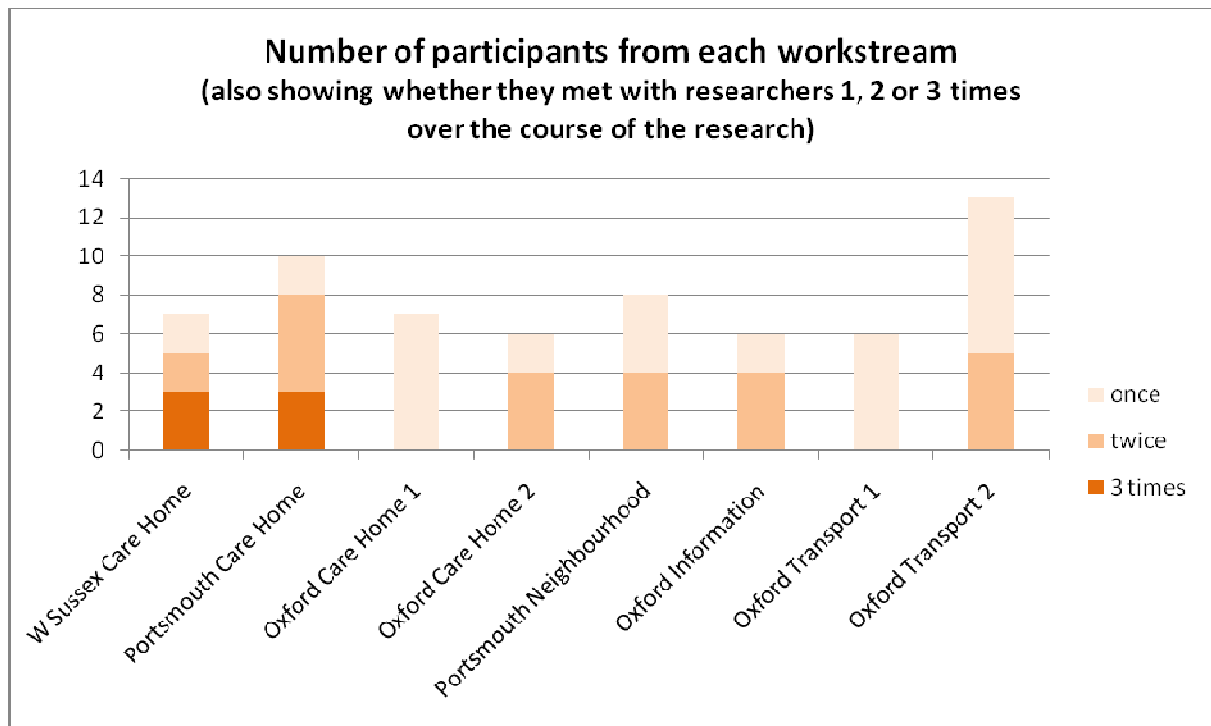
- Those engaged via interactive posters at the Portsmouth Neighbourhood event, Jan 2010
- Carers or consultees, other than where they were the only/main interviewee i.e. a secondary participant; in addition to the four 'secondary' participants counted in the above

figures, a further 16 carers / family members / neighbours were engaged as consultees in the research (i.e. helping to enable communication between the participant and the research team, but not themselves being the main 'interviewee').

Four participants are known to have died over the research period.

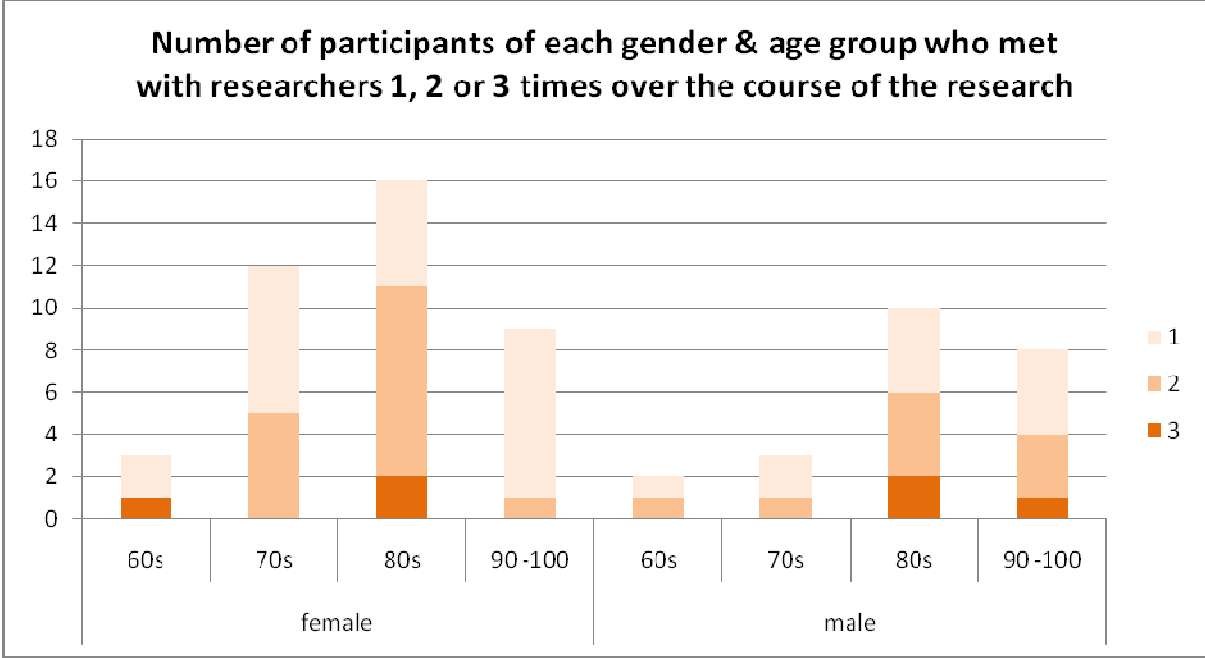
Part 2: Breakdown of overall research sample (63 participants) by key sampling criteria

Figure 1. Number of participants from each workstream, including the number of times they met with researcher.



Workstream	Number who met with researcher once	Number who met with researcher twice	Number who met with researcher three times
West Sussex Care Home	2	2	3
Portsmouth Care Home	2	5	3
Oxford Care Home 1	7	0	0
Oxford Care Home 2	2	4	0
Portsmouth Neighbourhood	4	4	0
Oxford Information Line	2	4	0
Oxford Transport 1	6	0	0
Oxford Transport 2	8	5	0

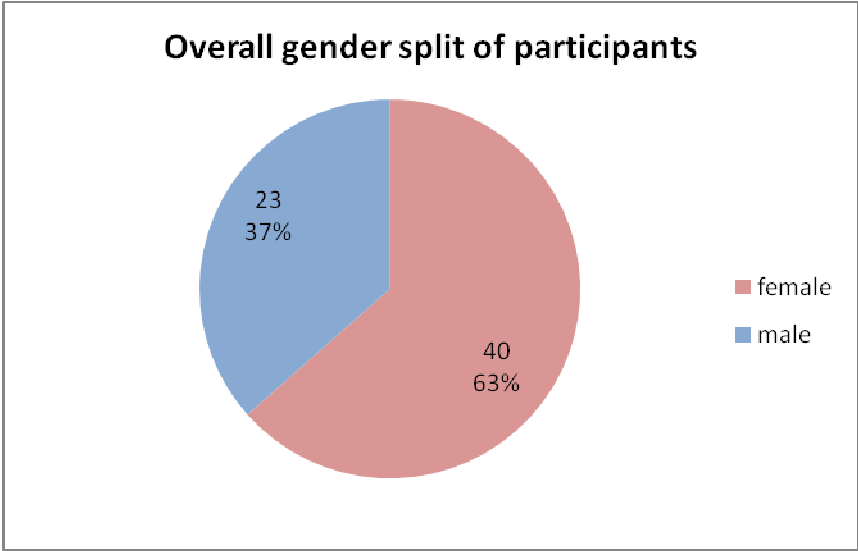
Figure 2: Number of male and female participants in each age group.



	Number who met with researcher once	Number who met with researcher twice	Number who met with researcher three times
Females in 60s	2	0	1
Females in 70s	7	5	0
Females in 80s	5	9	2
Females aged 90-100	8	1	0
Males in 60s	1	1	0
Males in 70s	2	1	0
Males in 80s	4	4	2
Males aged 90-100	4	3	1

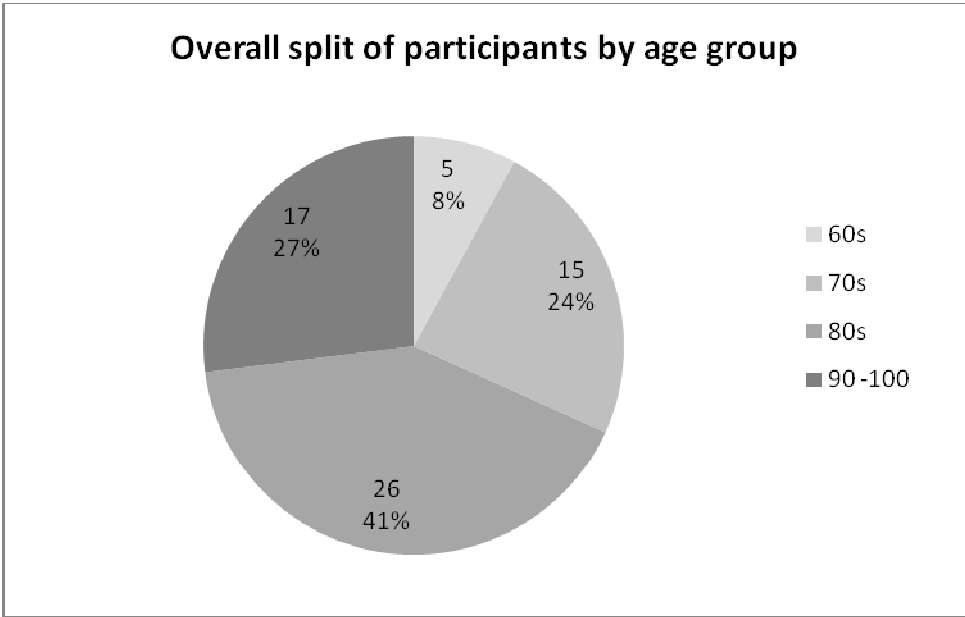
Gender, Age and Ethnicity

Figure 3: Number of male and female participants



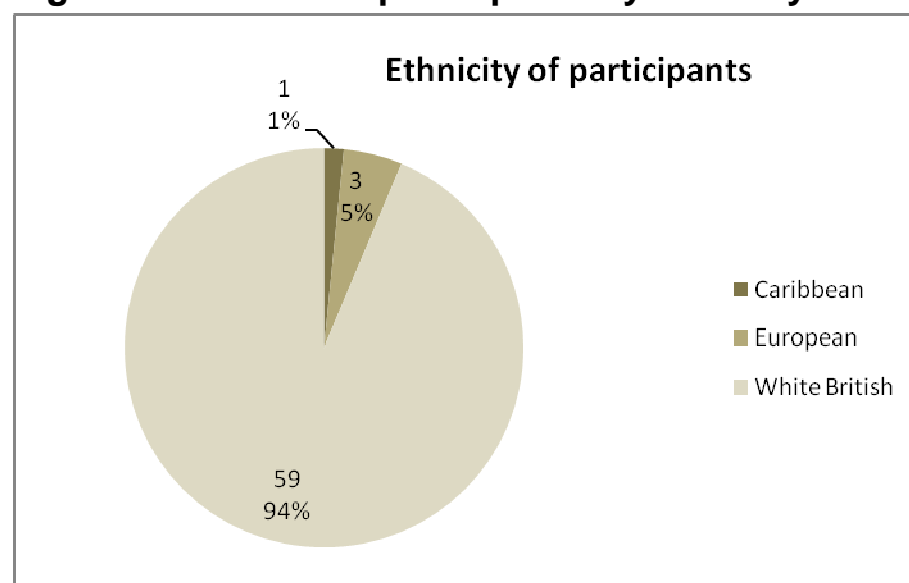
	Number	Percentage
Males	23	37%
Females	40	63%

Figure 4: Number of participants by age



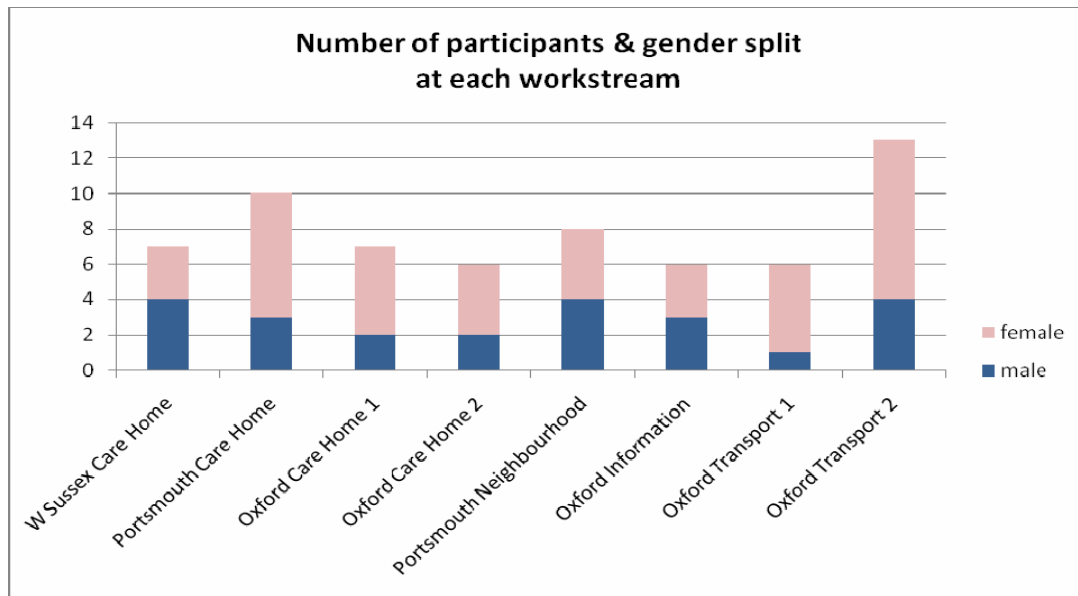
Age range	Number	Percentage
60s	5	8%
70s	15	24%
80s	26	41%
90 to 100	17	27%

Figure 5: Number of participants by ethnicity



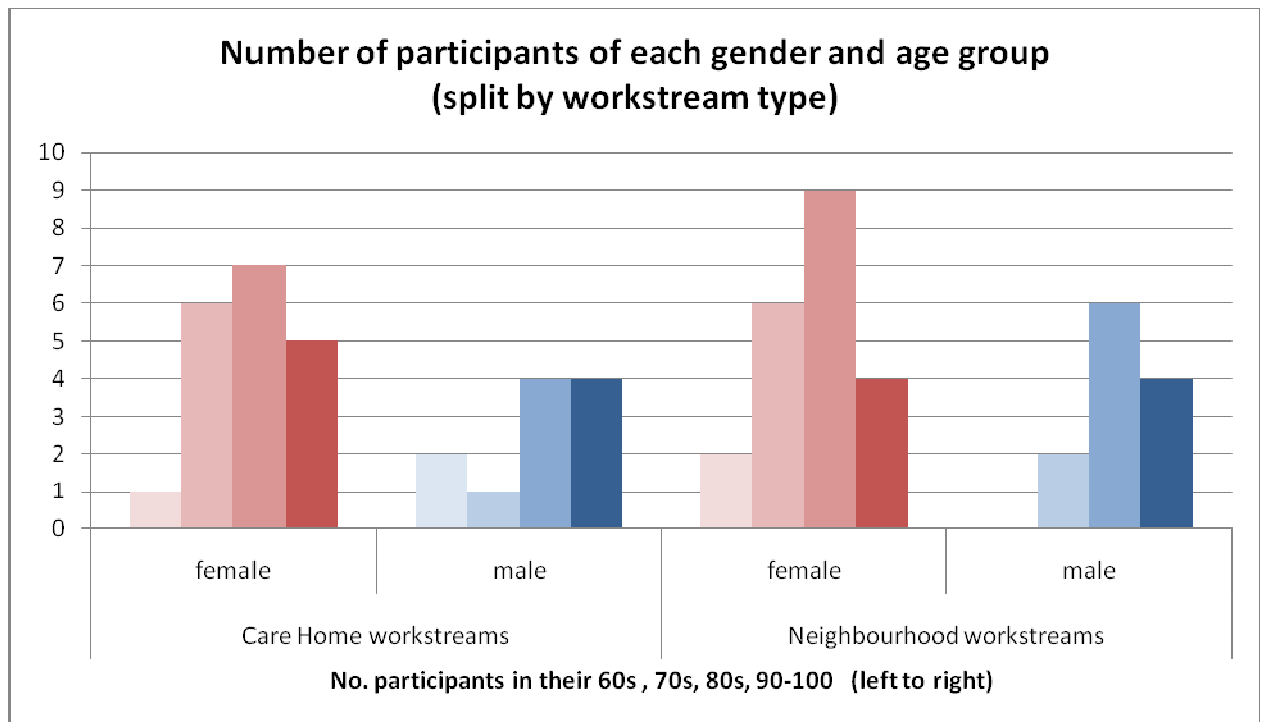
Ethnicity	Number	Percentage
Caribbean	1	1%
European	3	5%
White British	59	94%

Figure 6. Number of male and female participants at each workstream



	Male	Female
West Sussex Care Home	4	3
Portsmouth Care Home	3	7
Oxford Care Home 1	2	5
Oxford Care Home 2	2	4
Portsmouth Neighbourhood	4	4
Oxford Information Line	3	3
Oxford Transport 1	1	5
Oxford Transport 2	4	9

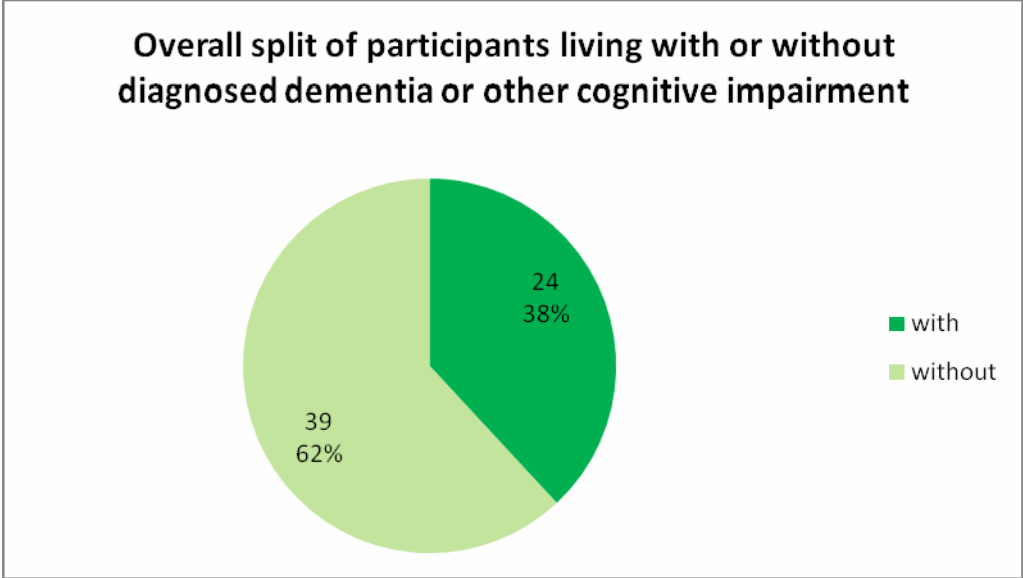
Figure 7. Number of male and female participants sorted by workstream



	Care Home workstreams	Neighbourhood workstreams
Females in 60s	1	2
Females in 70s	6	6
Females in 80s	7	9
Females aged 90-100	5	4
Males in 60s	2	0
Males in 70s	1	2
Males in 80s	4	6
Males aged 90-100	4	4

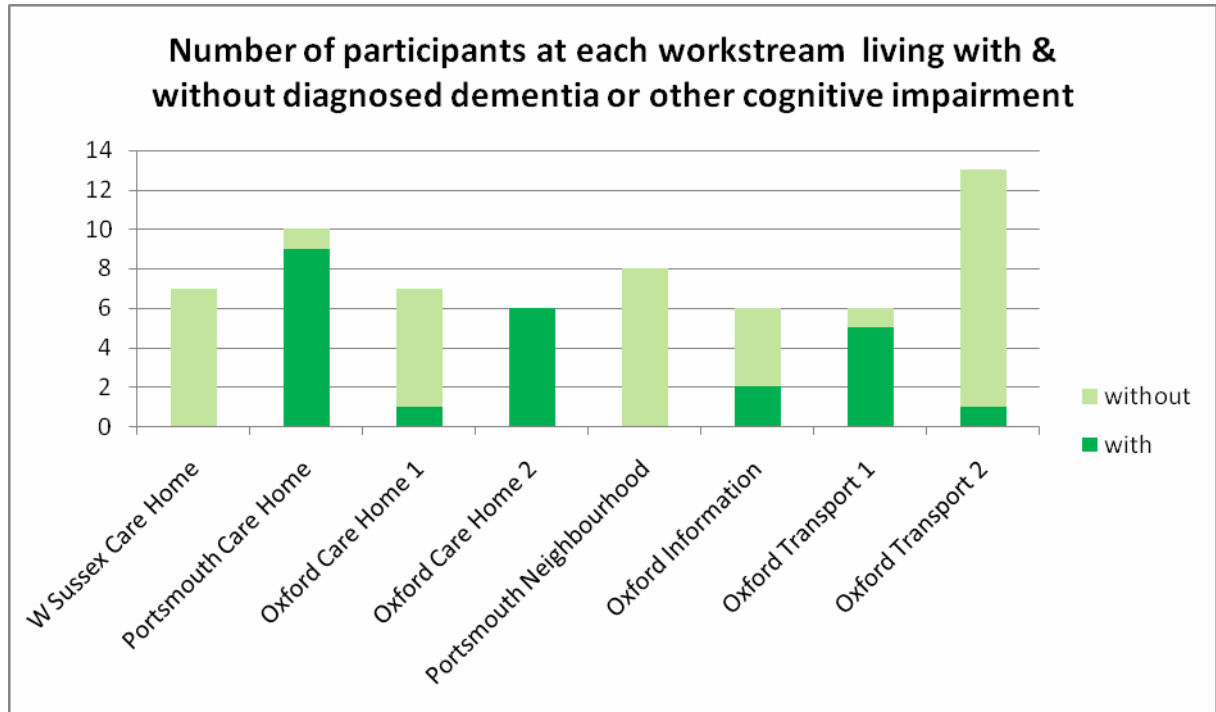
Dementia / cognitive impairment

Figure 8: Number of participants living with or without diagnosed dementia or other cognitive impairment



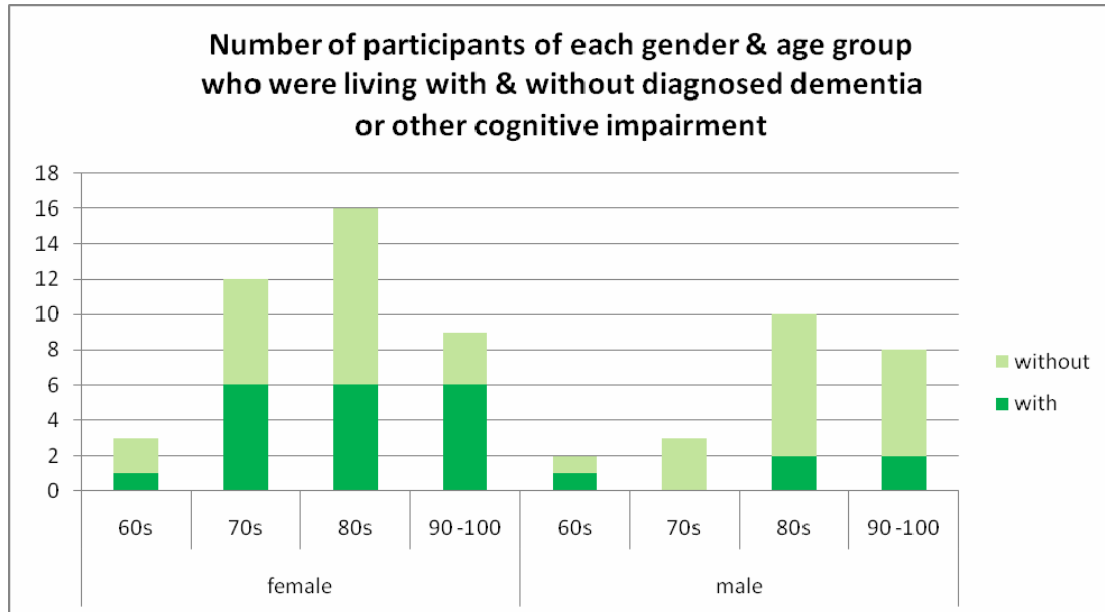
	Number	Percentage
Participants with diagnosed dementia or other cognitive impairment	24	38%
Participants without diagnosed dementia or other cognitive impairment	39	62%

Figure 9: Number of participants living with or without diagnosed dementia or other cognitive impairment at each workstream.



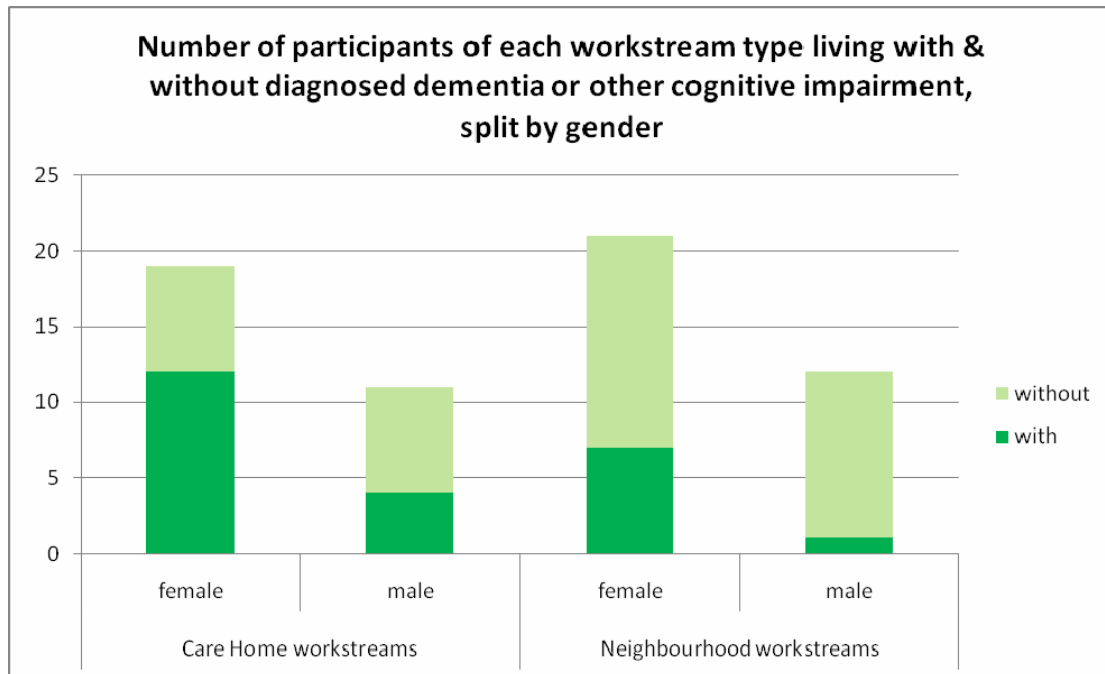
	With diagnosed dementia or other cognitive impairment	Without diagnosed dementia or other cognitive impairment
West Sussex Care Home	0	7
Portsmouth Care Home	9	1
Oxford Care Home 1	1	6
Oxford Care Home 2	6	0
Portsmouth Neighbourhood	0	8
Oxford Information Line	2	4
Oxford Transport 1	5	1
Oxford Transport 2	1	12

Figure 10: Number of participants living with or without diagnosed dementia or other cognitive impairment at each age group and gender.



	With diagnosed dementia or other cognitive impairment	Without diagnosed dementia or other cognitive impairment
Females in 60s	1	2
Females in 70s	6	6
Females in 80s	6	10
Females aged 90-100	6	3
Males in 60s	1	1
Males in 70s	0	3
Males in 80s	2	8
Males aged 90-100	2	6

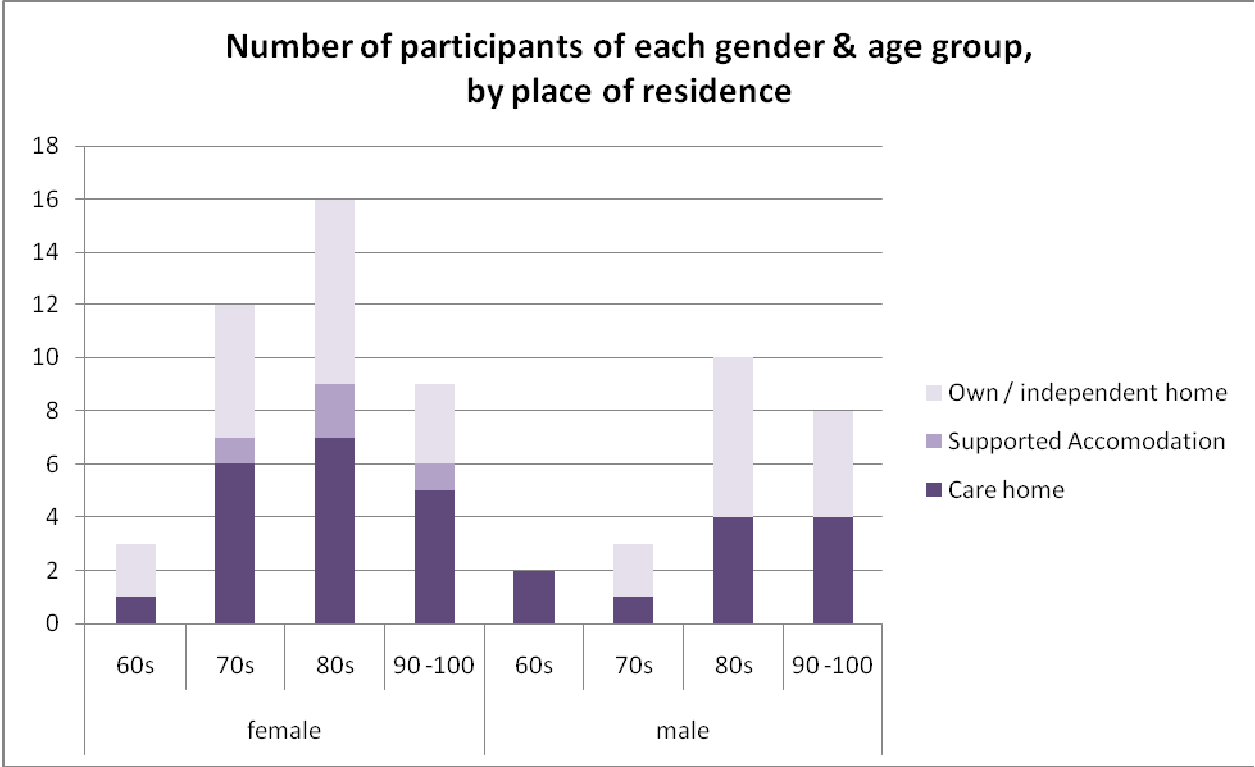
Figure 11: Number of participants living with or without diagnosed dementia or other cognitive impairment by gender and workstream type.



	Participants with diagnosed dementia or other cognitive impairment	Participants without diagnosed dementia or other cognitive impairment
Females in Care Home workstreams	12	7
Males in Care Home workstreams	4	7
Females in Care Home Neighbourhood workstreams	7	14
Males in Care Home Neighbourhood workstreams	1	11

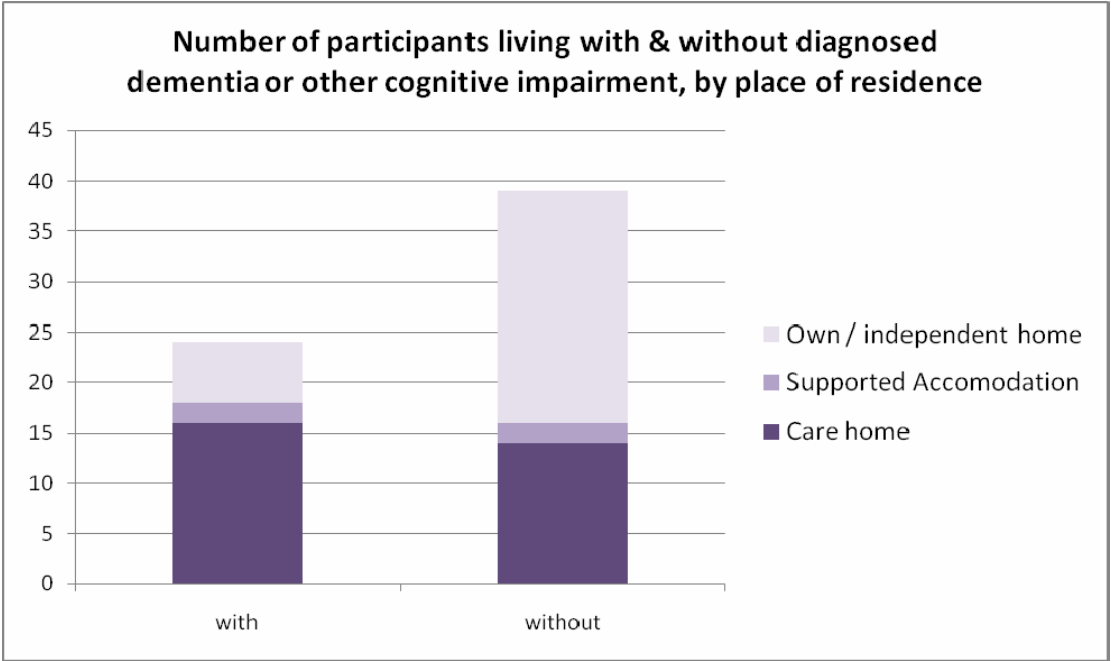
Place of residence

Figure 12: Number of participants of each age group and gender by place of residence.



	Own/independent home	Supported accommodation	Care home
Females in 60s	2	0	1
Females in 70s	5	1	6
Females in 80s	7	2	7
Females aged 90-100	3	1	5
Males in 60s	0	0	2
Males in 70s	2	0	1
Males in 80s	6	0	4
Males aged 90-100	4	0	4

Figure 13: Number of participants living with or without diagnosed dementia or other cognitive impairment by their place of residence.



	Own or independent home	Supported accommodation	Care Home
With diagnosed dementia or other cognitive impairment	6	2	16
Without diagnosed dementia or other cognitive impairment	23	2	14

Appendix 7 – Recruitment template

The recruitment template consisted of an excel spreadsheet, containing 50 blank rows in which we asked site leads (e.g. care home managers) to insert anonymised details about the people who had been on the receiving end of SERI initiatives. Once these spreadsheets had been completed, members of the NDTi research team then picked a sample of people to be invited to participate in the research.

The table on the following page shows what the excel spreadsheet looked like.

Recruitment template

Please help us identify potential participants in this research by completing the details below for all the older people with high support needs who are, or will be, receiving support through your ODI Regional Initiative activity. At this stage we do not want identifiable information for these people - once we have chosen our sample (from the anonymous information you provide below) we will be asking you to contact those people on our behalf, with information that we will provide. If at that stage they choose to be involved, we will contact them direct from then on.

If you would like more information about this spreadsheet, or the research in general, please contact Anita Wilkins at the National Development Team for Inclusion, on 07545 922 227, or Dr Gillian Granville, Chief Researcher, on 07738 101 788

Please return the completed spreadsheet to Anita Wilkins at:
anita.wilkins@ndti.org.uk

Site name:

Name/Contact detail for person completing this spreadsheet:

Each person recruited was asked the following:

- Age
- Gender
- Ethnicity
- Diagnosed with dementia or other cognitive impairment?

- Anything else it might be helpful for the researchers to know?
- As far as you are aware, is this person likely to need any particular support to help them interpret information and make decisions about participating in this research? If so, please indicate which of the below might be helpful for this person.
 - Large print version
 - Easy read version
 - A researcher to talk through information over the phone
 - Someone else (a 'consultee') may need to be involved, to help this person decide / communicate this person's preferences
 - Other type of support (please briefly describe)

Appendix 8: Interview Schedule Guide

(These questions are for RESEARCHER reference, to be used alongside graphic template and imagery*)

The purpose of the individual interviews is to find out the experiences of older people with high support needs living who are in residential or nursing care, or who are at risk of moving into residential or nursing care, and who have been involved in the Independent Living Regional Initiative. In particular, the areas of enquiry are:

- What are the individual's experiences and feelings of voice, choice and control now?
- What are the key influences on these experiences and feelings?
- What is changing, or has changed, for these individual's as a result of the Regional Initiative Activity?
- What has helped or hindered change?

The questions have been developed from recent research from the Joseph Rowntree Foundation that identified Older People's vision of "Keys to a Good Life".

There are to be two types of individual interviews:

1. Short semi-structured interviews lasting about 30 minutes with older people who may not want to talk for a long time or who need extra support to take part
2. Case study interviews lasting about one hour for people from the focus groups who indicate they would be happy to have a longer one to one interview.

Visual prompts and interactive templates tools will be used to assist in answering the questions.

*[nb Imagery from the interactive template is included at the end of this Appendix document – these templates were printed two sided on A3 paper, and folded to make an A4 ‘booklet’. Separate / larger versions of the individual diagrams, images and headings were also used by researchers (i.e. one A4 page per question / dimension)]

Introduction and welcome:

Researcher introduces herself and NDTi

- Check that person has received pre interview information (which will describe the purpose of the project)
- Quick recap on purpose of the project and interview
- Check that the purpose of the interview is clear and answer any initial questions
- Re-check any support needs
- Check that person agrees to interview and is OK to continue for the moment
- Reminder that interview can be terminated at any time the respondent wishes

Opening questions

- How long have you lived here? In this neighbourhood?
- Can you describe a typical week for you?
- Would you mind describing what a good day is for you?
- What happens on bad days?

1. Personal Identity

- Do people call you by the name you want them to?
- How much do you feel your wishes and views are taken into consideration?
- If you wanted to choose some clothes for yourself or a gift for a close friend or relative, would you be able to?

2. Meaningful relationships

- How much do you get to chose who you spend time with?

- To what extent do you think people are aware of your feelings and how they affect you at different times? How do they respond? Can you give any examples?

3. Personal Authority and Control

- Do you feel in charge of important decisions in your life?
- Do you have a choice about how your money is spent?
- When did you last ask for something different or new? What happened?

4. Home and personal surroundings

- How do you feel about living here?
- Do you feel like your environment/ room/ home is personal to you?
- Are you always able to have access drinking water water? Are you able to have something to drink when you feel like it?
- Do you have friends/ family visiting you?
- Where do you usually meet family and friends? How does that decision get made? Do you have a choice? Is there somewhere private if you wish?

5. Meaningful Daily and Community Life

- When was the last time you had an opportunity to do something for a friend or someone else? Are you able to do that as often as you wish?
- To what degree are you able to choose how you spend your time, both at home and outside/ in the community?

6. Personalised Support and Care

- What would improve your life here now?
- Do you feel you have the individual support you need to live a good life? Does the support happen in the way you want it to?
- What is done differently for you than other people you know who need support (or who are living here)?

The Most Significant Change and closing question

- Looking back over the last month, what do you think has been the most significant change in your life in this home/ community?
- What are your hopes and wishes for the future? How do you see things changing?

Thank you for taking part.

The following sheet shows the interactive prompt sheet template that was given to people participating in the interviews.

Participant sheet 1: Voice Choice and Control

Firstly a bit about you ... how long have you lived here?

This is a typical week for me:

- My Good Days
- My Bad Days.

Voice ? Choice & Control

Participant ID:
Date:

Firstly, a bit about you...



How long have you lived here?

A typical week for me:

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

GOOD 😊 DAYS

BAD ☹️ DAYS

Participant sheet 2: About me and my life

1. My identity – what makes me, 'me'
2. The people in my life – family, community, (paid) support, (unpaid) friends
3. Who decides – What I'd like? Where I live? How my money is spent?
4. Home and my personal surroundings
5. My daily and community life
6. Support and care that works for me

Finally, what is the most significant change in all these things?



Participant sheet 3: Looking to the future

What are my:

- Hopes
- Wishes
- Changes

and finally...

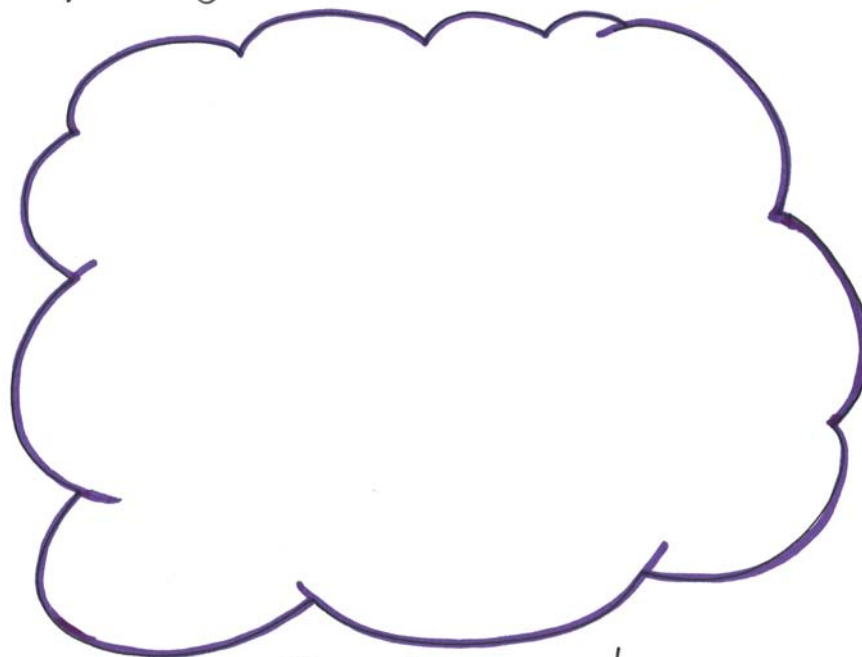
Looking to the

future...

★ Hopes?

★ Wishes?

★ Changes?



Thank You!

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