

Involving older people in improving their well-being

Shaping our Age

Voices on well-being

A report of research with
older people

November 2011

Acknowledgements

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We are especially grateful to the 163 people who took part in the focus groups and interviews and the 3 people who responded to our questions by email. Their involvement and insights are greatly appreciated.

Voices on well-being
A report of research with older people
November 2011

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The report is available to download at
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Summary

Introduction and background

Shaping our Age is a three-year, Big Lottery Funded project and unique partnership between WRVS, the Centre for Citizen Participation at Brunel University and the Centre for Social Action at De Montfort University. The project aims to provide new ideas and insights to the emerging issues around ageing by:

- Exploring how older people aged 65 and over understand and define their well-being (Phase One of the research)
- Selecting five WRVS services to participate in action and development projects (Phase Two)
- Developing participatory ways through local activities in which older people can help each other to achieve well-being (Phase Three)
- Providing the learning that can help to enable and support older people to improve their well-being (Phase Four).

The context

The numbers and proportion of older and very old people will continue to grow significantly. The debate surrounding this tends to frame older people as a problem especially at a time when cuts in public spending are imposing financial constraints on systems of care and adding to the 'cost burden' on a decreasing proportion of taxpayers. *Shaping our Age* challenges these negative perspectives and highlights the opportunity for older people to be supported and enabled to be active contributors to society and to challenge notions of dependency.

This report presents a summary of the key findings from Phase One of the project, in which a diverse range of older people define their well-being, the factors that shape it, the barriers to well-being, the impact of services on well-being and suggested improvements. Participants shared their views and concerns with us in focus groups and qualitative research interviews.

Definitions of well-being

Participants define well-being as feeling healthy, free from pain and able to lead a positive life. They describe the feelings of well-being as: happiness, contentment, satisfaction, peace of mind, comfort, enjoyment and euphoria. Well-being is also associated with feelings of self-worth and achievement.

Causes of well-being

By far the most frequently mentioned aspects that contribute to well-being are *relationships and social contacts* with family, friends and neighbours, providing fun,

support and feelings of belonging and being valued.

Also important is *getting out* and having a range of enjoyable *interests and activities* to fill the day. *Keeping busy* and having an active social life help to divert attention from problems arising from ill health and impairments. Particularly important are *groups and clubs*, which also provide structure to people's lives and 'something to look forward to'. The well-being benefits gained from *volunteering, supporting others and campaigning* include meeting people, feeling useful and building self-esteem.

Good health – Physical or mental health is for many the foundation for a positive, active and happy life. People who are able to foster a *positive outlook* and develop *self-motivation* are seen to be better placed to achieve well-being. This also seems to apply to people whose *faith, religion or spirituality* plays a central role in their lives.

Having sufficient *personal finances* to live comfortably and free from worry is considered to be highly important to well-being.

The impact of services on well-being

Positive aspects include good relationships and professional attention from GPs, good hospital services and treatment and support from a range of other health services including chiropodists and occupational therapists. Local council services contribute positively to well-being, especially housing, library and housing services. The voluntary sector is appreciated and associated with locally based services and personable volunteers. Concessionary bus fares and the social benefits of public and community transport are highlighted.

Participants identify far more **negative aspects** of services, especially so for health services where their main concerns include poor communication and difficulties in making appointments in GP surgeries. Poor treatment from hospital staff was a common theme along with a range of other issues including poor hospital hygiene, poor mental health and counselling services and poor disability awareness and understanding. Negative and discriminatory attitudes towards older people within public services are highlighted including lack of respect, empathy, listening, compassion and a neglectful culture.

Concerns are raised about irregular and inefficient public transport services, poor connections and access issues for older disabled people. Poor care services at home and in some residential homes is a concern for some. The cuts in public expenditure are causing anxiety and worry, particularly the closure of community centres, libraries, post offices and potential cutbacks in transport services and concessionary fares. Older people experience difficulties in accessing information about services, especially in an era of increasing use of electronic communication.

Barriers to well-being

The problems arising from having poor physical health and impairments are seen as the main barriers to well-being, especially conditions which create severe and

chronic pain, having negative impacts on mental health, mobility, social life, hobbies and activities. The ill health of others, especially close family, can also be a barrier to well-being especially for carers. Having *mental health* problems is a common issue raised and especially for people with depression and dementia. Other health problems mentioned include insomnia and the side effects of medication. A major impact of poor health is *fear of personal dependence*.

Isolation and loneliness in old age are considered by many to be serious problems and especially so for people who face barriers getting out of their homes, the recently bereaved and people unable to speak English.

Limited finances and poverty in old age are a concern for many. The main issues highlighted are inadequate state pension and unclaimed benefits.

Suggestions for improving well-being

Older people themselves have many suggestions for improving their well-being. Overall, there is a general desire that older people can play a more active role in improving their own well-being. At the same time, there is also a sense that many would need the help and support of others to achieve this. Particular improvements suggested by participants include *getting involved* in groups and activities, volunteering, campaigning and shaping services and policies. Suggestions for helping to facilitate wider forms of involvement include support for black and minority ethnic older people, better access for older people with physical and sensory impairments and reliable/accessible public and community transport.

A key message is to *treat older people with respect and equality* and to improve communication, build trust, give people more time and value the whole person.

There is a call for *practical help and support* in people's own homes by reliable competent and trustworthy people, in particular for help with small jobs about the house and garden and shopping. There is a need for *support at critical times* such as following bereavement, failing health, dealing with, and coming to terms with, impairments.

Participants call for more *intergenerational work* to build positive understanding.

The importance was raised of *providing relevant and accessible information* and promoting this information effectively to older people. This includes information on entitlements. There is also a need to challenge the assumption that all older people can use or have access to the internet.

A number of suggestions are put forward in relation to *personal finance* including help with on-going financial information about pensions, investments and savings.

Conclusions

The findings from Phase One of *Shaping our Age* challenge negative attitudes towards ageing and outdated perceptions that older people have little to offer. From

the outset, a key concern was to enable participants to engage in discussions and share their own views, experiences and suggestions for change.

In defining well-being, there is no one view but a complex picture emerges which tends to define well-being in both subjective and objective terms and at personal, family, community and societal levels.

Participants identify a range of factors that affect their *well-being*. While issues such as health, personal characteristics and faith featured prominently, the main factor highlighted is *relationships and social contacts* with family and friends and within communities. This highlights an important aspect of well-being in that for many older people it is best achieved in conjunction with others at the levels of the family, friends, neighbourhood and community. It is important to say that many older people are already building such relationships and social capital through involvement in a range of voluntary and community activities particularly at local level.

Discussions around services highlight both positive and negative aspects. On the one hand, these reveal that some services and approaches to helping people are working well and are greatly appreciated. However, at the same time, it also reveals how some services and professionals (and particularly health services) are falling far short of the expectations of older people.

Much of the discussion in relation to barriers centres on health and impairment issues although social, cultural and financial constraints are also highlighted. The focus of discussion on health and impairment reflects thinking around traditional models of ageing and disability with an emphasis on personal adjustment and medical interventions. This highlights the importance of the relationship between ageing and disability and health, re-emphasising the social aspects of all of these.

In keeping with participants' analyses of well-being and what shapes it, there is a strong message that it is about people being able to do what they want to do – to have choice and control. This finding highlights that the promotion of *individual and collective agency* is a vital component in achieving and sustaining well-being at both individual and societal levels. Older people may also need practical help and sufficient resources to facilitate this engagement. However, it also makes clear the importance of structural issues, including structural barriers and constraints. A key tension to emerge during the discussions and which runs counter to these aspirations for involvement and empowerment, shared by both older people and current policymakers is the negative impact of '*the cuts*' to public/voluntary services and to transport, which are undermining the positive aspirations to self-help and mutual aid within social policy.

In the next phases, *Shaping our Age* aims to explore new ways of involving older people in the development of services and support to enhance their own well-being. The issues raised in the consultations have contributed to the selection of five services. We plan to enable and support older people to be actively involved in a process of development and learning. The learning from the programme will inform WRVS and will be disseminated widely to inform service development at wider levels.

Introduction

Shaping our Age is about involving older people in improving their well-being. It is a unique partnership between WRVS, the Centre for Citizen Participation at Brunel University and the Centre for Social Action at De Montfort University. These three organisations share a commitment to involving older people in improving their well-being.

Shaping our Age aims to provide new ideas and insights to the new and emerging issues around ageing which now face us all. It has two key concerns; older people's well-being and their involvement. What is different about this UK-wide project is that it seeks to connect and interweave the two. We make a direct link between older people getting involved and improvements to their well-being. This is especially important because of the repeated failure to enable and support older people to be meaningfully involved in issues affecting their lives.

Shaping our Age is a participatory research project and is funded by the Big Lottery Fund for three years from 2010 to 2013. Its objectives are to:

- Explore how older people understand and define their well-being
- Develop participatory ways in which older people can help each other to achieve their well-being
- Provide the learning that can help to enable and support older people to improve their well-being

The project will be implemented in four phases:

- **Phase 1:** National consultation on well-being with a diverse range of older people across the UK
- **Phase 2:** Defining well-being and the selection of five WRVS services to participate in the action projects
- **Phase 3:** Local activities in the five local sites
- **Phase 4:** Dissemination and action

This report will present an overview of the findings from Phase One, conducted between January and May 2011. This involved a UK wide consultation with older people (ages 65 +) around the important concept of well-being. We worked hard to access, engage and include a diverse range of older people. We do not claim that the participants are representative of all older people. Nonetheless, they reflect the views of a diverse range of older people both within and outside WRVS, service users and carers, volunteers and activists. Most importantly, these voices include their understandings of well-being, *their* interpretations of what shapes it, *their* experiences of services, the barriers *they* encounter and *their* suggestions for change.

The next section provides the background to the study and why it was conducted.

The third section describes how the research was carried out. This is then followed by the largest and most important section, which summarises the key messages of participants and what they said about:

- Well-being, including their own understandings and definitions
- The factors that cause and shape well-being
- The barriers that get in the way of them achieving well-being
- The impact of services on their well-being
- Improvements that might help to achieve well-being

We conclude by pulling together the key messages from the research consultation and look to the next stage of the project. Appendix 1 gives details of the groups which took part. Appendix 2 provides a copy of the discussion guide. Appendix 3 provides information about the authors.

Background

Two fundamental changes in relation to ageing are currently taking place. These changes provide the background for *Shaping Our Age* and are the rationale for the project. The first of these changes is demographic. The numbers and proportion of older and very old people in our society have and will continue to grow significantly. The debate surrounding this has tended to frame older people as a burden and problem, as passive and with greatly increasing needs expected to come the way of public services because of a rapidly rising incidence of physical and mental impairments (Brindle, 2011; WRVS, 2011). At the same time, our capacity to pay for these increased needs is seen to diminish as a smaller proportion of taxpayers are predicted to have to meet the greatly increased 'cost burden'.

This negative perception of older people reveals a deeper concern. The problems of an ageing society are still seen within a traditional deficit model of 'care' and as something to be fixed by medical, psychological and other interventions. Within this model, older people are still largely viewed as passive recipients of ageing policies, strategies and services (JRF, 2004; Reed, 2007). The use of negative language in the media and the public domain runs the risk of promoting this view and these perceptions are compounded by the current recession and by ongoing reductions in public expenditure.

This negative perception of ageing ignores the gains of living longer, the many ways that older people contribute to society, to building personal relationships and social capital (WRVS, 2008; WRVS, 2011), the bonds and interactions between generations and makes un evidenced assumptions about the health risks of extended age. It is stuck in traditional service-based models of support, which ignore the key part that policies and practice based on seeing, valuing, and responding to the whole person can play in maintaining capacity, confidence and contribution.

The second change is the recent political and public interest in the idea of 'well-being'. It signals a welcome shift away from policy approaches that see ageing as a problem and older people in terms of deficit. However, so far, it has mainly been medically and health based, rather than paying equal attention to social and other issues that impact on people's lives. It has tended to rest on 'expert' and professional judgements of what constitutes well-being and has paid little attention to older people's voices, focusing on other groups and their valuable take on well-being has largely been overlooked. Consequently, levels of engagement of older people in these debates remain low and continue to be inclined toward the consumerist rather than the empowering ends of the spectrum (Carter & Beresford, 2000; Walker, 2007). This, when combined with often-low expectations of older people, has meant they have been largely excluded from the key debates. This exclusion is a particular problem for black and minority ethnic older people, older people with learning difficulties, older mental health service users, older disabled people and those with sensory impairments (JRF, 2000; Casey & Flint; 2009; Centre for Policy on Ageing, 2011).

Both of these debates tend to be framed in negative and narrow terms. At the same

time, both offer major opportunities for improving the life chances of older people. It is also important to acknowledge the work that has been conducted in this area and its contribution (Bowling et al, 2003; JRF, 2006; JRF, 2009; NEF, 2009). *Shaping our Age* wants to build on these debates but to approach them in a new way by exploring older people's well-being within a participatory framework. Our starting point is older people. We believe that a cultural shift is needed in how we view older people and ageing. So instead of a 'sickness' approach which focuses on illness, or a 'welfare' one preoccupied with 'special interventions', breakdown and disadvantage, the emphasis is placed on promoting well-being within people and communities.

The project approach

Shaping our Age starts with the strengths, knowledge, skills and experience of older people. We need to see older people as less a problem group with specific needs and focus on how they can be supported to be active contributors in society. Older people's involvement is a crucial starting point in this process and is essential if negative perceptions of ageing and notions of dependency are to be challenged. *Shaping our Age* underlines the importance of older people being active both individually and collectively to improve their well-being. Older people need the opportunities and the support to shape their own visions of what constitutes a better life for them, and help to address the practical challenges of ageing. This is a critical starting point to devising new approaches to improving the well-being of older people.

The relationship between well-being and inequalities is also crucial. Older people cannot be abstracted from wider social forces that have largely determined their life chances and continue to impact on the resources at their disposal and the choices they make (Bond & Corner, 2004). Both diversity and inequality highlight the importance of hearing a range of voices and particularly those older people who are most excluded in our society. As part of exploring new models, it is crucial that we acknowledge that older people are a highly diverse and heterogeneous population. In addition to issues of age, there will be many different experiences based on categories such as gender, race, sexual orientation, religion, class, culture and physical and mental ability. In addition, there are many cultural differences based on national boundaries and particularly within the context of devolved political administrations in Scotland, Wales and Northern Ireland. Diversity also raises issues about individual/community differences and whether it is possible to achieve a societal consensus on well-being.

WRVS has committed itself to incorporating the lessons learned from this initiative in its own future operation. The project is running at a time of exciting change within WRVS with the roll out of its new Service Delivery Strategy system based on a person-centred approach. WRVS plans to create a network of service hubs throughout Britain which will provide an integrated range of services. *Shaping our Age* will bring new learning and insights to enhance this new and evolving approach to service delivery. It thus provides a test ground for a new participatory approach to service delivery, which will lead to improvements in older people's well-being and has potentially wider relevance both nationally and internationally.

Methodology

This section of the report describes the research approach and methods used in this UK-wide consultation programme.

1 Participatory research

This study aims to explore the meaning and intensity of older people's views about well-being and to gain authentic insight into their experiences and understanding of the term. Focus groups and qualitative interviews were undertaken to allow older people to explore their understandings of well-being and to express their opinions freely in their own terms. During focus group sessions, researchers encouraged participants to debate and react to each other's experiences and opinions and to pursue their own priorities whilst the interviews enabled them to present their individual stories, experiences, opinions and feelings in some depth. The project adopted a participatory approach to research seeking to involve older people in all aspects and stages of its work.

2 Recruitment

The participation of older people from a wide range of backgrounds, areas, communities and with differing needs and experiences was crucial to understanding what 'well-being' means to older people and its many causes and barriers. This project adopted a method typically used in participatory research for contacting hard to reach and vulnerable groups, namely the use of trusted intermediaries, or 'gatekeepers'.

Key gatekeepers

WRVS is a national charity with a comprehensive network of staff and volunteers throughout England, Wales and Scotland running support services for older people including luncheon and day clubs, community transport, Independent Living and Home Support schemes. WRVS staff are also well connected to community support services and networks. *Shaping our Age* was well placed, therefore, to recruit a diverse range of older people to the research through WRVS 'gatekeepers' and their contacts.

Further contacts were provided by the two groups that were recruited as advisers to the project. Firstly, the Partners Group includes representatives from government departments and public, private and voluntary sector organisations. Secondly, the Older People's Reference Group comprises 15 older people with diverse experiences and skills from locations around the UK. These two groups provided advice and recruitment contacts. Significantly, our partner in Belfast, Engage with Age, acted as gatekeeper in Northern Ireland, where WRVS does not currently have a presence.

A recruitment guide was devised on the basis of:

- a Geography
 - i Rural / Urban*
 - ii Six key regions/cities in England, Wales, Scotland and Northern Ireland*
- b Black and minority ethnic people
- c Disabled people or people with health problems
 - i mental health users*
 - ii people with dementia*
 - iii people with sensory impairments*
 - iv disabled people*
 - v people with life-limiting illnesses and conditions*
- d People living in residential care
- e Older carers
- f Lesbian, gay, bisexual and transgender (LGBT) people
- g People with learning difficulties
- h People on low income
- i Prisoners or ex-prisoners
- j Homeless people
- k Other reasons
 - i Older people in paid employment*
 - ii Single older men*

The recruitment guide was an 'active' document which changed as some groups proved to be inaccessible and others emerged. Although six key locations were identified as the focus for research, consultations also took place in other areas of the UK.

Recruitment was undertaken by three researchers who also conducted most of the consultations. Some interviews and focus groups were conducted in minority languages and facilitators with native language skills in Urdu, Welsh and Cantonese were recruited to run these sessions.

The researchers sent gatekeepers information about the project and requested help in recruiting men and women aged 65 and over to take part in the consultations. In the main, focus group participants were recruited from pre-existing voluntary and community-based organisations including luncheon and day clubs, older people's forums and older volunteers. It could be argued that using this approach focuses on people who are engaged in activities and connected to their communities and misses people who are more isolated. Moreover, a group of people who meet regularly might well share common views and experiences which are not representative of the wider community of older people. However, we feel that the

number and diversity of older people covered in the focus groups has helped to address these issues. In addition, participants involved in older people's groups have extensive experience and their insights considerably enriched the consultations. Individual interviews were also conducted with people who were living alone or in care homes.

Participant profiles

In total 163 people were consulted: 38 were interviewed and 125 took part in focus groups. There was a good cross-section of participants by age, gender, location, ethnicity and disability. Another three people returned their responses by email (not included in Table 1). Appendix 1 includes a list of the individual consultations achieved.

Number of participants	163 in total 125 in 16 focus groups 38 in 30 individual or paired interviews
Age	65-69: 24% 70s: 43% 80s: 29% 90s: 4%
Gender	48 Men (29%) 115 Women (71%)
Ethnic origin	23% Black and minority ethnic communities 77% White British
Location	Urban: 60% Rural: 40%
Day to day activities limited because of a health problem or disability which has lasted or is expected to last, at least 12 months	No: 37% A little: 36% A lot: 27%

All profiling data were self-defined by participants.

Pilot focus groups and interviews were undertaken to test and improve recruitment processes, topic guides, information sheets and methods for achieving informed consent.

3 Data collection

Discussion guides for the interviews and focus groups were designed and based around the following main topics:

- Defining the term 'well-being'
- Causes of well-being
- Barriers or blocks to well-being
- The role played by local services in shaping well-being
- Improvements needed to enhance well-being in older people

A full discussion guide is included as Appendix 2 to this report.

4 Ethical considerations

Before the consultations began, ethical approval for the project was granted by the Faculty Research Ethics Committee, Health and Life Sciences, De Montfort University.

During recruitment, gatekeepers were asked to hand out information sheets, explaining the project and purpose of the consultations so that older people could give their informed consent or otherwise. Before each session, participants were asked to sign consent forms for taking part, for audio recording and for anonymous quotations and materials to be used in reports and academic papers by WRVS, Brunel University and De Montfort University.

Researchers assured participants that their comments would be treated in confidence and that they would not be identified in any report of the findings. Participants were offered a summary report of the findings.

In some cases, and where necessary, we covered the costs of travel expenses and room hire.

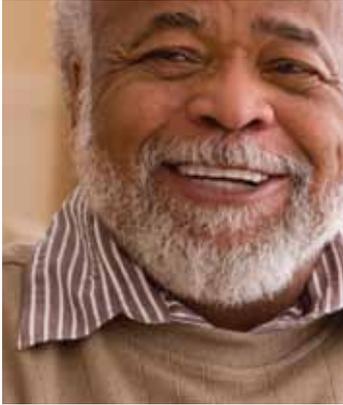
5 Analysis

Each interview and focus group was audio recorded and fully transcribed. The three main researchers together devised a broad thematic framework for qualitative analysis based upon their experiences of facilitating the sessions and reviewing the scripts. This framework was used to guide detailed coding of the transcripts using the text analysis programme, NVivo (NVivo 9 SP2 qualitative software). Whilst coding, researchers were careful to use evidence from the scripts rather than basing interpretations on any prior assumptions and the original

framework was adapted as coding progressed to accommodate emerging themes.

Researchers summarised the initial findings into a presentation to a meeting of the Older People's Reference Group (the group made up of older people from the four UK countries to advise the project). Three focus groups comprising members of this group discussed the results and provided useful feedback, giving further validity to the findings.

As far as possible, we feel that analysis has been thoughtful and thorough and that this report presents an honest presentation of the views of the participants and it identifies indicators of well-being of older people living in the UK.



Well-being is in your head, isn't it?



Well-being is independence, definitely independence



Definitions of well-being

For many participants the term 'well-being' is not one that they would use in everyday life or conversation, although some who are involved in voluntary work or through professional experience said that they do, or would have, used the term. Most participants had little difficulty defining the term although they had much more to say about the causes of well-being as presented in Section 5.

Participants were asked to describe how it feels to have a sense of well-being. For many, feeling healthy, fit, free from pain and able to lead an independent life are the main aspects which define well-being for them. The strong association between good physical health, mobility and independence are highlighted by many along with the interplay between feeling physically and mentally healthy:

Having good health you look at things in a positive way and of course good health makes me have a real sense of well-being.

(Well-being is) independence, definitely independence.

For many, well-being is purely defined by a person's mental health:

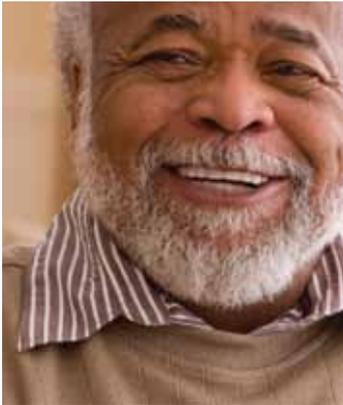
'Well-being' is in your head, isn't it? It isn't a physical state, it's a mental state: how you are with yourself and other people.

(Well-being is) a warm feeling in the mind.

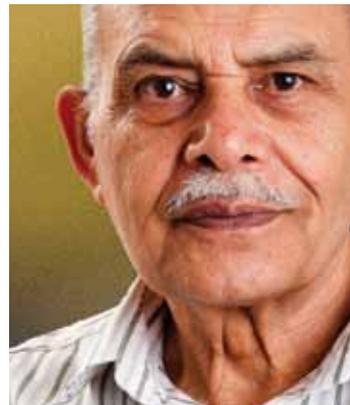
Participants draw on a variety of words to define their feelings of well-being. The most commonly used are happiness, contentment, satisfaction, peace of mind, comfort, enjoyment and euphoria. Participants also suggest that well-being is to do with an acceptance of their circumstances or of being at ease with themselves:

I think peace of mind and if you don't have peace of mind you can't be happy and contented ... it means that you've a reasonable amount of health and you don't need to be wealthy but you do need to have enough finance to cover your needs every day ... Security, yes, independence. I think once you become completely dependent on people you lose your peace of mind ... there's nobody that's happy to be totally dependent on either relations or the state.

I'm quite happy with what I've got actually, I'm quite happy. I accept what I've got and I'm quite happy at the moment.



Well-being is coming here to the [community] centre



We have a good laugh ... a day to look forward to



Causes of well-being

Participants were asked to identify the causes of well-being and while they were by no means an homogenous group of older people, many common themes emerge. These are presented in this section broadly in order of the frequency of mention by participants. This is a convenient way of ordering the themes but it should be noted that this order is not the same for every individual and changes according to circumstance and experience. Themes mentioned by relatively few participants should be considered important to the discussion as they are significant to the individuals concerned and highlight the complex issues faced by this diverse group of older people.

1 Relationships and social contacts

By far the most frequently mentioned aspects of life that contribute to well-being for participants are relationships and social contacts. This applies to people from all walks of life and in all circumstances. Many mention that being with other people focuses their minds on matters other than their own worries and puts any concerns into perspective:

It's diverting your mind, its making you think about other things.

Family

Having fun with and being cared for, loved and valued by close family members are the most important aspects contributing to well-being for many participants, even for those whose families are at a distance:

Family warmth, I think. Knowing that they care. Even if they're not there ... they're not near you, you know they care. They're on the phone.

Participants particularly value their relationships with their children and grandchildren although siblings and partners are also mentioned. As well as deriving enjoyment from spending time with family, the support and care from family provides a sense of security and lessens anxiety for many participants:

Now my family moved back to this area and it's absolutely brilliant and I just need to pick up the phone and if it's (help with) technology it's my 10 or 15 year old grandson. If it's something else it's my son. I feel I've got more security because of that.

Many are wary, however, of imposing too many demands or becoming burdensome to their families:

And if I want anything they're there but I don't trouble them unless I'm absolutely forced. I try to manage.

Grandchildren are a source of pleasure and pride and many said that their grandchildren help to take their minds off their problems and ailments. Some participants provide childminding support which gives pleasure and keeps them closely involved with family:

Oh I've got ... two very hungry grandsons who come from school every day and eat us out of house and home ... Oh I just feel elated, just feel good you know; good to

see them you know.

Knowing that their children are settled and their grandchildren are doing well is a great source of satisfaction and well-being to participants:

I mean, I'm a thinking person and I think, well, all my children have got jobs, I've got no grandchildren that have gone 'off the rails', as yet. They're all doing well at school.

Friends, company, neighbours

For many participants, friends are just as important as or even more important to their well-being than family and for those without family at all or without family living close the support of friends and neighbours is particularly valued:

Because your family have got to go to work, earn a living and they haven't always got that time, whereas if you've got a friend or friends you can go and talk to them.

The therapeutic power of good conversation and laughter are highlighted by many participants as are the practical benefits arising from supportive friendships:

You know; if you have laughter it's worth a bomb, init? It really is.

The people that I've met since I've been a widower have all been very ... can't find a very good word for it, actually? They never look down on you ... They treat you as what you are and they've all been very, very ... very, very helpful.

Groups and clubs

Groups and clubs take on a variety of forms from Older People's Forums to Day Clubs and as well as offering social interaction they give structure to people's lives and 'something to look forward to'. They also provide a sense of belonging and of feeling welcomed and valued by others:

We have friends here that we can talk to and we have a good laugh by having games and a day to look forward to.

Some men mention the benefits gained from men only groups and activities in retirement:

It's mostly females that I meet and so one of the reasons I play golf is because I meet men like, you know. Men's company is far different than women's company. You talk about different things – it is very, very important. Yes I would miss that ... When we were in work it doesn't really matter because I met men all the time you know.

Participants suggest that instead of medication and counselling, many people would be better served by joining groups and meeting people. Our partner organisation in Northern Ireland, Engage with Age, actively encourages isolated people to join clubs and groups to improve their self-esteem, confidence and quality of life:

Well we just look for opportunities and exploit the opportunities to help older people, you know if there's any opportunity out there that we run across we use that to try and get older people out of their homes, especially isolated older people ... so the minute we hear of someone who is on their own but would be interested in getting

out we're straight in there and we try to get them into groups ... it sort of prepares them for being in groups and getting used to being with other people in that sort of atmosphere and then once they do that then they can also choose to go into second or third groups if they want to.

The contribution of clubs/groups towards maintaining cultural values is highlighted by participants from Asian and West Indian backgrounds:

... so it was to keep people with Caribbean heritage, it was to keep them connected, make sure that all the heritage and the culture is passed between people, different generations.

Interests and activities

Keeping busy with interests and activities and 'filling the day' is frequently associated by participants with feelings of enjoyment, accomplishment and self-esteem. The most popular hobbies and interests are reading, gardening, sewing, knitting, art, other crafts and sport:

I'm a keen gardener. I specialise in Dahlias. I'm self supportive in veg. I've still got beans and runner beans in the freezer from last year. I do me own pickled onions and I sell them at a pound a jar for the WRVS.

It's where the craft groups come in ... so beneficial. I was doing wood carving, which I'd never done before ...

Television is highlighted by participants not only for entertainment but also for company:

But I mean to say if you hadn't the television I don't know what you'd do. I mean in the evening when you never go out I mean you can't be doing things all the time, it does help.

Marked changes in circumstances or traumatic events can trigger new interests:

Since I lost my husband I've taken up Bridge which I love. And I've bought a laptop which is taxing me to the absolute extreme.

Many participants are aware of the physical and mental benefits of keeping active and mentioned their regular activities including walking, yoga, bowls, golf, badminton, volley ball, dancing, swimming, cycling, keep fit and table tennis. The social benefits of keeping fit are mentioned by several participants who exercise in classes or with a group of friends:

Every Thursday morning, there's Keep Fit for Over 50s. That's good for socialising too.

Going out

Going out can involve meeting up with people at various events and groups, but just getting out of the house on their own is enough for some people to benefit from fresh air and exercise:

Well if you've got something to think about when you wake up in the morning, oh I'm going out today, that gives you a lift you know, makes you feel happy.

Places of worship

For a great many participants their place of worship plays a significant part in their well-being and a central role in their lives. As well as spiritual comfort, places of worship offer opportunities for socialising and support from other people. Many churches and chapels hold events and groups and organise trips and holidays geared to older people:

I'm in the Mothers' Union, I go to all the activities there ... Well once a month we'll have a meeting and we have a speaker and then we have tea or coffee, some refreshments and then activities. We have an outing in the summer, we have a meal at Christmas and anything else that crops up and we're part of the church. We arrange things, activities.

Volunteering, supporting others and campaigning

Many participants are active volunteers, whether formally for organisations or informally helping others within their communities. They highlight the many benefits gained from voluntary work, campaigning and helping others with *small acts of kindness*. These benefits include mixing with people, giving something back to the community, achieving a sense of belonging, feeling useful and valued, keeping alert and fulfilled, achieving meaning to life and building self-esteem:

Well I suppose it means that you're worth something, you've got value and that you are actually still using your mind, your ability to think hopefully coherently and put over a case.

I feel fulfilled and meeting other people on a daily basis keeps my mind active and outward focused rather than inwards focused. My health is poor at times but remaining focused on others keeps me from 'wallowing' in self-pity.

2 Good health

Good health, whether physical or mental is considered by most participants to be the foundation for a positive, active and happy life and many regard themselves fortunate in reaching advanced years with relatively few health problems. For many good health is the most important cause of well-being:

That's first and foremost, because you can't enjoy anything if you haven't got a decent level of health, can you?

Good mental health is considered central to a sense of well-being for many participants. Whilst physical and mental health are linked, many agree that even with poor health and limited mobility, older people can achieve a sense of well-being:

Even if I do not have good health I am still a very happy person. I do not let things get to me.

I think even if you haven't got good health you could have a sense of well-being to the sense that as much as you can accomplish ... you get a certain sense of well-being out of the amount that you can do and there will be some days you can do better and it could improve and it could improve your health too.

3 Having a sense of independence

The ability to go about their daily duties without having to rely on the support of others is something that participants hope to retain for as long as possible. Many see having control of their daily lives as essential to their dignity and well-being:

That you feel well enough to be able to carry on with everyday life, like cleaning the house, going to town and that nothing stops you from doing what you want to do.

It nearly always comes back to independence. And the dignity ... the word dignity – that's gotta come in there as well.

Being able to think straight and make your own decisions still.

Regaining a sense of being independent after traumatic illness is highlighted by a few participants. One man describes how recovering from a stroke and regaining control motivated him to such an extent that he is now not only able to look after himself but also works hard at helping other people:

I enjoy getting out, I enjoy meeting people, I enjoy trying to help people and ... four years ago, as far as I was concerned my life was finished. I couldn't move. I couldn't do anything for myself. Then I started living on my own and I'm independent ... independence is a very great motivator and hopefully I'll keep going on from strength to strength.

4 Place and environment

The contributions of place and environment to well-being are mentioned by a number of participants and particularly the part played by living in and belonging to a supportive community and being proud of where they live:

The goodwill in this area is fantastic. Absolutely fantastic.

Well he's (David Cameron) on about this big community like but in Stoke-on-Trent it's always gone on. Everybody looks after one another, they have no choice really ... It's not new is what I'm saying, it's not new.

Being able to see passers-by from home is a comfort for participants:

Yeah well I'm lucky because I live on the main road and different people will call, you know, and again the Post Office up here, people are coming past all the time.

Being comfortable and happy at home is mentioned as a source of well-being:

I mean I'm quite happy in my own home, I've got a nice comfortable home.

Those living in sheltered accommodation highlight the many benefits as safety and security, a good social life, warden assistance and freedom from the worry of upkeep:

It's wonderful, absolutely wonderful because you can ... either join in all the activities, which you know are on every day, or you can, you know, sort of be independent and stay on your own if you want to.

Other aspects of place and environment which contribute to the well-being of

participants include:

- Feeling safe and secure in the neighbourhood/local area
- Sunny weather and taking pleasure in the outdoors
- An attractive natural environment – scenery, flora and wildlife

5 Positive attitude

Some participants believe that being able to have a positive attitude to life makes it more possible to attain a sense of well-being:

I've been happy despite the adversity and I'd always wondered about that. I could never understand it. So, health is a kind of double-sided thing ... and some people do go under because they have bad health, but other people – and I know quite a few – seem to flourish, despite their bad health.

Others refer to self-motivation as being important to achieving well-being and living a full life:

You know and everybody has that in them to self-motivate themselves, they just need to bring it out a bit that's all you know.

The need to take responsibility for well-being of self is an often-repeated sentiment, particularly regarding diet and physical health:

Well I think well-being ... you do things to improve your health and then you can have your own independence, even if you're not feeling well sometimes. Yes I do think you have to work at it. It's no use sitting down.

Having the strength of character to adapt to changing circumstances is a common theme:

When you get to a point of change – I was a keen sportsman. I played cricket, football, up to a certain amount. When I got to a certain age I couldn't do that anymore. And I suppose, it's about two years before it gets into you that you've gotta find something else or do something else.

Memories

Many participants derive pleasure from remembering their past lives:

That's something that enriches your life; your memories. And you build memories if you're lucky enough to build memories together.

Accomplishments

Participants frequently mention that their achievements or accomplishments, whether in the present or in the recent or distant past, contribute to their feelings of well-being and self-worth. These accomplishments include, for example, every day domestic tasks, academic success, learning a new skill or receiving the offer of a job:

I cut a hedge yesterday and cut myself to pieces with it but I were pleased.

6 Faith, religion and spirituality

For a great many participants faith, belief, religion and spirituality play a fundamental role in their lives and help to shape their feelings of well-being:

Well, during the bad times, it was very comforting because I did feel that I could, sort of, hand it over to somebody else, I guess, when I was really down. So my belief is really quite powerful in that respect. ... But I get quite a lot of ... I don't know ... mental help, I suppose, from that - mental support from my belief.

Reading the Koran and praying daily is a particular source of comfort to Muslim participants:

She was saying that it's obviously important in her daily life because when she reads her Koran and reads her daily prayers, she says it gives her like a sense of serenity in her life (through an interpreter).

A few participants stress that other kinds of spiritual experience can add value and well-being to life:

There are people who have no religious affiliation at all, yet still have a great deal of spirituality. It can be about places, it can be about people, it can be about animals ... pets.

I have a great belief in spirituality, which I think goes way beyond most people's religion. It's a sense that we are all interconnected and we're all part of the same thing ... and because we're all interconnected we all matter to each other.

7 Finances

Having sufficient personal finances to live comfortably and free from worry is mentioned. Some participants see financial security as second only to health in terms of its importance to well-being:

Health, straight away. Then, financials, obviously.

Some feel that they are more comfortably off than in their younger days and describe how this contributes to their quality of life and 'peace of mind':

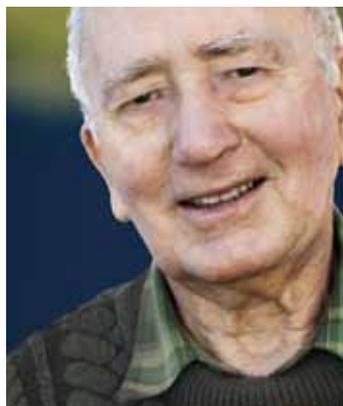
I've never been better off in my life ... that's why I'm still living and quite happy with everything ... it's nice to have something behind you isn't it? I can go to bed at night and lie straight in bed and go to sleep because I don't owe anybody anything.

Other participants describe how they need to be careful with money and live within their modest means to ensure contentment:

It's not a lot what you've got but you do make the best of it don't you.

Well you cut your garment according to your cloth don't you? If you haven't got it you don't spend it.

Thank goodness
the free bus has
been ... saved
for the moment



People deciding
what's good for
you, not asking/
thinking what's
good for you

The impact of services on well-being

Under this section, we asked participants questions such as: How important are local services in creating wellbeing for older people? This enabled participants to reflect on their own experiences as a service user and to share these individually and collectively. From these responses, there is a clear message that older people's well-being can be greatly enhanced by having positive experiences of particular services.

1 Positive impact of services

Overall, there is a very clear message that older people value good public, health and social services and that these are important to them:

... the Health Act of 1948 was something very wonderful.

GP services

Many participants stress the value of the health services and particularly the relationship with the GP as being important contributors to retaining a sense of well-being. It was also felt important that GPs are accessible, approachable and that appointments are arranged promptly:

The doctors down there are lovely. They're really nice.

Hospital services

There is a lot of praise for good hospital services and the positive impact of good treatment from consultants and hospital staff on people's sense of well-being:

Luckily, we've had a very good consultant ... and it's made our lives wonderful.

Other health services

Other services are also mentioned as providing vital support that influences well-being. These include nursing, pharmacy, chiropody, podiatry, occupational therapy, optical, dentistry, pain management and mobility aid services.

Housing, library and leisure services

There are positive feelings and regard for local council services such as sheltered accommodation, libraries and leisure facilities.

Voluntary services and volunteers

Another area highlighted is the significant role played by voluntary sector organisations such as WRVS in providing services. A number of participants feel that voluntary organisations are locally based, easier to contact and more approachable than large public organisations. Furthermore, some participants stress the value of

social support organised around local social groups and centres. In particular, they mention the importance of luncheon clubs:

Luncheon clubs, I think, are a fantastic idea. If you've got a luncheon club and you've got a place that you regularly go to and that.

Volunteers

Most participants value the role of volunteers in providing particular services and organising social activities such as bingo, raffles, lunches, birthdays, singing, music and so on. It was generally felt that volunteers provide a very different service to paid staff. Many and particularly those who are volunteers themselves stress that helping others contributes to creating a sense of their own well-being:

But I think volunteers primarily are more caring ... they're wanting to do it.

If you can help others, you will feel better yourself.

Public and community transport

The positive impact of transport arises in most discussions and particularly the importance of having efficient and accessible transport when needed. Participants emphasise the value of the free bus pass and the social benefits of public and community transport particularly in rural areas:

Well free bus pass I just get on a bus, I go to a town, have lunch and I come back, and thank goodness the free bus has been secured or saved for the moment.

The social benefits of public transport are also highlighted. Some participants also raised the value of assisted travel for disabled people, particularly for long journeys. Similarly, a number of participants from rural areas highlight the value of community transport.

2 Negative impact of services

At the same time, participants also recall negative experiences of services and feel that these affect their sense of well-being. It is important to note that participants express far more negative than positive comments about services and that many who spoke positively about services share significant concerns, particularly in relation to hospital and GP services. Their main concerns can be listed:

Negative attitudes

A key issue to emerge from the discussions is negative and discriminatory attitudes towards older people within public services. In particular, the perceived lack of respect, empathy, listening and compassion. Some participants feel that a negative and neglectful culture exists in some areas and among certain staff which affects the quality and delivery of services and especially for older disabled people:

I feel as we are getting older they have stopped caring and it's become a big burden on our well-being feeling that no-one cares.

... people deciding what's good for you, not asking/thinking what's good for you.

Poor health services

Some participants argue forcibly that the health service contributes very little to well-being. Others stress that a 'post code lottery' exists with some areas offering excellent provision while others deliver poor services. The main concerns in relation to health services can be listed as follows:

Difficulties in obtaining GP appointments are a common concern. This clearly creates a lot of anxiety for people and particularly for older people who are coping with long-term health conditions. Some participants associate these difficulties with unhelpful reception staff:

The most annoying thing is that I just cannot get an appointment.

Poor services from GPs

Some participants also feel that some GPs and staff share the negative and dismissive attitudes towards older people described above. Although many older people acknowledge that ageing and ill health often go together, they feel that some GPs do not take their concerns seriously:

Some doctors, unfortunately, tend to think that when people get to a certain age, well what do you expect ... you've got to a certain age.

Poor communication

Another issue that emerges is around poor communication and lack of human contact with doctors. Participants argue that recent changes to the nature of the GP service have meant that it is now difficult to establish meaningful communication with doctors.

Poor treatment in hospitals

A number of participants highlight poor treatment from hospital staff:

I'm going for another scan tomorrow and I'm dreading it because I went for this scan and the way they treated me, well the carer was with me, it was dreadful.

Reluctance to complain

On the one hand, participants spoke freely to us about their negative experiences of services. When asked if they complain about this treatment most participants respond by saying there is little point or that they are concerned there might be repercussions:

Because older people at home with no family are very much at risk because they're frightened. You know ... 'If I say anything?

Other health related concerns

- Lack of disability awareness and equality in surgeries
- Poor hygiene in hospitals

- Poor mental health and counselling services including bereavement counselling
- Problems of access to minority languages
- Non-availability of GP coverage over weekends / out of hours home visits
- Poor palliative/end of life care
- Poor quality of service provided by NHS Direct

Poor transport services

Transport is a big issue for older people. Many older people do not drive and depend on public and community transport to get out of the house, to access basic services such as shopping, the GP, hospital visits and to keep in touch with family and friends. While most participants value the services provided (see earlier) a number raise concerns particularly in relation to irregular and inefficient services and access issues:

... there are a lot of older people at home, staying at home because they have no means of getting out.

Irregular, unreliable and inefficient services

In discussions about transport services, a majority of participants raised a number of issues particularly pertaining to rural areas. These include concerns about service and connections, constant changes to timetables and access to service bus stops.

Transport and disability

A number of older disabled people raise the issue of transport and are concerned about access issues especially in Wales.

Other negative impacts of services

A number of other areas of concern are raised by participants. These mainly relate to anxiety and fear about cutbacks to public and other services, access and information about services and in home /residential care.

The cuts

Across the UK, we encountered a great deal of concern about the ongoing cuts to public expenditure and particularly in relation to local cuts to older people's services. Participants question current government policies in these areas and are very concerned about the implications of cuts on vulnerable, older people:

I think there are an awful lot of people who are extremely worried at the moment and I think that is blocking well-being for an awful lot of people.

Specifically, participants are concerned about:

- The closure of community centres, day services, libraries and post offices
- The impact of cutbacks on transport services

Government is cutting back on all that flexible transport.

- The phasing out of meals on wheels services in some areas
- The increasing expectation that voluntary and community organisations will and can take over local services that have been previously funded by the state. Despite a clear commitment within communities to ensure services will continue to be provided, there is a clear message that a proper infrastructure such as core funding needs to be in place to ensure the delivery of quality services:

David Cameron wants more people to volunteer. As I see it, they're taking the funding from us.

- Perceived threats to the free bus pass
- The impact of transport cuts on social contacts

Difficulties in accessing services

A number of participants raise difficulties in relation to the accessibility of public services, obtaining information when needed and getting beyond 'red tape':

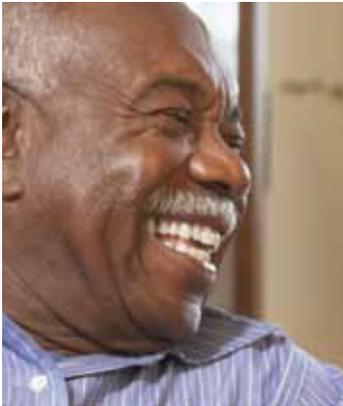
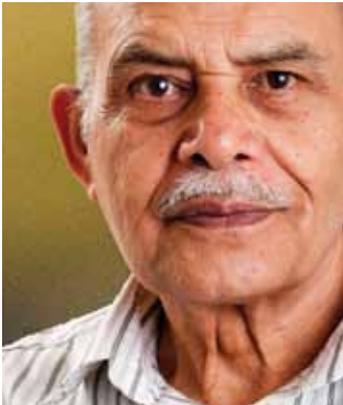
I find it very hard now to get the services that you require because there's a lot of red tape.

Some participants feel that government departments are increasingly putting information on websites. This is very useful and helpful for those who can use and have access to the internet. However, some participants feel that this can also exclude many others.

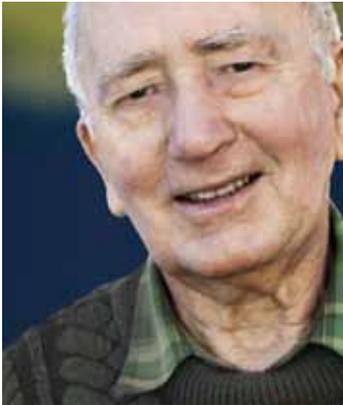
Poor home and care services

Some discussions touch on the issues of care and support. Participants acknowledge that many older people are well treated by competent and caring staff all over the UK. At the same time, concerns are raised about the quality of care provided both at home and in residential/nursing settings. The main issues are in relation to the care and support of older disabled people and the importance of good communication between residents and staff.

High expenses,
cost of living
these days is
leading to not
having a sense a
well-being



Well, the back
pain is constant



Barriers to well-being

Participants were asked about the factors that get in the way of achieving well-being. Much of this discussion focuses on health and impairment issues although a wide range of social, cultural and other barriers are identified.

1 Having poor physical health and impairments

Poor physical health is considered by most participants to be the major barrier to well-being. The wider consequences of poor health upon other aspects of life including personal independence, mental health, activities, social life, hobbies and mobility are also raised.

Participants mention a wide range of physical conditions that they experience, most common amongst these being arthritis which limits mobility through pain to varying degrees. Participants identify a range of other age-related conditions including diabetes and high blood pressure. There were also some participants with cancer (including three participants with terminal cancer) and people who have had heart attacks and strokes. Two participants have undergone triple heart bypass operations and several have had hip and knee replacements. A range of other physical impairments are also mentioned. The negative impact of poor health upon well-being is stressed by many:

If you're continually ill or feeling unwell your quality of life is not very good.

The impact of severe trauma on participants and their families is also highlighted:

I've had a triple bypass which came on suddenly and it takes you a good two years to come to. I couldn't do nothing, I hadn't to go upstairs till I went to bed and my husband had to do everything for me.

Ill health in close family

As well as personal ill health, a number of participants highlight the impact of the illness of other people – particularly close relatives - on their own quality of life and well-being:

But I think a lot about my husband, I mean he was an invalid and couldn't go out ... He was crippled with arthritis all over every limb ... he couldn't walk so he used to get very depressed ... and it was very hard and it was very hard for me as well. Very, very hard ... well I'll be honest, I used to get fed up. I used to think ooh all these people, their husbands are alright, going out with their husbands and I couldn't do anything like that.

Limited mobility

The loss of mobility - owing to various types of illness and impairment, but mainly arthritis, has a major impact on the lives of many participants, including isolation, depression and a loss in confidence. Regrets about the inability to undertake past

activities are a common theme:

I was a hill walker and a rock climber ... So the whole life in terms of that was destroyed ... well the back pain is constant. You know everything is a problem really.

My whole body is deteriorating and it makes me feel that you can't do the things you want to do. I've got so much talent in these hands and when I think they're wasted that gets me bad.

Effects of medication

A number of participants are concerned that their medication adversely affects their well-being:

When I take my tablets I worry about all the side effects and if I do not take the tablets I become more ill. This can be very frustrating.

But you know if you try and relieve the pain to actually accommodate some sort of movement then of course the analgesic drugs you know dull the personality and change it to some extent ... and the drugs which had caused an adverse reaction ... which, you know, can cause people to become homicidal and suicidal.

2 Having poor mental health

Many participants say they feel low or depressed and this is a significant barrier to their well-being. They describe a state in which they become lethargic, detached and lack interest or motivation:

I was so depressed inside, that I couldn't make conversation, and it hit me one day and I thought, well, where am I? I'm disappearing, you know, within myself. And that's what is not a well-being thing. I couldn't walk, I couldn't get about much at all, but it's that feeling of inadequacy. And that's something that you don't ... Only you know about it.

The impact of severe pain upon mental health and well-being is highlighted by a number of participants:

It's very easy to go back into a negative state ... you know if you get a twinge or a spasm in your back then it's very easy to actually click into overdrive in terms of perceptions and what this is going to lead to, so you can easily trigger off some depressive thoughts.

I tend to have some good days and some bad days (with pain). The worst thing is that this affects my personality.

Insomnia is highlighted as an issue for some participants and pain and anxiety are often the causes:

That's all I want in life. I'm getting old now and I don't want no upsets and ... cos most of the nights I can't sleep for pain. And then when this happens my mind won't let me go asleep.

Some participants say that they have a real fear of developing mental health problems, particularly Alzheimer's disease or dementia:

I dread mental illness. I'm aware that my memory is not as good as it was and I hope it's just a case of my memory not being as good as it was but I have a fear of Alzheimer's or dementia whatever.

3 Problems from having sensory impairments

A few participants have long-term sensory impairments. For more participants, however, failing sight and hearing are impairments that have arisen during old age. Loss of eyesight can severely limit mobility and independence and cause anxiety:

I've got to have someone with me all the time. I can't go shopping without my husband. I can do most things but I'm losing my sight and have to depend on other people to cross the road etc ... I'm not as confident outside the house.

Sensory impairments can lead to isolation:

Because of my eyes, as well, I can't see my friends until they're up close and I feel like I've lost my friends because of that.

The sheer hard work involved and emotional response to losing sight is highlighted:

This is what I found when I first lost my eyesight ... I'd do something and I was exhausted and I thought, you know, this is weird. But then, I suddenly began to realise that whereas before I'd see something ... I had to look for everything now and scan it and it is hard work.

Because when it first happened to me, I remember, I was so low. I said to my husband, I said, 'I don't wanna live anymore. I really don't wanna live anymore. There's no point to living anymore. But thankfully that passed.

4 Fear of dependency

Decreasing health and loss of mobility can lead to an increasing sense of dependence on others. This, in turn, can have an adverse impact on mental health and well-being as mentioned by several participants. Fear of becoming dependent is a common theme:

The more independent people can be, you feel more in control and I think people, say, that have had a heart attack, stroke, they've suddenly lost a huge measure of independence, then they struggle with frustration because they can't do the things they used to do and it's a spiral to depression.

I think once you become completely dependent on people you lose your peace of mind ... there's nobody that's happy to be totally dependent on either relations or the state.

Well the thought of being dependent fills me with total dread, absolute dread.

5 Feeling lonely

Many participants consider that feeling lonely in old age is the biggest problem:

When I feel the pain, I stay home. And no one knows I am not well. Sometimes I want people to help me to massage the joint. But no one can help me. Very lonely. Because I am a widow. I lost my husband when I was very young. All my children are grown up. They all have their own family to look after and care for.

Oh, I don't like living on my own. I hate living on my own, I really hate it. Hate the quietness. I can't stand it being quiet. Have the telly on all the time when I'm home. I can't stand it being quiet.

Some talk about how in spite of being out and about and meeting people during the day, the sense of loneliness returns once at home and alone:

Well there is a difference in the daytime than in the evenings. Because you go in, you shut your door and it's just you. You're alone. Or if something interesting has happened during the day there's no one to discuss it with.

There are particular problems for older people within the lesbian, gay, bisexual and transgender (LGBT) community:

A lot of gay people live on their own, especially if they've lost their partners or they're separated from their partner ... especially in the case where they've been chucked out by their families so they don't have family to go to ... (that) is quite common ... most of them are single or on their own ... I think it's a problem which increases as you get older because once you're over 30 you're old on the gay scene and people don't feel happy going in and mixing with the younger ones because they're then, you know, sort of oh what's that ancient person doing in here on our territory kind of thing.

Some participants who volunteer draw attention to the significant challenges and the need for patience and sensitivity when addressing loneliness:

If you see someone lonely I find that you've got to persevere. It took me six years coaxing on and off with one lady ... our Wednesday club didn't suit her but at the end of six years she came and it changed her life, but I mean it took perseverance to get her to come. This is what I find with old people, they don't want to change their habits; they get set in their habits.

We have to respect, some people choose to be isolated, they choose to be behind their doors and they may be emotionally well. Others aren't - they go on a downward spiral, so it's a matter of being sensitive to the needs of certain people ... we've tried to get people out of doors to day care centres and lunch clubs and it's not for them. We have to respect that.

Bereavement

The devastating impact of the loss of close family members, including partners, is highlighted by many participants who describe the feeling of loss, isolation, guilt and

depression that accompany bereavement:

It's the awful trauma of being on your own when you've had a close partner for 50 or 60 years. It's unbelievable what you suffer. It's so traumatic. I have never got over it. I will never get over it.

Well I used to do a lot and then when my husband died I lost interest in everything and I'm really only this past year starting back again.

I still regret and live with the guilt that I should have refused him to go to [name] and stayed here. I didn't know this at the time that I could have had all the care in the world to look after him in his own home ... and I should have found out more details and what I should have done is taken him home.

Once over the immediate effects of loss of a spouse - and this can take years – many participants said that '... life goes on and you learn to live with it':

It takes time. It's very sad at the time but as the years go on ... you never get over it but you've just got to get on with life.

Two participants have each experienced the loss of a son through cancer – both young men in their early twenties. The participants both describe the pain they feel and particularly when other people talk about their families:

Unfortunately I only had one son that died and that... that is a big factor. I mean my friend has got a son and a daughter and she's got two grandsons and you know they talk about them and not only that but I just feel like I'm a step apart. I feel it. I mean it's the worst thing that can happen.

Other important issues raised about bereavement include the following:

- Distress caused by the arrival of unsolicited letters and phone calls to the deceased person
- The inadequate provision for bereavement counselling in many areas
- The poor provision of palliative care and access to information about care services available.

Having difficulty in getting outside the house

For many participants, the worst situation of all is being unable to go out at all or only when assistance is available. Volunteers who visit people in their own homes say that they often meet people who feel lonely and isolated:

Yeah I went to visit somebody one day and she kept me there two hours, I could not get away. As soon as the conversation stopped on one subject and I was just now ready to go, straight away she jumped in with another...

She says that because she lives on her own, going through days without seeing people can create anxiety for her because she doesn't feel that she's seeing people. She also used to go to two day care centres but one closed due to funding cuts

so at the moment, she's only going to one so she says she looks forward to that once a week but other than that she says she's got to an age now when she's quite housebound so that creates anxiety for her because she can go days without seeing people. She says that as her age is becoming greater she feels like she's getting less and less interaction with the outside community. (through an interpreter)

Increasing segregation and de-personalisation

Many participants express regret at what they see as changing values and circumstances which have resulted in fragmented families and unsupportive communities, leaving older people vulnerable and increasingly dependent on care services:

I mean families move away now. They're much more mobile, so elderly people are, you know, living on their own but there's no immediate family, sons, daughters to pop in to see how granny is ... so there could be a huge gap ... if the care facilities aren't put in.

The opportunity for informal contact and socialising in local communities through visiting local shops and post offices has declined as these shops have closed owing to competition from supermarkets. In addition, staff in small local shops can provide an informal system of care for vulnerable people, which disappears as these shops are lost:

Well, the post office has gone and there's not much opportunity to socialise in the village any more ... It's good to go to the shop and have a chat on the way – but we can't do that anymore ... That used to be an important part of village life.

And I think that the fact that we've almost become a supermarket city has been disastrous for keeping an eye on things and this is where the newsagent's shop ... if so and so doesn't come in at a certain time of the day, I wonder ... and if she doesn't come in a second day it wouldn't surprise me that maybe the (assistant) from behind the counter would make it their business to know why she wasn't there.

Participants stress other ways in which services are being dehumanised and contributing to increasing isolation:

- Poor and limited neighbourhood facilities and support
- The cancellation of Meals on Wheels contracts and the replacement of the daily personal deliveries of hot food by occasional deliveries of frozen meals
- The introduction of self service tills in shops reducing opportunities for informal human interaction
- Increasing use of electronic communication and dependency on online information and services. While some do, many older people do not use the internet and consequently see themselves as disadvantaged and isolated from essential information
- Telecare services, which despite their safety benefits, are considered by some to isolate older people at home and *'make them retreat further and further into their hermetically sealed box.'*

Language barriers

Some participants cite difficulties in speaking or understanding English as a factor that isolates them within their communities and from members of their immediate families (the following quotations as voiced by translators):

They are good (neighbours) but I don't communicate with them because I don't speak English.

And then they sent an ambulance and she was trying to tell them to phone her son because she wanted him to be here but nobody was there to understand what she was saying.

I don't communicate much with them (grandchildren) because they only speak English and I speak Cantonese. We don't talk to each other much ...

6 Experiences of inequality

Participants share their opinions about various forms of inequality including what they interpret to be discrimination owing to race, disability and sexual orientation. However, the most frequently mentioned is the unjust and discriminatory treatment of older people. Some participants say that they are treated with a lack of respect and are patronised by others in their daily lives whilst some are also concerned that older people are regarded as a burden on society:

Well, the one thing that's aggravating the hell out of me at the moment is the constant reiteration by media and the government, about how older people are a burden. And that comes across every day...

I do get a lot of bullying - because you are Chinese. They throw eggs at your window, stones at your door. It's usually the teenagers doing this. (via a translator)

A lot of the elderly feel that they don't get the respect ... from everybody around them ... even shop assistants, doctors, even hospital, they don't talk to you, they talk at you and you know.

7 Finance

Having enough to live on in old age is a concern for many participants and the inadequate state pension is particularly concerning to some:

High expenses, cost of living these days is leading to not having a sense a well-being. Financial concerns are truly making people mentally ill.

The pension we get means that we have to think whether we can afford to buy things. That shouldn't come into it, but it does.

You have to have enough money to live, especially after the weather we've had. We shouldn't have to think whether we can put more coal on the fire. We have to be able to keep the house warm.

The issue of unclaimed benefits is highlighted, along with the difficulties of pensioners who are particularly disadvantaged because they are just under the threshold for pension credit:

You know, they could direct benefits, clearly, to people who would qualify for benefits if they just got their finger out a bit and targeted these 2 million pensioners who are not getting benefits but should have benefits.

I think we have to mention the fact that the majority of older people are living with incomes less than subsistence level. And that we've got two lots of pensioners; we've got pensioners who qualify for Pension Credit, and then we've got another group of poor pensioners who don't qualify, but they're only a pound, two pounds over the limit. And so they've created another group of poor pensioners.

Other financial concerns and anxieties voiced by participants include:

- Having to pay tax on private pensions
- Feeling worse off for saving throughout life than people who have no savings and are, therefore, eligible for a range of benefits
- Carers' Allowance finishing at pension age, which can lead to hardship
- The high cost of residential care and the low threshold at which people have to start paying for their own care; also the need to sell homes in order to fund care
- Housing costs and problems in affording maintenance leading to poor housing standards
- Transport costs, particularly for people with limited mobility who are unable to use inaccessible public transport and are heavily reliant on more expensive taxis
- The digital divide disadvantages people who are not able to access cheaper online shopping and this applies to high proportions of older people
- Costly equipment necessary to support independent living for people with impairments
- The culture of younger people living in debt and concerns over the cost of living and the implications for children and grandchildren. Some older people feel that it is their responsibility to help their grandchildren financially and this causes anxiety

8 Other concerns

A whole range of other issues and concerns are raised by participants as barriers to well-being. These are each mentioned by relatively few participants but nonetheless help to shape an understanding of people's lives and the many and diverse challenges faced by older people:

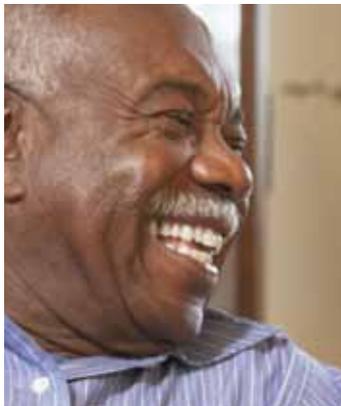
- **A faster pace of life** – Participants regret what they perceive to be a culture of self-interest with people working hard in an individualised way in the pursuit

of materialism at the expense of relationships, neighbourhood, family and community

- **Struggling to retain cultural values** – Muslim male participants express concerns that younger members of their families seem to be rejecting their own culture and traditions
- **Weather and season** – Some participants identify Seasonal Affective Disorder (SAD) and poor weather as making them feel down. Also for some, winter is a time of increased loneliness as the days are shorter and time spent alone is longer particularly during severe weather, when it can be difficult to go out
- **Family problems** – Tensions and issues within the family can cause concerns and worries to participants affecting their well-being. These include illness, divorce and family disputes
- **Political problems** – Very few people mention that politics affects their sense of well-being apart from a group of Pakistani men who are troubled by the political situation in their homeland
- **Neighbours** – A few people refer to anxieties caused by problems with neighbours



I could do with someone to help in the garden



More community between the younger people and the older people



Suggestions for improving well-being

An improvement to the well-being of older people includes recognition that older people can achieve set goals and that they have a voice in shaping their role in society and their future.

Overall, there is a general desire that older people play a more active role in improving their own well-being. At the same time, there is also a sense that many would need the help and support of others to achieve this. A key message is that older people can, and have a right to be involved in improving their own well-being within society. Participants identify a number of areas where they feel older people's well-being could be improved. We deal with each of these in turn.

1 Getting involved

Getting involved is a key theme to emerge from these discussions. This includes a range of activities and approaches such as older people's groups and activities, volunteering, campaigning and shaping services and policies.

Older people's groups

For many participants, *being connected with others* through involvement in the social, cultural and religious life of communities is very important. They speak positively about the benefits of being 'connected' to others in formal or informal groups for motivation, friendship, interest, a sense of belonging, support and 'having a laugh'. In addition, it is felt that having these connections helps people to cope with problems of loneliness and isolation.

Volunteering

It is generally felt that there should be more emphasis on promoting and supporting volunteering – in both a formal and informal sense. Some argue that volunteers are an untapped resource and much more should be done to attract and train volunteers and to give them wider roles and higher status. It is felt that this would lead to positive gains for volunteers and service users.

Campaigning

Another area of involvement mentioned is campaigning or lobbying for positive change.

Meaningful consultations

Some participants want more of a voice in shaping services and policies and argue for more meaningful consultations to include more diverse voices. Others stress the importance of valuing older people's contribution and that effective consultation requires time, resources and proper feedback. One woman sets out what she thinks is required:

Spend more time and money in creating environments in which older people feel comfortable and able to express their views / ask questions in which they feel that their

concerns / contributions are valued and accepted ... No matter how limited the contribution might be, that contribution MUST be respected and acknowledged.

Overcoming barriers to the involvement of excluded groups

On the one hand, there is a clear call for more involvement. However, at the same time, there is also recognition that many barriers exist (see earlier section) and that help and support is required to enable equal participation. For instance, those who speak little English, or older disabled people, may be reluctant to get involved in groups and services that are sometimes insensitive to differences. Participants make a number of suggestions that would help to facilitate wider forms of involvement:

- Well-being needs to be understood in relation to different cultures and to acknowledge the importance of language support for some groups. It is also important to support black and minority ethnic older people to retain connection with what they describe as their 'home countries'
- More work with travellers '*... let somebody hear our voice. Give us a chance in life*' (Traveller woman, Sidcup)
- Better access for older disabled people to buildings and public transport. Some older people, especially those with sensory impairments, see the outside world as a difficult place to negotiate and particularly the physical and sensory barriers. Participants suggested the following improvements:
 - Improved access arrangements for blind people who use buses
 - High contrast marking to help partially sighted people
 - Organisations producing material in accessible formats
- Voluntary organisations for older people need to develop an awareness of the link between old age and disability. As one participant stated: '*... they don't acknowledge disability, they only look at age*'
- Reliable public and community transport
- More disability awareness at GP surgeries

Respecting individual choices

While many participants promote the benefits of involvement, others feel that not everyone is a joiner. Some question the assumption that people who choose to be alone are necessarily feeling isolated or in need of befriending and suggest that such contacts need to be handled sensitively.

2 Choice, equality and control

A key message is to treat older people fairly and equally. There is a clear call here to organisations and professionals to focus their work more on people, to improve communication, to build trust, to give people more time and to value the whole person. As part of this discussion, participants stress the importance of key elements of the helping relationship.

First, *it needs people that really care.*

Second, to give people time:

... just time to sit. I don't mean to sit all day but time to be human for want of a better word ... and spend a bit of time - quality time - with people.

Third, listening combined with treating people with respect:

You need someone that's a listener ... you want a good listener.

A number of participants argued that for many older people, and particularly for those with a life limiting or terminal illness, it is not just a case of being the object of 'treatment' but that it should be more about how that treatment is delivered by health service staff:

... we have to get out of the habit which says the NHS is there to cure people. It's there to make people's lives better ... That's part of what the NHS should be doing not simply can we make someone's life longer but can we make whatever time they've got as valuable for them as possible, give them the highest level of well-being.

3 Practical help and support

An area that crops up in many of the discussions is the need for practical help and support in people's own homes, in particular, help with small jobs about the house and garden. There is also a clear message that as one gets older there are additional costs involved as a result of not being able to do routine domestic tasks. Participants identify the main areas of help needed:

- The home: Cleaning, repairs
- The garden: Many people get great pleasure from their gardens. However, some are unable to look after them anymore and need help with maintenance
- Shopping: Particularly for people unable to leave their homes

One of the key problems that come up repeatedly is the difficulty in finding reliable and competent people who can do these tasks. Alongside this is the anxiety about trusting people and inviting strangers into the house:

I could do with someone to help in the garden and someone to help clean the house, but I don't know where to go to look for someone? And that causes me a bit of a problem because being ... living here, seventy five, on my own, I do think I've got to be a bit cautious who I invite into the house.

In addition, a number of participants seek help with going out and having friends:

Yeah ... I would like to find somebody that could come away on holiday with me and be that kind of a friend.

4 Help from others at critical times

An important point raised by some participants is the need for support at critical times

in their lives such as after bereavement, and coming to terms with failing health and impairments:

If there was someone you could turn to if you were bereaved ...

5 Intergenerational work

A number of participants raise the importance and benefits of intergenerational work and particularly the involvement of schools and colleges. Participants feel that intergenerational work helps break down negative perceptions on both sides and addresses issues such as community safety:

I think there should be more community between the younger people and the older people ... I think if they could get together and talk, there would be so much learnt on both sides.

6 Information and communication

The importance of providing relevant and accessible information and promoting this information effectively to older people is raised on a number of occasions. Concerns are raised that people only became aware of their entitlements following a problem. They stress the importance of communication in getting the message across and having people who can act as go-between:

So, as I say, it all comes down to communication. People just don't know what's available to them and choice is just not there if communication is not telling them what they're entitled to and what they can get.

Another issue that arises frequently is the need to challenge the assumption that all older people can use or have access to the internet:

There is an assumption that the information is available on the web.

7 Finance

Some participants feel that when it comes to income, there are two categories of older people. Those who qualify for certain benefits and credits and those who are increasingly excluded from state assistance due to having personal pensions and other assets. From discussions around finance, a number of proposals are put forward:

- The need for a universal approach to income for older people rather than reliance on a system of means testing
- The need for a proper pension
- More help with council tax
- Less tax for older people
- Earlier and ongoing financial advice about pensions, investments and savings

Conclusions

In conclusion, we pull together the main themes that emerge from this consultation. In doing so, we offer our own comments and make links to current debates and ideas.

We have undertaken an inclusive consultation with older people around the important concept of well-being to gain a full understanding of what well-being means to them in all its complexity. In the past, older people have been marginalised in such discussions that were often narrowly focussed around individual rather than holistic understandings of the concept. This thinking reflects negative attitudes towards ageing and outdated perceptions that older people have little to offer. The findings of Phase One of *Shaping our Age* challenge this and clearly reveal that older people have important things to say, which have not necessarily either been heard or listened to before.

From the outset, a key concern for the research team was to enable participants to engage in discussions and share their own views, experiences and suggestions for change. We wanted to move beyond traditional models of research in this field and to embrace the heterogeneous and cultural aspects of ageing. This involved a huge commitment of time and effort from the research team to ensure that the participatory ethos that underpins the methodology was achieved. In addition, we sought to ensure that the Older People's Reference Group (OPRG) had the opportunity to be involved and to discuss the early results. At the end of this phase, we feel that our efforts to ensure maximum involvement have been worthwhile.

The views presented tend to be consistent with and complement earlier studies in this area of research. Moreover, they highlight some important messages that are central to well-being and set a clear agenda for action.

Participants brought their own personal feelings, experiences and opinions to the discussion of the concept of well-being. There is no one view but a complex picture emerges which defines well-being in both subjective and objective terms and at personal, family, community and societal levels.

Participants identify a range of factors that affect their well-being, in particular, individual, family, social and environmental factors are most frequently raised. While issues such as health, personal characteristics and faith feature prominently, the main factor highlighted is *relationships and social contacts* with family, friends and communities. This is a key finding which the research team identified at an early stage. This highlights an important aspect of well-being in that for many older people it is best achieved in conjunction with others at the levels of family, friends, neighbourhood and community. It is important to say that many older people are already building such relationships and social capital through involvement in activities, clubs and groups. Many are also actively supporting other older people whether it is help in overcoming loneliness or with practical help to enable them to live a safe and comfortable life at home. This highlights that many people lead active and fulfilling

lives well into old age and this includes contributing positively to community life by being a good friend or neighbour or by volunteering or campaigning for changes.

Discussions around services highlight both positive and negative aspects. On the one hand, these reveal that some services and approaches to helping people are working well and are greatly appreciated. However, at the same time, it also reveals how some services and professionals (particularly health services) are falling far short of the expectations of older people. Significantly, negative comments and experiences greatly outnumber positive ones.

Much of the discussion in relation to barriers centres on health and impairment issues although social, cultural, financial and other constraints are highlighted. The focus of discussion on health and impairments can be interpreted as reflecting traditional models and understandings of ageing with an emphasis on personal adjustment and medical interventions. Hence, it highlights the importance of the relationship between *ageing and disability/health* in the lives of older people and how this is experienced at individual levels. This experience of physical/mental decline can be associated with feelings of powerlessness and helplessness and often internalised on a personal level. This view of ageing contrasts with the Social Model of Disability which emphasises the 'social barriers', over an individual's medical and impairment issues. While not denying the limitations of personal impairment, it locates the problems in societal rather than individual terms. From this perspective, ageing would not necessarily be viewed as a natural process of physical and mental decline to which older people would have to adjust. Serious consideration and priority would also be given to how such individual difficulties might be prevented, ameliorated or overcome by social and societal changes and interventions.

In keeping with participants' analyses of well-being and what shapes it, there is a strong message that it is about people being able to do what they want to do. This finding highlights that the promotion of *individual and collective agency* is a vital component in achieving and sustaining well-being at the levels of the individual, the community and society. One of the ways to achieve this is through engagement with others in a variety of personal and social activities. A related and equally strong message is that older people can really benefit from that 'little bit of help' to achieve a level of autonomy and independence. In other words, people want a certain amount of support to be actively engaged with the world.

The nature of the support defined by participants tends to be very practical and includes help such as assistance to facilitate involvement with others, to be as independent as possible at home, to be treated equally by service providers and to be able to access information and sufficient resources for a decent standard of life. In doing so, participants could be said to place the achievement of well-being within a preventative approach. However, a key tension to emerge during the discussions and which runs counter to these aspirations is the negative impact of the cuts on public services and transport. These are clearly causing anxiety and worry and are having a direct impact on people's well-being and undermining the positive aspirations to self-help within social policy.

In the next phases, *Shaping our Age* aims to explore new ways of involving older people in the development of services to enhance their own well-being. Older people will be engaged in participatory projects in five WRVS services over the following 18 months of the project. The issues raised in the consultations have contributed to the selection of those five services. We plan to enable and support older people to be actively involved in a process of development and learning. The learning from the programme will inform WRVS and will be disseminated widely to inform involvement in service development.

Appendix 1

Consultations achieved

FG: Focus groups M: Male I: Interviews F: Female

	Type	Participants	
		M	F
Pilots			
Pilot group, Cardiff (urban)	FG		8
Pilot group, West Wales Carmarthenshire (rural)	FG	4	7
Pilot interview man, Gower, Swansea (rural)	I	1	
Pilot interview man, Rhondda Cynon Taff (urban)	I	1	
Main Programme			
Belfast South Senior Citizens Forum (urban)	FG	3	4
Belfast East Senior Citizens Forum (urban)	FG	2	5
West Wales Carmarthenshire (in Welsh rural)	FG		9
Ribble Valley Volunteers (rural)	FG	1	5
Ribble Valley lunch club (rural)	FG	1	8
Stoke on Trent day Club (urban)	FG	1	9
Inverness Senior Citizens Forum (rural)	FG	4	8
Tongue (Highlands) Community group	FG		3*
West of Scotland Senior Citizens Forum, Glasgow (urban)	FG	2	5
SE Coast England (urban), Crawley	FG	3	3
Epilepsy Support Group/Methodist Church, Connah's Quay	FG	3	4
Men's group, Batley (in Urdu)	FG	8	
Women's group, Batley (in Urdu)	FG		8
Jamaican National Association, Huddersfield	FG	1	5
Partially Sighted, Hailsham, E Sussex	FG		4
SE Coast England, Crawley (urban)	I		1

SE Coast England, Crawley (urban)	I		1
Woman, community organisation, Leeds	I		1
Woman living in Welsh Valleys	I		1
With learning difficulties, Lambeth	I	1	1
Physically disabled man and partner (carer), Neath	I	1	1
Physically disabled man, Conwy	I	1	
Woman unable to leave home without help, Ribble Valley	I		1
Man unable to leave home without help, Ribble Valley	I	1	
In residential care, Ludlow	I		3
Pakistani woman, unable to leave home, Dewsbury (through translator)	I		1
Barbadan woman, unable to leave home, Huddersfield	I		1
Mixed race couple, Leeds	I	1	1
Indian woman carer, Leeds	I		1
Chinese people, Leicester	I	1	2
Terminally ill woman and volunteer, Leyland	I	1	1
Terminally ill woman, Preston	I		1
Terminally ill man, Durham	I	1	
Gay man with HIV, Hanley	I	1	
Woman carer, Cambridge	I		1
People in paid employment, Poole	I	1	1
Woman traveller, Sidcup	I		1
Deaf couple, Ebbw Vale	I	1	1
Hearing impaired man, Cardiff	I	1	
Blind Man and Carer, Cardiff	I	1	1
		48	115
		Total participants	163
		Total FGs inc pilots	16
		Total interviews	30

* People in this session already counted in Inverness FG

Appendix 2

Discussion guide for focus groups

Please note: the interview guide included the same questions and probes.

This discussion guide was a guide only and used to prompt researchers when necessary. Our approach was to encourage participants to speak freely and to explore issues in their own time and in their own way. In the focus groups, we aimed to stimulate discussion and debate. In other words, we aimed to hand the agenda to the older people once the main questions had been posed and returned to the discussion guide where necessary to stimulate further interaction.

Introduction

- Introduce researcher name and WRVS
- Introduction to project
 - This group has been organised as part of a three-year programme of research about the well-being of older people. The research is being funded by the Big Lottery Fund, and is being run by WRVS and the universities of Brunel and De Montfort.
 - As a first - and important - stage in the research we are running another 14 focus groups like this one and about 30 individual interviews with older people. These are being held all over the country and with a diverse range of older people.
 - For this study we define older people as those who are aged 65 and over.
 - In the next stage of the project we will be working closely with five services over two years and from this we hope to learn how to shape services that meet the real needs and wants of older people and which encourage older people to help themselves and others to achieve well-being. Based on the findings, the WRVS has agreed to change the way its services are delivered. There is also the potential to influence the way other services are delivered to older people across the UK.
 - Mention that if any project worker is present that they will observe the session and remain silent (NB: researcher to brief project worker prior to session about this).
- Recording
 - We hope that you will feel comfortable to share your thoughts and opinions openly with us and that we'll get a good discussion going.
 - I need to ask your permission to record this session. This is for research purposes only and will help me to ensure that we represent your views fairly and accurately. The recording will be destroyed once it has been transcribed. Check that they

agree to the recording.

– Also, can we please talk one at a time – not talk over each other - throughout the session? This will make sure that we don't miss anything.

- Anonymity / confidentiality
 - Before we start I need to tell you that anything you say here will be treated in confidence and we will not identify you in any way in reporting your comments and opinions.
- Questions?
 - Is there anything that you want to ask about me or the project before we start? Anything else you'd like to ask?
- Participant Introductions
 - First name, a little bit about you eg family/living circumstances, interests, the work you do or used to do and age (if possible)
 - If participants raise particular issues at this stage these can be noted and returned to later in the discussion

Introductory exercise

Write down three things that are good about your life at the moment.

Write down three things that are not so good.

Write down 3 things you would like to change

We collect the post-its in sequence from each individual in turn and look for common issues and themes which then underpin the remainder of the FG.

Discussion topics

What is well-being?

- What is well-being to you? What does the term 'well-being' mean? What words would you use to describe it?

Probe

- How do we know when we have well-being?
- What does well-being mean for you? - Areas of well-being in your life
- What sort of things for you go to make up 'well-being' (make a list from comments and explore it with people)
- How does it feel?
- Is there consensus of what well-being means for them

- How would you describe not having a sense of well-being?

Probe

- Can you think of a time when your sense of well-being was low – what did it feel like?
- Is there consensus about what not having well-being means?
- Well-being as a term
- Is well-being a term that you use about yourself and others?
- What kind of terms do you tend to use
- Is it a useful term?

Causes of well-being

- What causes or creates a sense of well-being? Refer back to opening exercise.
- What blocks (frustrations/disappointments) get in the way of us achieving well-being?
- How much is our well-being of our own making? How much are we responsible for our own well-being?

Probe

- What do you think you can do on your own etc
- Active participation eg volunteering, interests, hobbies
- Positive attitudes and feelings
- Good relationships
- How important are other people to you in achieving a sense of well-being?

Probe

- Family, friends, neighbours, community / positive relationships
- How important are local services in creating well-being for older people? Why?

Probe

- Local authority services
- Health services
- Voluntary services
- Does a sense of well-being change (Through life? Day by day?) Why? What factors cause those changes?

How to improve well-being in older people

- What should be done to improve well-being for older people?
 - Is there any bit of help that would make a big difference to your life/improve your well-being? (Refer to opening exercise)
 - Is there anything that you could do yourself to make this difference?
 - What would need to happen for you to do this - what support would you need?
 - What do you think about older people becoming more active in improving their own lives by making things happen for themselves?
 - Is there anything that you as a group can do to improve your well-being overall? What support would you need?
 - What partner organisations do you think you could work with to help you to improve your lives? What support would you need from them?
- The government has ideas for enhancing the well-being of older people. Let's discuss some of these in turn? (Some of these might have been covered already).
 - Tackling discrimination against older people
 - Treating older people with dignity and respect
 - Free transport
 - Promoting better health
 - Feeling part of a neighbourhood or community
 - Improved services with more choice
 - More income
 - Improved support for carers
 - Opportunities for volunteering and getting involved

And Finally ...

- We are coming to the end of the session.
 - Have you any further comments you would like to make before we close?
 - Opportunity for people to raise topics or issues that they feel are relevant to this project and which have not been covered during the session.
- What to you are the most important messages arising from this session?
- Thanks and mention that a summary report will be provided if they leave their address on the consent form. Also mention that this could take some months to arrive owing to length of process.

Appendix 3

Biographies of the *Shaping our Age* research team

Martin Hoban is a part-time research project worker for *Shaping our Age*. Prior to joining the project, Martin worked as a community worker in the South Wales Valleys, the North East of England and in Ireland. He has a background in the Disability Movement and has considerable experience of involving service users as a development worker, educator and researcher.

Vicki James is WRVS Research Manager and as part of that role shares the *Shaping our Age* Project Worker post for two days a week with Martin Hoban. Vicki has worked as a researcher and consultant in a variety of roles within the public, private and University sectors over the last 30 years. Before joining WRVS in 2010 she worked in a social research agency and before that as consultant in an international tourism consultancy. She has a particular interest in qualitative research and welcomes the opportunity for involvement in participative and action research offered by *Shaping our Age*.

Peter Beresford OBE is Professor of Social Policy and Director of the Centre for Citizen Participation at Brunel University. He is also a long-term user of mental health services and Chair of Shaping Our Lives, the national independent service user controlled organisation and network. He has a longstanding involvement in issues of participation and empowerment as writer, researcher, educator, service user and campaigner. He is a member of the Ministerial Reference Group for Adult Social Care a Trustee of the National Skills Academy for Social Care and a member of the Advisory Board of the National Institute for Health Research.

Jennie Fleming is Reader in Participatory Research and Social Action Director of Centre for Social Action at De Montfort University. Before coming to De Montfort University she has many years professional work experience as a community worker and social worker and is professionally qualified in both disciplines. Jennie is committed to working in a participative and empowering way; whilst being at the Centre she has been active in the development of participative research methodologies working with community members and service users ensuring their input and contribution to research projects that affect them.

Kirsty Pattrick, Researcher, WRVS *Shaping our Age*. Kirsty has researched and managed projects for WRVS across the heritage and health & adult social care sectors since 2004, in the areas of reminiscence, oral history, intergenerational and cross-cultural work. She is now a Freelance Researcher and Independent Consultant.

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