

the Aspirations and Expectations of

TOMORROW'S OLDER PEOPLE

margaret godel

"Suddenly 50 hits you, and there's more to life"



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The Aspirations and Expectations of Tomorrow's Older People

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acknowledgments

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SUMMARY

This small scale project has focussed on finding out about the expectations and aspirations of those currently approaching retirement in Oxfordshire. The aim has been to inform the implementation of Putting People First, Transforming Social Care and associated preventive policies, whose objective is to keep people as independent as possible in later life.

Understanding what is important for people's quality of life, now, as they approach retirement, and how they expect to maintain it as they get older, can help determine the role and implementation of policies such as Self-Directed Support, Extra-Care Housing, and Day Services, when people come to need more help. Implementing these policies in ways that support individuals' existing resources could help people to continue to realise their aspirations and potential despite limitation through the ill health of self or others.

key points

- ▶ Compared with the apparent certainties of previous generations, retirement appears to have become a fuzzy concept for most. People are questioning the idea of a retirement predicated on leaving paid employment at a particular and predictable age.
- ▶ There is an expectation that people retiring now will live longer and be healthier in their later years than their parents. Although many of those participating in these discussions expressed similar views, others questioned the likelihood of this. This scepticism may be justified for those who feel that the stress of their working lives has led to ill health, who are on lower incomes or in lower socio-economic groups, or who know of people who have died soon after giving up work.
- ▶ For various reasons people find it hard to think about becoming limited by illness or disability and to plan for these eventualities. People are aware of others, or have experience themselves, of falling prey to illness which disrupts plans. Uncertainties surrounding health and longevity influence the extent to which people are willing to make plans for tomorrow rather than live only for today. As a consequence most people prefer not to think about it.

- ▶ Planning, in a formal sense, is difficult, with most preferring not to think about how their lives might change if they become ill or disabled. However, when prompted, most have views on what they would and would not like to happen to them if they become more limited, which they are able to discuss when prompted.
- ▶ Many found the structure and format of the discussion groups useful for exploring issues and sharing experiences and ideas relating to retirement and limitation in later life.

daily living

- ▶ Work is the dominant issue for most in day to day life, pre retirement. However, people are concerned about redundancy and early retirement, and the effect that these will have on their income in retirement. Many expect to have to keep working to maintain their life styles. Others want to work, at least part time, in retirement, for the social benefits associated with work. Yet others feel that they have skills and experience to offer and would like to make a paid contribution to society, despite being older. There
- ▶ Work is seen as being part of one's identity, thereby giving status and meaning to life. Many thought that this was important for continued health and well-being. For them there was a link between work and health and well-being, as they reflected on those they knew who 'dropped dead' soon after retirement.
- ▶ Many have concerns about ageist attitudes at work, and in society in general, and worry about the implied lack of status and respect that ageing might bring. Ageist attitudes are particularly telling for those wanting to continue in paid work as long as they can. Opportunities that bring together those wanting work and employers would be welcomed.
- ▶ Some are already doing voluntary work and others would like to, but are not sure what is available or how one finds out about volunteering opportunities.
- ▶ The ability to save for retirement is limited for some, especially those maintaining teenage and adult children either at home, at university, or in the early stages of home ownership. These demands compete and, for those on low incomes in particular, financial resources do not stretch to do both and immediate demands are prioritised.
- ▶ Good health underpins quality of life, and most feel that money is no good if you do not have the health to enjoy it. Many are looking after their health but people are concerned about how to do this when work no longer provides opportunities for physical activity and lack of money prevents them from joining clubs.

- ▶ People take their independence for granted now. Remaining independent is seen as affecting their ability to get out and about (mobility), the sort of accommodation people have, and their ability to exercise choice and control over financial affairs.
- ▶ Opinion is divided over who should care for people as they get older. Fear of becoming dependent is common. Most do not want to be a burden on their families, although many hope that their children will help them out if needed. Some feel strongly that, as a last resort, they would rather be put in a home than become dependent on their children, and others still, would rather end their lives than merely exist with seriously life limiting health problems.

housing

- ▶ Environment and community are the main factors influencing people's housing choices now. However, most feel that they will need to downsize if they are not actively doing so already. Some plan to move into urban areas to be nearer to shops and facilities. Some plan to move abroad, but others want to stay where they are.
- ▶ Most recognised that, if they became less mobile, steps and stairs between the different levels in their current homes would be a problem and they would need to move to more suitable accommodation.
- ▶ Those who have heard about managed lease schemes are sceptical and do not trust them. It is not clear, however, if they really understand what these schemes involve, and they may be muddling them up with equity release schemes.
- ▶ Most who own their own house now want to continue to do so, even if they move. For these people, home ownership is seen as the best way of ensuring independence, choice and control. Some, however, are willing to give up home ownership if it means that they can pass the equity on to their children. This sacrifice of choice and control needs to be assessed in the light of strongly expressed views about State-provided care.
- ▶ If limited by illness and disability, most want to stay in their own homes, and everyone wants to remain independent for as long as possible. People see moving to a residential home as the very last choice, precipitated by inability to function without considerable input from others.
- ▶ All are willing to take advantage of any assistive technology available, although some fear that it might not work, and others are concerned about being watched all the time and losing their privacy.
- ▶ People are not sure what extra care housing is, but would be happy to have high levels of support within the community if they can stay in their own homes. Most stressed the importance of opportunities for flexible and interesting activity tailored to their interests and reflecting their needs for stimulation, rather than activities

based on assumptions about what they can and cannot, or will and will not do, if they become more limited.

money choice control

- ▶ People worry about not having enough money to live now and save for retirement. Whilst some are concerned about maintaining their life styles, others, particularly those supporting teenage and adult children at home, struggle with daily living costs.
- ▶ Many misunderstood the way that National Insurance payments and social and health care budgets work. They felt that they had paid in to a system that should provide them with what they need, when they need it, without further cost. They felt disillusioned that this was not the case and they will not have the control and choice they would wish for if they need to pay for care. Some expressed vociferously their concern that the system penalised them unfairly for saving, and rewarded those who had not saved.
- ▶ Many people who own their houses feel strongly that their home should not be used to pay for their care costs. Rather, they see it as a capital asset which that want their children to inherit.
- ▶ People like the idea of Self-Directed Support although they are sceptical about intentions. There are questions about how this initiative would work in practice, who would be eligible, and how much it would cost.

access and information

- ▶ Some concern was expressed about maintaining and developing the infrastructure of communities so that the needs of older residents can be met.
- ▶ Access to services and facilities was a concern, particularly for people in rural areas, especially in relation to decisions about moving, and remaining mobile and independent.
- ▶ People with private or occupational pensions were concerned about the quality of advice available in the light of pension funds under performing, and pension terms changing. Knowing who to trust and where to go for good financial advice was a significant issue for them.
- ▶ Those relying on the State Pension were also concerned about their retirement income. However, some women were not aware of basic National Insurance options that might improve their State Pension.

- ▶ Knowing what is available and where to go for information was raised in all groups. People do not go to one place, or person only, nor do they need information at one time only, or in only one form. Information needs depend on individual circumstances and preferences, and the extent to which information is accessible by particular individuals.
- ▶ Overall, people were very concerned about the the extent to which they could trust sources of information of all sorts. Poor quality advice that leads to poor decisions, and conflicting advice, lead people to distrust all sources and to question the impartiality of advice and information providers, and avoid seeking advice at all.
- ▶ The public profile and reputation of organisations and professionals were important in determining whether or not sources were trustworthy.
- ▶ People consistently preferred, to get information and advice from specialist organisations, like Age Concern, and GPs, and family and friends. Information delivered in person is preferred over other methods, and leaflets are valued too as back-up that one could take away and read later. When people think about where they go to find information, again specialist organisations and GP surgeries are rated most highly, followed by the Citizens Advice Bureau and Social Services offices.
- ▶ The accessibility and availability of advice and information was important in determining whether or not organisations are consulted. Social Services and the CAB would have been more highly regarded overall had they been perceived as more accessible and more efficient.
- ▶ There is an assumption that information can be provided via the internet because those retiring in the future will be internet savvy. Whilst many were actively using the internet to communicate with family and friends and for surfing, many would not go to the internet for information. Reasons include not knowing how to use it, or computers in general, searching for information being confusing and information pages when they are found being difficult to navigate. Some, but not all, were willing to learn in order to access information.

WHY TOMORROW'S OLDER PEOPLE?

Public policy, such as Putting People First, Transforming Social Care and associated preventive policy, is becoming focussed more and more around a personalisation agenda which is all about developing and designing services that help support peoples' existing resources in ways that help them remain as independent as possible in their later years. These resources can include their own experience, skills and strategies for meeting their needs.¹ This marks a change from services where needs are met with a package of care determined and undertaken by service providers, albeit in consultation with clients, on a reactive basis. In other words, once there is a problem rather than before the problem arises.

To help progress their work in this new personal and preventive climate, the commissioners of this study were most interested in how policy relating to housing, Self-Directed Support, day services, access, and communication might be shaped to meet the needs of the next generation of older people in proactive rather than reactive ways. This requires a very different way of thinking about 'services' and how they are delivered, which, in turn need a different sort of information and a good deal more knowledge about peoples' likely needs, their resources and any gaps. Predicting on this basis is not at all easy and requires us to know more about people's lives and their expectations and aspirations for their lives both now and in the future, since the things that are important for the quality of life now, are likely to be the things that people value in their later lives too.

There is an enduring fear in public services that asking people about their expectations will open the flood gates, overwhelming those charged with providing services with impossible demands which cannot be met from over pressured budgets. Experience with consultation about current services suggests people are not unrealistic in their demands if they know the limits of what is on offer, and, unless there is engagement between providers and the public about the current agenda, there is a serious risk that the new policy agenda will not succeed and that future clients will not get the sorts of services and support that will help them remain independent.

how we did it

This small project focussed on the issue of understanding what people might need from services in later life by exploring current quality of life, since aspirations and expectations of later life will be informed by the 'grain' of life as it is lived now. The idea is that understanding the 'grain' of life now, can help us understand individuals'

¹ For more on the extent to which people build on their existing skills to manage needs and demands in their lives, see Godel (2007) 'Get the Picture: Older people's day to day lives in West Oxfordshire 2004-2007'. Age Concern Oxfordshire: Abingdon.

approaches to their own ageing, and that this in turn, can help us understand potential needs, identify resources to meet needs, and spot potential gaps in resources.

So, this project did not ask people directly about the policy areas of interest. Instead we began by asking about quality of life now, so that people could talk naturally about what was important or problematic about their day to day life, about their housing arrangements, and about how money influences choice and control in decision making. The focus on quality of life was then extended to peoples' expectation of life in retirement and to quality of life if, when, or as they became affected by ill health, disability, and other life limiting events. The three main areas of discussion map on to the main policy areas of day services, housing, and Self-Directed Support, allowing us to build a picture of the issues that might be important when people come to need these services. In addition, we explored with people the cross cutting themes of access to services and facilities that sustain quality of life, and how people access information and become aware of what is available.

who participated

Five groups were held in three rural hub towns: Banbury, Witney and Wallingford. The other two were held in central Oxford, and Blackbird Leys respectively. The hope was that by using locations throughout Oxfordshire, we would attract a wide variety of people to participate. A further group in Abingdon had to be cancelled because of problems recruiting, and time did not allow us to reschedule this group.

Participants were recruited by an agency to ensure that no one had a connection to either Oxfordshire County Council or Age Concern Oxfordshire. This was to avoid including those who might already be alert to policy and issues of ageing by virtue of their association with these organisations.

The study was not designed to focus on, black and minority ethnic groups, first generation and recent white European immigrants, and those not working through ill health or long term disability, however, members of these groups could be included in the groups if they met the criteria for inclusion.

The agency was instructed to recruit people to the six discussion groups, although, one was cancelled. Participants had to be aged between 50-64, that is, under the current official retirement age for men, and could have the following attributes:

- ▶ men or women
- ▶ single or married or partnered couples, attending alone or together
- ▶ still working, at least part time, and not yet retired fully, job seekers, spouses not working through choice, or those who have never worked

- ▶ working, broadly professional, managerial, or skilled manual work, or semi- or unskilled manual work.

Further, people were included who owned or rented their homes, and lived in rural and urban locations.

There were some difference between the sample recruited and the sample validated and these differences are noted briefly in the following paragraphs.

The following table gives details of participants attending the group:

42 participants attending 5 groups		professional / managerial / technical		skilled / semi skilled / unskilled	
		village/ rural	urban/hub	village/ rural	urban/hub
single men and women	owns home	3	1	0	1
	rents home	0	1	1	3
couples attending alone or together	owns home	5	5	3	14
	rents home	0	1	1	3
		8	8	5	21

Forty two people were recruited to five groups. All were white in terms of ethnicity. Twenty nine percent were aged 50 to 54, 21% 55 to 59, and 50% were in the 60 to 64 age bracket. Forty eight percent were men and 52% women, and 76% were married or had partners.

Only two people identified themselves as carers but during discussions more people described their experience of caring either for parents, in-laws, and grown children with or without problems. Most active carers are still women, although at least one man is expecting to take on a caring role earlier than either he or his wife expected.

In several group discussions it emerged that people had grown up children living at home. There were a variety of reasons for this including a shortage of affordable housing. In terms of financial planning for retirement however, if money is in short supply, this affects people’s ability to put some by for the time when they are not able to work. Others were helping their grown children financially in other ways.

Seventy six percent owned their own home compared with 24% who rented. Sixty nine percent lived in urban locations which we defined as Oxford, rural hub towns and fringe developments, and 31% in rural locations which by which we mean villages, hamlets, and single dwellings such as farms and isolated houses. During discussions it became clear that some people part own and part rent their homes, and these figures do not take account of this variation. In addition, during validation it

became apparent that some from urban areas had been classified as living in rural areas when in fact, they live in urban locations. This means that people from rural areas are not as well represented as we would have liked.

Thirty eight percent of participants were recruited to the two groups comprising people with professional, managerial or technical occupations and 62% to the three groups comprising people with skilled, semi skilled or unskilled work. However, work status proved difficult to pin down in the end. Most, 81%, were in regular work of some sort. Fourteen percent were semi-retired. Ten percent were completely retired and data on work status was not collected for 17%. Whilst 81% were in regular employment, less than half, 38%, were working full time. Of the rest, 29% were in part time work, 17% were retired and apparently not working at all, and no data was collected for 17%. In discussions it emerged that some who appear to be working part time are in fact doing irregular, opportunistic work, most of those who are semi retired are also working part time, and a number of those who are retired also do some irregular, opportunistic work.

Whilst the income of those in full time work comes from their salary, the incomes of 55% who are semi-retired or doing part time work either regularly or irregularly, is made up from a combinations of sources including pensions and investments, however small these might be. This figure also includes those who are not working because they do not need to, or because they are retired or they have retired through injury but are intending to go back to work as soon as they can, or have been made redundant. Time has not allowed us to look at this more closely but it does suggest that neither work nor retirement can be defined simplistically.

The original idea was to recruit people into groups according to their expected income at retirement, however, we were advised that this was not possible. Whilst recruiting people into groups with others of broadly occupational grouping might make those involved feel more comfortable in the group, these social groupings do not necessarily reflect expected income in retirement, and so this data was collected when people attended the groups. Not everyone was clear about the type of pension they had. Twenty nine percent of participants will be depending on the State Pension only although 33% said that they are expecting an income not higher than the State Pension. Seventy one percent are expecting to have an occupational or private pension, or, in some cases both, in addition to the State Pension when they retire. Some expecting only the State Pension also have very small investments which are difficult to classify as pensions but may contribute towards a retirement income. Thirty eight percent are expecting that their income in retirement will be between £6191 (the current value of the State Pension plus Pensions Credit) and £12380, which is twice this. 29% expect that they will have an income of over twice the State Pension. Forty eight percent expect to have over £20,000 in savings by the time they retire, but 52% expect to retire with less than £20,000 saved. There is not necessarily a correspondence between the amount of pension someone expects and their savings,

and again, time has not allowed us to unpack the complexities of pension arrangements.

discussion groups and data

The research was designed with input from the Oxfordshire County Council leads in the key policy areas. Three main areas of people's lives were explored: quality of life, now, when one retires, and when or if life becomes more limited through illness or disability or through caring for a spouse or partner². The main reason for this oblique approach, is that people do not think about their lives in terms of policy areas, and nor do they relate specific future needs to the public services that might be available. Rather, people understand their own experience and build on this throughout their lives, developing strategies and gathering resources of one sort or another as they go. Understanding what is important for peoples' quality of life generates and allows discussion to develop to cover policy areas of interest, namely day to day activities - relating to day services, housing - relating to extra care housing, money, choice and control - relating to self directed support, and access and information, relating to localism and communication. The discussions were led by the author, an independent researcher. Not all questions needed to be asked explicitly; however, one assistant checked that all areas of the guide were being covered. and another assistant took detailed notes, verbatim where possible. The sessions were recorded in case it was necessary to check the accuracy of the notes.

The sessions were between two and a half to three hours long. This is a long time for people to concentrate and breaks in discussion can break the momentum. To avoid these problems, the sessions were divided into a number of sections which included a variety of activities. This allowed people to take a break but not lose the thread.

Participants used a specially designed workbook which had a number of functions³. It helped structure the sessions allowing people some thinking time before plunging into discussions, and it afforded a change of activity to help keep peoples' attention. At specific points in the session, participants were asked to spend a few moments jotting down their thoughts about what is important for their quality of life. The book was also used to note individual preferences in the ranking exercises, which were also completed as a group exercise.

In the discussion about quality of life if one becomes limited, a vignette was developed initially for use if discussion flagged or needed to be directed⁴. The methodology was piloted with the first group, and worked well with one exception. The group was very lively all the way through, but it became clear that people did

² See appendix 1

³ See appendix 2

⁴ See appendix 3

not really relate to the idea that events might limit them. In the second group, there was the same sense that people were not really grasping the nettle. The vignettes we were using were re-drafted into one long narrative in which we followed a character as she made decisions following a stroke. This worked well in the third group except that people still did not want to engage with their own ageing, despite more directive prompting. Instead they preferred to relate directly to the character in the vignette or their own experience of their parents' ageing and illness. When the third group had similar difficulty, the inability to contemplate the limitations of ageing in your own life ceased to be a methodological problem, and became of interest in its own right, and this is discussed in later sections.

The data from the discussion groups was analysed with the help of TAMS, which stands for Text Analysis Markup System⁵. Using this software each piece of information from the groups is coded to produce an elaborate index of the data which can be sorted and searched for patterns and connections.

limitations and advantages

Different research methods are useful for different purposes but all have their limitations which need to be pointed out so that decisions made on the basis of findings can take account of these limits. The advantage of qualitative methods such as the focussed discussions used for this research is that one can explore experiences, views and opinions, and the reasons why people do or think as they do. As such, the qualitative approaches on this scale cannot tell you whether any particular views are held more widely than not.

Within our approach we did ask people to do some individual and group exercises where they rated various options in order of preference. This information is presented in charts later on, however, these must be viewed as indicative rather than definitive.

We were unable to target specifically black and minority ethnic groups or those choosing alternative lifestyles and making assumptions about these groups on the basis of this study would be unwise.

People in the group quickly create a culture which affects the discussion. People develop threads which need to be followed. They also relate much of their experience as stories or narratives and build their responses to questions about the future on these.

Discussion guides can only ever guide discussion, they cannot dictate what actually happens in a group. The guide we developed with the help of policy leads explored several areas of life, each one potentially dense. However, each group had its own

⁵ REF Weinstein, M (2006) <http://tamsys.sourceforge.net/osxtams/>

culture, and some areas of the topic guide seemed to encourage more discussion than others. In one case this had interesting consequences for both method, data and findings, which were discussed in the previous section.

The data emerging from this study is very rich and offers much food for thought which is another way of saying that people had a lot to say about their lives and expectations. What they did not or could not say could be just as interesting. However, this study has been relatively small and has had to cover a great deal of ground. Within the time frame allowed for this work, it has not been possible to go into some of the issues raised in the groups in any depth, nor have we been able to examine in any detail different groupings within the sample of forty two. However, within these constraints, the findings which follow should prove helpful in developing and focussing policy interventions in the future.

QUALITY OF LIFE NOW

Factors that are important for quality of life for those who are 50+ vary considerably and depend on life circumstances:

“My quality of life is to do with being a humanist. That philosophy is very important to me.” g3 ABC1

“What’s important? Having enough money. Work.” g2 ABC1

“Family. Companionship. Opportunities to spend my private pension.” g4 C2DE

“An adequate income and good living conditions, most of the things you need in close proximity, and good health.” g5 C2DE

“Health is the main thing. If you haven’t got your health, you haven’t got a good quality of life.” g1 C2DE

“Life is stressful, financially and morally ... My quality of life absolutely crap.” g4 C2DE

“Bloody mindedness keeps me going – refusal to give in ... I need to learn to slow down. I’ve always gone at everything like a bull at a gate. On you go. Blindly mostly. But on you go anyway.” g4 C2DE

daily living

- ▶ almost everyone feels that it’s good to be alive if you are 50+
- ▶ for most, work dominates daily living, along with family and socialising
- ▶ negative life events, and life circumstances, can get in the way of leading the life you want
- ▶ good health underpins quality of life

Daily living is filled with a variety of activity as one might expect, primarily work, family and socialising. Some help friends and people in their community on an informal basis, whilst other do organised voluntary work. Many value leisure pursuits and hobbies, and also travelling and holidays abroad.

Good health is seen as underpinning quality of life for just about everyone. Many leisure activities are health related in that they combine the exercise with a pleasurable pastime such as walking the dog or cycling:

“Cycle to work which helps to keep fit – work is a reason to be active. I am concerned about my health deteriorating when I no longer go to work and have a reason to stay active.” g2 ABC1

Life circumstances get in the way of living the life you want and some, who still have teenage and adult children living at home, are seriously stressed emotionally and financially. These problems seem intractable. Adult children are living in the parental home because the cost of housing and the shortage of housing makes it difficult for them to move.

Some feel that their work is stressful and has caused ill health, or injury. A number have been made redundant or are facing redundancy. Some become semi-retired as a result, but most do not welcome redundancy and retirement. Although one or two feel that it has brought a more relaxed pace to life, others continue to work as hard as ever. For some this means working part time, and for others, working from home.

Redundancy and enforced retirement raise big questions about being well enough to work and the availability of work for those who are 50+. These and other drains on finances all impact on peoples ability to cover the costs of necessities, pay for an accustomed life style, and to save for the future.

There are concerns about ageism in relation to work:

“People retire but they don’t want to or need to and then it takes three graduates to do the same job. It’s as if people are saying ‘you’re 65. Go and dribble in a corner somewhere’” g2 ABC1

“The thought that a 65 year old man is finished angers me. They owe us more respect, but we don’t get what we deserve.” g3 ABC1 (c2de)

“Our generation is caught in the middle. We’re experiencing significant social change, and we’re caught between two generations.” g3 ABC1

At the end of this section of the discussion, people were asked to list three things in their lives now that they did not want to lose. This exercise showed that at this stage of life, the focus for most is on the familial and social networks underpinning health and social well being. Family, spouses, independence, mobility and health, are considered to be the most important things for maintaining quality of life.

housing

- ▶ most people like living where they are now
- ▶ environment and community infrastructure, good transport, health and council services are important factors in home location

People see the benefits of living where they live now in terms of social networks and social activities, the environment, access to amenities and in rural areas, proximity to the countryside.

Small towns like Wallingford are appreciated for neighbourliness and the sense of community. Infrastructure is recognised as important, but threatened, if planning decisions support the development of dormitory type communities rather than communities that provide supportive and active environments for retired people.

Inevitably, in rural areas, transport is an issue and most people own cars to get around. Despite this, people both in rural and urban areas, hope for better public transport.

Additionally, there is general concern that health services and council services are maintained, albeit, there is also a fair degree of protest at rises in council tax.

money choice control

- ▶ people worry about money and pensions
- ▶ many are very concerned about where to go for advice you can trust
- ▶ some women are unaware of opportunities to improve their State Pension with National Insurance contributions
- ▶ most feel that money is no good if you do not have good health so that you can enjoy it

Attitudes to money vary considerably. Some have always saved whilst others, for various reasons, find it difficult. Some prefer not to worry about tomorrow, but others are very concerned about how they will make ends meet. People worry variously about rising costs, whether they can afford holidays, cars, children's education, the mortgage, day to day expenses, and, of course, contributing to a pension and saving for retirement.

The big issue for those who have money is where to go for advice you can trust. The falling value of investments and investment linked pensions, means that people fear having to work over normal retirement age if they are to have the life styles they expect. This is quite different from the feeling of wanting to continue working for money in addition to an already adequate pension, or for other benefits such as a sense of identity or for status, or social contact.

For those with less disposable income and relying on the State Pension only, there are immediate concerns about meeting the costs of day to day life, especially if they still have children living at home, or if they are supporting children at school or

university. These immediate concerns are added to worries about whether or not the State Pension will cover bills and daily living expenses. People in these circumstances feel that they will never be able to retire from paid work.

Some women who will be relying on a State Pension, are not aware of basic National Insurance information that would ensure a maximum income in retirement.

Health is typically seen as more important than money since without health one cannot enjoy the money. However, this only really applies to those who are not struggling financially. For those who are on low incomes, health is important so that they can continue to work to make ends meet.

EXPECTED QUALITY OF LIFE IN RETIREMENT

Retirement has become a 'fuzzy concept' for many and there is confusion about what retirement means in today's world:

"I don't know what retirement is. Is it leaving your main job? Is it age? Is it downward trajectory to the grave? Or upward to heaven?" g2 ABC1

"I don't have any plans but I won't sit in a window and wait to die. I enjoy work and staying active. I can't imagine it any other way." g1 C2DE

Previous generations understood retirement as retirement from paid work at a fixed age, whether people wanted it or not. The parents of those involved in this project are part of a generation that retired early to enjoy, mostly, a long and active retirement with varying degrees of illness and disability.

However, now we no longer reach 60 or 65 and leave paid work. Those involved in this project reflect this quite clearly with their differing work and retirement statuses and patterns. Financial considerations and maintaining activity that confers status and meaning, plus an emphasis on later retirement by government, have all introduced increasing elements of choice. However, choice is accompanied by confusion.

Most are getting used to the idea of living longer and being healthier in retirement than previous generations of older people. However, some feel that a long and happy retirement is "a bit of a myth". Having experienced ill health themselves, and seen or heard of people dying soon after retirement, these people question this 'myth'. Their questions include:

Will I leave work and drop dead, or otherwise have a bored, worn-out and meaningless existence like my grandparents after retirement?

Will I be financially secure enough to pay the bills and fit enough to enjoy life?

Where will care come from if I need it?

It is not clear if there is less confusion among the C2DE groups, but it was noticeable that the ABC1 groups were much exercised by issues of work, retirement, redundancy and money.

daily living

- ▶ planning is difficult in an uncertain world
- ▶ ageism in the workplace and in society in general is a continuing concern

For those who are working, some expect life to change for the better once they retire and they expect to have more time to do the things they want to do. Others, however, expect their quality of life to diminish and are concerned about having to continue working to cover the cost of necessities or to maintain a particular life style.

Some are already semi-retired or retired for health reasons or because of redundancy. This has a significant impact on financial planning. Some who retired early have gone back to work. Many plan to continue working because they need the income, or for stimulation and social contact, or because it gives them a sense of satisfaction, identity and self worth, or a combination of these factors.

Some who are already doing voluntary work plan to continue. Others express an interest in 'putting something back' but do not know how to find out what is available. Yet others help their friends and neighbours in informal ways. One person effectively cares for a older man who has given him power of attorney to prevent the family taking advantage of him.

People express continued concern for ageist attitudes and in particular the apparent lack of respect for older people on the part of young people, and the importance of maintaining dignity in later years.

Many do not want to plan because they prefer to take things a day at a time and not worry. Others are too busy coping with today to think about tomorrow. Yet others have noticed that family and friends, or indeed they themselves, have planned but, through illness or death, have not enjoyed the culmination of their plans. They feel that life is too uncertain and there is no point in planning because things change and your plans and dreams can be upset by unexpected events.

"We had an active retirement planned but my wife has developed mobility problems and this means a dramatic review. My wife will not be able to walk. We had thought about moving but this is not an option now. We are having to adjust to circumstances and our problem now is how to reconcile active and passive retirement needs. I'm aware of the need to keep active and maintain my current interests but at the same time concerned that doing

so may appear selfish, if my wife is unable to be equally active. In a sense I am avoiding it all by carrying on working.” g2 ABC1

Some are living with long-term health problems such as diabetes, heart conditions, or mobility problems, which are beginning to limit life. Experiences of limitation like this influence planning for the future either by encouraging people to think more about what they might need, or by discouraging planning because life and health may take unexpected turns and the best way to cope is to take things as they come and not plan too much.

In retirement, people emphasise strongly independence, health, family, and social networks. However, people also say that they value mobility, leisure, money, and mental well being. Some feel that the quality of their lives will remain the same, others are convinced that it will deteriorate, primarily because of a drop in income.

housing

- ▶ most plan to stay in their own home when they retire although this might not be the same house that they live in now
- ▶ some plan to downsize
- ▶ some plan to move abroad
- ▶ some want to stay where they are
- ▶ most home owners feel that home ownership is for inheritance not care costs

Most are planning to stay in their own homes, some to downsize and some people are planning to get away from something or go to something by living abroad:

“I’ll move to the coast, have a little beach hut. Sell deck chairs.” g2 ABC1

“We have 2 places abroad – Cyprus and Spain - and we will chase the sun. They’re ready for the family to use. We plan to keep going back and forth and share it with the family. A month at a time 3 or 4 times during the winter – we will come back for my hospital appointments.” g4 C2DE

There is a lot of concern about home ownership. People see their homes as assets that they want to pass on to their children. They fear that they may be forced to give up their homes to pay for care, and see this as unfair when those who do not have this sort of asset get care paid for. Some have deliberately chosen not to own a home at this stage of their lives for this reason, having had the opportunity to rethink home ownership for other reasons.

There is some interest and support for retirement villages. Life style, social networks, and amenities that are on offer in these communities are attractive to some, although many appeared not to have heard of them.

There are relatively fewer amenities and shops in rural areas, and so some people are considering moving to urban areas for this reason, and others will move to be closer to amenities in urban areas because they feel that it will be too expensive to run a car.

“There’s nothing in our village – no shop, no post office. We’re on the outskirts of town, so we’ll need to think about facilities.” g1 C2DE

Finances are intimately bound up with housing decisions.

“Finances and inflation might mean down-sizing.” g3 ABC1

“I live in a 3-bedroom house and will have to downsize. My family are all scattered around. There are always financial considerations. I’m downsizing everything, and paying everything off now, including my mortgage.” g3 ABC1

“We’ll probably downsize to a bungalow which will be easier with my knees. We had an endowment mortgage which has cost us a lot. I’d hope to square the mortgage by downsizing. 5g C2DE

money choice control

- ▶ people are concerned about having an adequate income in retirement
- ▶ many feel they will have to work to earn enough for the necessities of life
- ▶ others see themselves working to maintain a particular life style

For most retirement from paid work will mean a drop in income or an uncertain income because market fluctuations affect pension investments.

“My biggest fear is my income dropping massively.” g3 ABC1

Many are expecting to continue to work to earn money to maintain life styles which include travelling abroad. Others feel confident that their pension incomes will be enough to provide necessities if not luxuries. However, whatever their level of income, from whatever source, most feel that they could do with more money.

Those who are better prepared financially for retirement, tended to have a familial culture that encouraged financial planning, and/or had taken out private pensions, and/or had occupational pensions. A few had one or more properties abroad which they regard as part of their retirement provision. Some plan to rent their UK homes to provide an income so that they can live abroad in retirement, temporarily if not

permanently. Others also plan to use their current home to provide a retirement income by moving to a smaller property and releasing capital:

I'll maintain my quality of life by selling my home and investing in a smaller one and releasing capital. That coupled with a pension will be my income when I stop working. g1 C2DE

One issue that arose with an Oxford group was the presence of a loan company in the area which offered continuing loans and charged extortionate rates of interest. This is a 'service' offered to those who might otherwise be refused credit or who are unaware of, or unable to access, fairer borrowing options. Critically, arrangements like this trap people with low incomes in a cycle of debt from which it is hard to escape. The effect on people's ability to save is, potentially or actually, quite dramatic. The local Credit Union works hard to encourage responsible borrowing and saving to prevent people falling foul of the loan companies, which, whilst operating inside the law, never-the-less, are still taking advantage people's circumstances and compounding disadvantage:

"I don't get into borrowing. When I was a kid my mum used [a loan company] to clothe us. They are, near as damn it, loan sharks. They never let you get out. The interest is astronomical - up to 80%. They come to the door and they'll lend you anything. No checks. If you can't pay they just offer another loan. And more interest. I hate debt. I live in mortal dread of it. If I can't afford it I don't have I. It's as simple as that. We've got a lot more now than we ever had." g4 C2DE

Although no one involved in this project was involved with a loan company of this type, some had experience of them in the past through their parents, and one participant was actively involved in Credit Union activities to provide alternatives. Supporting alternative, fair finance, and providing information about it widely in areas where these companies are known to operate might help some to avoid becoming embroiled and, perhaps make better financial decisions.

QUALITY OF LIFE IF LIMITED

For various reasons, many people found it very difficult to imagine life limiting circumstances and to engage with themselves as older:

"I've not really thought about [limiting life events]. I still have young children - teens - at home, so I don't look too far ahead in time." g4 C2DE

However, narrative proved to be an important way of trying to make a link between what I have been or experienced in the past, what I am or experience now and what I might become or experience in the future; with consequent reflection on what one did or does about it. Peoples narratives were about caring or watching parents age and die:

“The sickness and death of my parents in last 3-4 years has made me think about sickness and disability for the first time, but I haven’t really acknowledged yet that it might happen to me or my wife. So I haven’t made any contingency plans ... Have I thought about it? Hardly at all. Why? Perhaps I’m in denial.” g2 ABC1

It was only with prompting that people were able to make a shift from ‘this is what happened or happens to older people’ to ‘I would or would not want this for myself’; and from ‘this is what happened or happens’ and ‘something should be done about it’ to ‘This is what I would or would not like to do or have happen if this were me’.

Experience also shapes views and attitudes to one’s own potential limitation in powerful ways, whether it is ones own experience of illness or injury or that of parents, or, perhaps, both. Even so, many do not want to think about limitation much less plan for it. However, as discussion continued it seemed that although people do not have concrete plans they certainly have ideas and opinions and imaginings about limitation in later life, although this thinking is not often assigned the status of ‘planning’.

Looking across the groups, it is difficult to escape the impression that those with most to lose find it hardest to engage with the idea of loss and limitation. This may be worthy of further investigation as, for now, this must remain an impression only.

daily living

- ▶ maintaining independence is important even when one becomes more more limited
- ▶ people question who should care for them when they become more limited
- ▶ people do not want to vegetate, but rather maintain and develop their interests via tailored day service activity

When people did engage with the idea of becoming limited they, naturally enough, felt that their lives could change dramatically. Independence, the ability to make decisions and remain in control of their lives, mental and physical health, and mobility were the things that most people did not want to lose at this stage in their lives. All these issues are related one to another, a change in mental or physical health could affect seriously the degree of agency one has in day to day life.

So, independence is important to everyone. No one wants to become dependent. Discussion about being a burden turned, in some groups, to discussions about the choice to end of life:

“I want to grow old disgracefully. When it all falls to bits, I’ll just jump off a cliff.” g3 ABC1

"I don't want to be a burden. I would do something. I would take an overdose. My mother is the living dead and has no quality of life. I have two sons, but they have their own lives. I'd go out with dignity." g1 C2DE

"If people don't want to carry on, they shouldn't have to. I want that option. I don't want to be a burden." g3 ABC1

It also lead to discussions about who would or should care you if you need help:

"I hope the children will have learnt from my example in looking after my parents. I hate Care Homes. I wouldn't wish them on anyone." g4 C2DE

"I feel 100% that family shouldn't be responsible for looking after you. I'd expect to be put into a home. Don't believe in families looking after you. They're too close to you." g2 ABC1

"I don't mind people being a burden to me but I don't want to be a burden to them. If I have dementia, I'd want to be put in a Home. I wouldn't want anyone to have to look after me like that. If I was dying I wouldn't ask my son to help me. My grand-daughter maybe." g4 C2DE

"We have an unwritten rule. My sons have said that when anything happens to me and I need help it will not be a problem." g5 C2DE

Whatever happens in individual cases, people have expectations both of family and care services, and these expectations have implications for the way that services are organised.

These expectations include what they might do if they have to have care services. For example, people cannot envisage stopping work, or not being healthy and active, and this appears in discussions about life limiting circumstances, as concern about maintaining physical, mental and social well being. Thus options for day services activities that maintain current interests and develop new ones are far more attractive than the activities that people's parents may accept when they go to day centres now. Suggestions for day service activities, include, for example, learning opportunities, cultural visits to exhibitions, opera and the theatre, and soft porn. This last is, possibly, a frivolous suggestion, but never the less indicates a desire not to vegetate, or be pigeonholed as "past it"!

housing

- ▶ most want to stay their own homes
- ▶ some think about the suitability of housing should they become less mobile
- ▶ there is a division of opinion about owning property at this stage of life

- ▶ most want to take advantage of assistive technology, although there are concerns about efficacy and privacy
- ▶ people are not familiar with the concept of extra care housing

Independence is very important to people and for most this means staying in their own homes even if they intend to downsize or move to sheltered accommodation:

“As long as I’m able to climb the stairs, I’ll stay at home. Then we’d move into a flat. I want independence.” g1 C2DE

Those who have thought about it feel that their present home is not suitable if they become more limited. Although some want to remain where they are if the house could be adapted, downsizing and moving to a more urban setting is an option that is being actively considered by some. Most do not want to live with their children although they hope that their children will help them if they need it.

Most express a preference for continuing to own property. They view their home as an asset that they want to pass on to their children and are very concerned that this might not happen if they have to use it to pay for care. Some would prefer not to own for this reason. There is some distrust of managed lease schemes.

Most will take all the assistance they can get if it means remaining independent however, assistive technology is viewed with distrust by some who have experience of alarms not working or who view being monitored as ‘big brotherish’. Perceptions of being watched, with consequent lack of privacy, may or may not have foundations in the reality of assistive technology, but for some this is enough to put them off the idea.

A move to residential care would be prompted if people are completely unable to cope [see the previous section about ‘being a burden’] but this option is far from popular:

“I’d want to keep out of Nursing Homes for as long as possible. They are horrible places. I’d hope the kids would help but I don’t know.” g5 C2DE

“I’d like to stay at home and would be happy to go to a Day Centre. They’re pretty good.” g4 C2DE

It is interesting to note that Extra-Care Housing is not a familiar option to people and so it was difficult for them to understand what it would mean for them to make this choice. Like other choices, the answer so often is that a decision in favour of one or other option depends on what the need at the time is. People do not know what will happen and so do not know what their needs will be.

money choice control

- ▶ disillusion and the social contract
- ▶ whose money is it anyway?

Some have made plans to hand over financial decision making to children. There are various reasons why people make these arrangements at this earlier stage in life, but for some, the impetus came from a serious health problem:

"She: "It was a wake-up call [F's illness]. It's only fair to the children to have some guidance on what to do in terms of care. We had a big discussion with the kids. They will make decisions if we are unable in the future. You need to get power of attorney sorted early.

He: I don't mind. The kids would have my best interests at heart. It would be difficult for us all but I trust them." g3 ABC1

For others disposing of assets and handing over financial control came from a desire to make sure that their assets could not be used to pay for their care:

"I would not want to go into a residential home, sell the house and let them [the authorities] get their hands on the money. It's important to make arrangements for the money well in advance. My children have had power of attorney for the last 3 years." g4 C2DE

Care costs paid from capital assets, such as a property, are seen as something the State takes from you, preventing you from having what you expect and want and feel is yours by right. Accumulated wealth and assets are handed on to one's children not to pay for care costs.

There was a sense across groups that the State Pension pays, or should pay, for the necessities of life and care services, that one's own pension pays for life's little or big luxuries, and that one's capital assets are to be inherited by children. People with property, or who have saved for retirement, feel penalised, and that it has not been 'worth it'. This is despite the fact that people are continuing to save and accrue wealth if they can, and feel they must continue to work in order to make ends meet.

Although there was some dissent, there was also considerable resentment from many that immigrants and people who have not been thrifty are perceived to get State 'handouts' whereas you do not if you have been careful and saved for retirement. There appears to be no reward for 'wise virgins' in this world and many conclude that one might as well eat drink and be merry for tomorrow the State will take it all away one way or another. In contrast, 'foolish virgins' are given all that they need despite their dilatory habits.

For those on low incomes, the debate about immigrants takes a slightly different turn in that they feel that there is less for them, and that they cannot get help as easily as those who have just arrived in this country.

In general, people are not clear about the way in which State funds for local care services are allocated. Whether people have made financial arrangements or not, and whatever their views about the allocations of care services, there was a strong sense for many that a social contract had been broken. This contract is between the State and the individual, and is about the individual's understanding that the State will provide for them when they need either social or health care. A number of people in the groups did not distinguish between health and social care, or the different entitlements, or the different ways that services are organised and funded nationally and locally. There is a misunderstanding about how national insurance works. People see it as a savings or insurance scheme, and feel that they have paid in to it all their lives and are, therefore, entitled to care free of charge, when they need it. However, their perception is that the care is not there when they need it, and not free of charge:

"I can't see why I should have worked all my life and paid into a system to look after me and then pay again for it." g5 C2DE

Only one or two dissented from this view, feeling that it was good to pay if one could because one had more power to make choices and control outcomes.

The debate around who should or should not pay for long term care is alive and well, and people need help to understand what they can realistically expect. Unrealistic expectations spell trouble further down the line, when people are at their most weak and vulnerable, and least able to cope with it. Proper choice and control can only be exercised if one knows what choices to are available.

Self-Directed Support

- ▶ people like the idea of Self-Directed Support, but are sceptical about intentions
- ▶ people have question about the planning process, the cost and how you find out what is available

The idea of Self-Directed Support was approved by most:

"It sounds like a good idea. Seems to empower rather than take more away." g1 C2DE

"What we have at the moment is one size fits all. This allows for more individuality." g5 C2DE

"It's a very good idea. You'd have more control. We abuse stuff that's handed out for free. If it comes with more control attached to it, we'd take more care to spend wisely so there may be savings." g5 C2DE

"In a village, people might work for several people. I can see it working." g2 ABC1

However, people are distrustful about intentions, and diffident about turning to social services for help. They feel that Self-Directed Support is a good idea 'in theory' but do not believe that it will happen:

"It sounds like doing things on the cheap to me." g1 C2CE

"There is no such thing as a free lunch." g3 ABC1

People also think that there is a catch, because their perception is that there always is a catch with social care. As part of this scepticism people questioned:

the care planning process:

"Providing your needs are defined by you and your family or someone you know and not a faceless bureaucrat who says you need this, this and this when in fact you need that. That's the important thing" g5 C2DE

"Your needs might be different from what your family thinks your needs are. There's a lot of anger in families about this. Different agendas come in. Some people don't have any time for older people. It's a complex picture. Safeguards would need to be built in." g4 C2DE

the cost:

"Will there be enough money to make it work?" g2 ABC1

"There's a question over who gets it. Is it means tested? That would cut out lots of people." g1 C2DE

what would be available, and how one would find out about it:

"Do they provide a list of what's available? You have to know what's there to help." g4 C2DE

"If it's simple and you can get the information you need, it would be very good." g4 C2DE

and the quality of care that might be on offer:

"Carers vary and they are not paid much. Some really care, others do a bad job. If you were more in control you might be able to influence this." g5 C2DE

Finally, there are implications for Self-Directed Support for those with grown up children still living at home. If work is an issue for them, they may be a willing and able work force if the person for whom they might care is agreeable. However, as we

have already noted, not everyone wants to be cared for by a member of their own family.

ACCESS AND INFORMATION

- ▶ independence afforded by personal mobility is important for accessing facilities and service
- ▶ people want local access and an environment that takes account of older peoples' needs
- ▶ people do not know where to go for trustworthy advice
- ▶ for those on low incomes, planning and advice is particularly important
- ▶ women did not know about National Insurance options that would improve their State Pensions
- ▶ for information generally, there is a need for the right information to be available at the right time, in the right place, and from the right people
- ▶ precisely what information depends on peoples' circumstances

Throughout the discussions, there was an emphasis on independence and mobility, and how important this is for accessing facilities and services. People expressed concerns about the lack of facilities in rural areas and the effect that diminishing mobility might have on decisions to stay in their community or move. The nature of community as a safe environment was raised also, in terms of town planning. People were concerned that planning processes should take into account infrastructures that meet the communal needs of older people.

There were also significant concerns about trust worthy advice, financial advice in particular, at all levels. This is especially important for those on low incomes. Information and advice for women, in particular, about National Insurance options was specifically identified as a concern that needs to be addressed.

Throughout the discussions people returned to the idea that it is not easy to know what's available or where to go to find information, and they had suggestions about what might help:

"Someone should come up with a bill of rights – something to tell people what they're entitled to." g1 C2DE

"It should be the council or the Department of Work and Pension and not an outside organisation [that lets people know what is available financially]" g1 C2DE

People taking part in the groups did various preference rating exercises individually around information needs, and these were repeated in the group. Generally individual and group preferences mirror each other, and the reasoning recorded during the group work gives an insight into why people go to particular sources for information. However, it was difficult for groups to agree definitive preferences in these exercises. Instead they clustered the options. This suggests that people do not go to one place, or person, nor do they need information at one time only, or only in one form.

when do you want information?

Wanting information *‘when I have a problem but whilst I’m still managing’*, and *‘when I’ve been managing a while and know what I want’* are really different ways of expressing the same thing. However, it is interesting that many expressed a preference for the more active form, *‘when I know what I need’*, although there was some uncertainty about where information would come from.

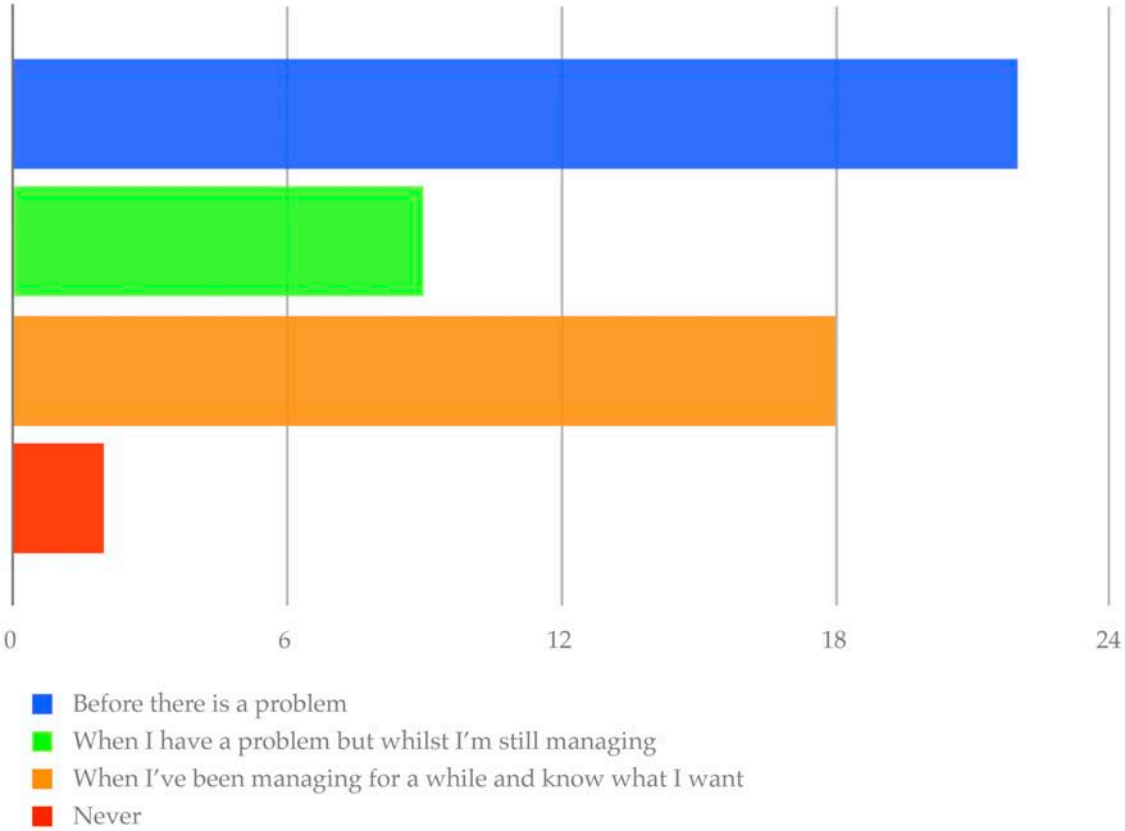


Figure 1: When would you like to get information: individual preferences

Naturally opinions differ in the individual exercise but reasons for disagreement became clearer in the group exercise. Some want information before they have a problem because *“knowledge is power and if I disagree, I can argue if it’s before”*. Others

chose this option because they want to be able to think ahead and plan whilst they are able. People expressing this preference want to know, at least where to go for help, even though they accept that they may need more experience of what it is like trying to manage with whatever the problem is before they know what information they really need. The point was made that if you do not know what the problem is you cannot know what information you need. Since you cannot predict the problem, usually, the sort of information you need will depend on your situation when you know what the problem is. In other words information is best given reactively not proactively.

who would you go to for information?

The top choice for delivering information are specialist organisations. People felt that these organisations could be trusted, and that, if they did not have the information wanted, they would know some one who did. GPs were also highly regarded as people to give information, closely followed by family and friends. All these are seen having general, specialist and comprehensive knowledge, and could be trusted if they had a sufficiently good reputation. If their reputation was tarnished in some way then people did not trust the information they might offer.

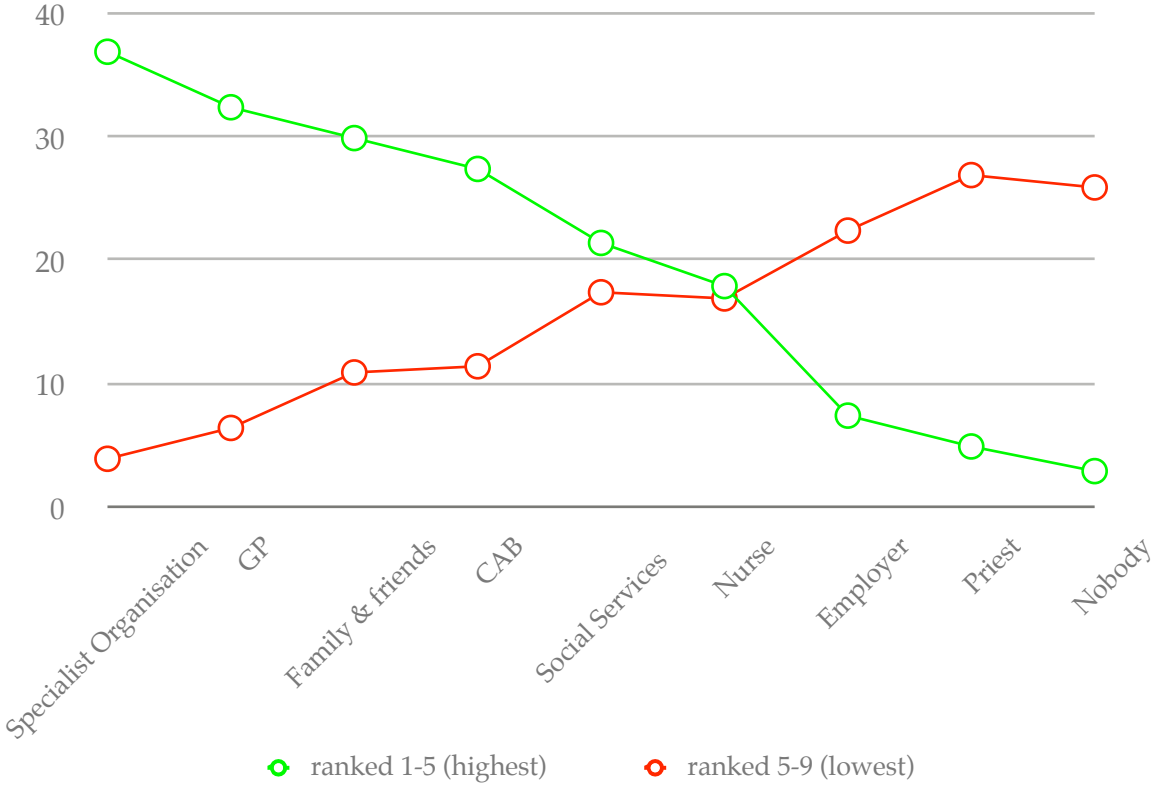


Figure 2: From whom would you like to get information: individually ranked preferences, clustered. NB rank 5 split evenly between two clusters

Not surprisingly the medical profession were the people to go to if one had medical problems, but, interestingly, they were also seen as people who would know of other sources of information, and so were seen as a good starting point. The medicalisation of ageing was questioned by one person. This issue was not taken up by others, probably because time was limited, and the discussion was focussed on limitation. However it would be interesting to engage people about the extent to which ageing is equated with increasing physical and mental frailty, rather than more positive aspects of later life. Notwithstanding that health is important in realising and releasing the potential of older people, health is also important no matter how old or young you are, and this point feeds into the debate about what retirement means these days.

The Citizens Advice Bureau gets a mixed review with some thinking that they were very good and others very bad. One reason for not placing them in the first cluster was that *“you can never get to see them but if you could get an appointment they would be good”*. Although some included social services in the first cluster of choices, they were often, in the middle or last cluster.

Although some knew that their employers offered courses, many were semi retired and so this option was not apparently available to them. In any case, many were definitely not happy to have information from their employer. Time did not allow us to explore the reason for this, but one might speculate that people may have been thinking about their immediate line managers rather than seeing their employers as an organisation with a duty of care that might include making appropriate information available to employees.

Priests or vicars were the least favoured choice in both individual and groups exercises, although one or two felt that they would want to talk to the leaders of their faith community.

what form do you like information to take?

The most popular option for the form that information might take, was *‘in person’*, and the reason given during the group version of this exercise was *“because you absorb stuff better in this way”*. However, leaflets can back up face to face communications also because *“literature helps you to absorb stuff later”*, especially as people may forget if there is nothing in writing.

There was a suggestion that the internet should be free if you were over 70, however, the internet was problematic as a category in this exercise. In some groups, discussion of the internet as an option for accessing information generated fierce debate because not all are *‘internet savvy’*. Some people who do not use the internet at the moment would be willing to learn. However, even some of those that do know how to access information on line felt that it was difficult to navigate web pages and

get a sense of the quality of the information when you found it. Information did not always apply to their particular circumstances.

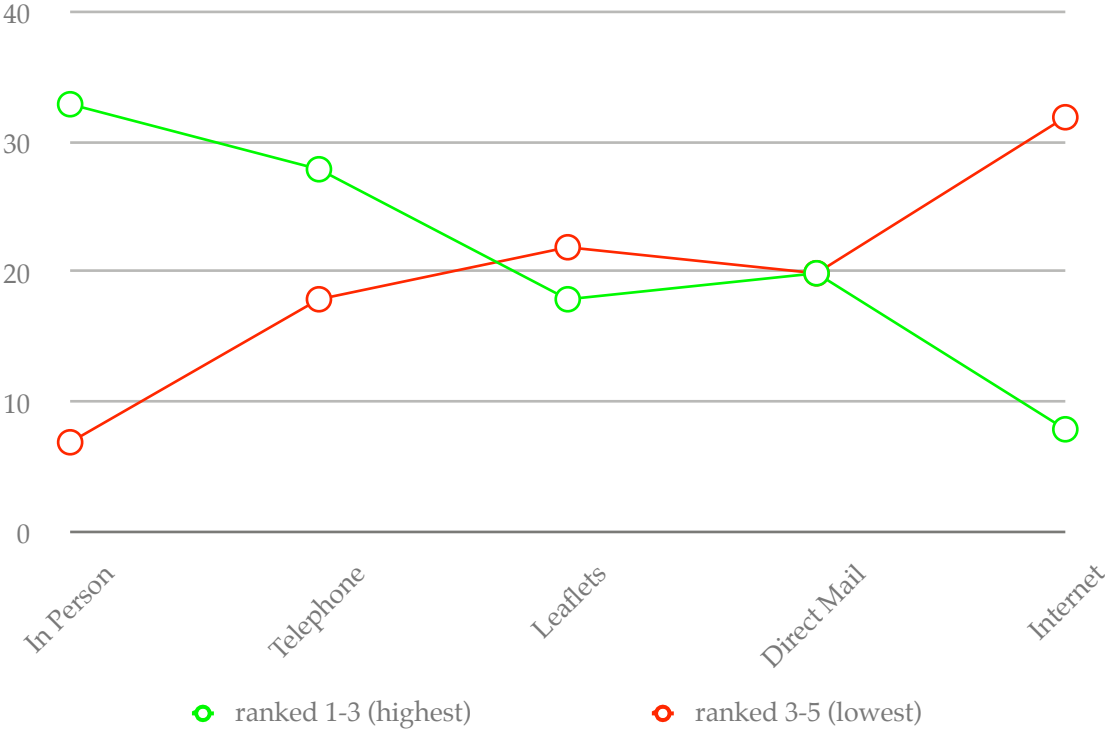


Figure 3: In what form would you like information: individually ranked preferences, clustered. NB rank 3 split evenly between two clusters

Unsolicited and direct mail were the least popular options. Although some would want information sent in this way others felt that there is there’s too much mail of this sort and that *“information needs would be too specific for randomly targeted drops”*.

where would you go for information?

Trust was again an issue in group choices about where to go for information. Also at issue was the likelihood of finding the information you want or being directed to a place that would be able to help. Specialist organisations, GP surgeries, the Citizens Advice Bureau, the library, and the internet were all places that would *“get you off to a good start”*. Family and friends were not included often in the highest or the lowest group clusters, and specially organised events were included once in the highest cluster, with the suggestion that they be advertised in local shop windows. The internet was, again, the subject of some argument.

Peoples’ perceptions of social services varied and some had strongly negative views affected by *“a lot of bad publicity nationally”*. The general feeling in one group was that *“they have the information but take ages before anything moves on. If they could get their act together they would be top of the list”*.

People would not go to hospitals specially for information, but would pick up information if they were there for other reasons. Community centres, church, shop windows and work were placed in the lowest cluster on the grounds that people had no experience of these as sources of information, and none were sufficiently specialist to have the right information or necessarily know where to direct enquiries. There was suspicion that churches “*want your soul and are a last step before the box*”, shops “*want to sell you something*”, and that one’s place of work wants to “*take from you and give nothing back*”.

Exceptions were made by some individuals, for example those who felt that their church would be amongst the places that they would go for information; and one couple who found that their community centre in Kidlington was a place where “*face-to-face, you can ask questions and get answers, and pick up leaflets*”.

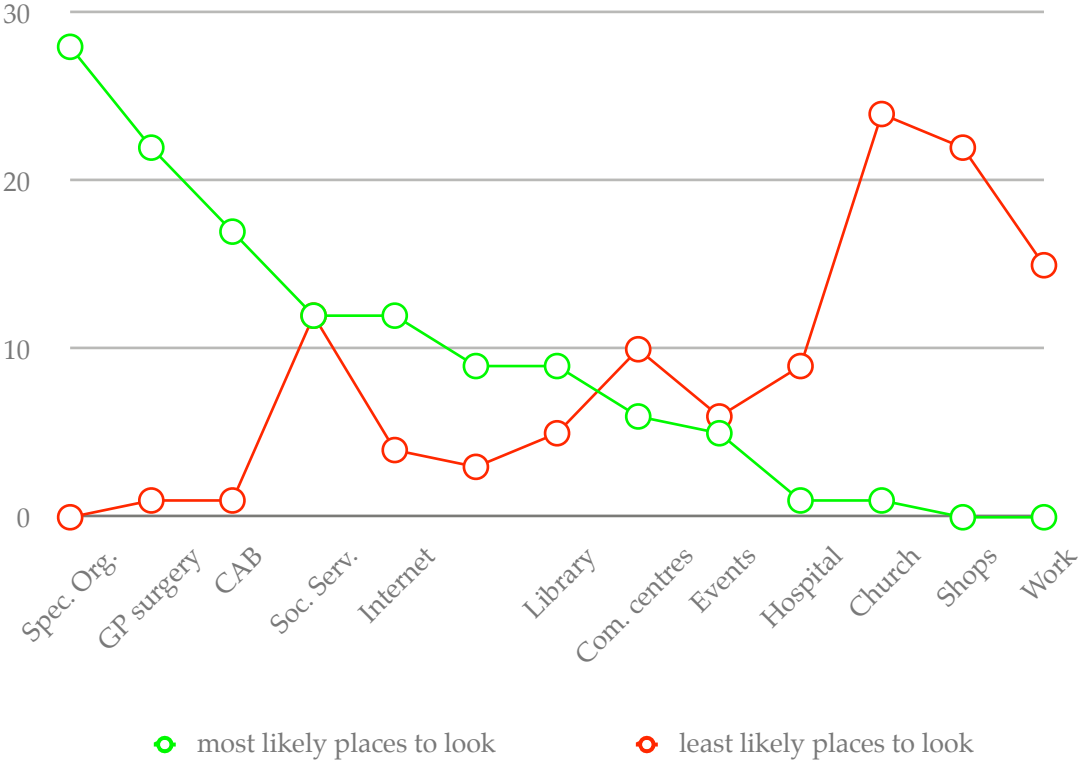


Figure 4: Where would you go to find information: individually ranked preferences, clustered

Perhaps the most important point to make about information seeking, giving, and getting, is that people need the right information, at the right time, in the right place, from the right people. There is no definitive form, time, place, or person for information because ‘*it depends*’ on a variety of factors, among them: what the problem is, what stage you are at in thinking about it, who you relate to best, what resources you have yourself for finding information, and the sources you have access to that might help with your enquiry.

THE SHAPE OF THINGS TO COME

- ▶ meeting realistic expectations means continuing to listen to people
- ▶ it also means helping them to understand how public services are funded and the limitations of public resources
- ▶ in order to support aspirations and independence it is important to understand how difficult it is for people to imagine what it might be like to be more limited than they are now
- ▶ implementing the new personalisation agenda means promoting well-being, preventing poverty, and encouraging earlier life planning
- ▶ participants found it interesting and useful to discuss retirement issues with others and, in an age of anxiety and uncertainty, earlier life planning could be encouraged

It is clear that people want to be independent and active as long as possible. They want control over where they live and how they spend their money.

Some also want to continue working as long as they can either because they feel they need the money, or because work offers them intellectual stimulation, or because it offers a sense of belonging and purposeful activity that they might not have otherwise. Many expressed concern that opportunities for work may be limited by ageist attitudes in the work place and in society at large. This willingness to work, at least part time, for as long as possible, would suggest that there is a pool of skill and experience, and people willing to learn new skills, that could be tapped in the future. However, there is work to be done to change attitudes since there is little evidence that older people are any less able than younger people in the work place. Variances within the huge population of older people are matched by variances in the equally large population of younger people, thus some will be more or less flexible in their attitudes to work, more or less willing and able to learn new things, more or less creative and so on. Age is not the issue. Public services, and employers, facilitating opportunities for older people to continue making a paid contribution to society would be welcomed by those in our groups wanting to remain in paid work at least part time.

People are aware of the importance of financial planning for retirement and most who are able have made provision. Some have made power of attorney decisions. There is a serious gap in women's knowledge about Nation Insurance contributions that would cost them little but would help provide them with a full State Pension. Some people are unable to save because of ongoing family commitments which drain financial resources.

People are telling us that they do not want what appears to have satisfied their parents. They expect to be active and healthy for most of their later years. To this end, but with reservations, they will accept whatever help is on offer, and move to accommodation that will enable them to remain independent. Residential care, however, is a last resort.

People find it hard to look further than this at the possibilities of limitation and its consequences, and the sorts of services they might want and what these might look like in practice. People in these groups are telling us that 'it depends' and that it is too early to make realistic decisions at this level of detail. This suggests that consultations need to be ongoing and systems and services flexible.

If the shift towards Transforming Social Care is to be successful, it's clear that individuals need to have a better understanding of what might be required of them and what is available for them. This suggests a more interventionist strategy in the form of support for Life Planning earlier in life than retirement or the decade pre traditional retirement. This is particularly important in view of the confusion around what retirement means these days.

Currently, planning for retirement happens late in working life, and people tend not to think about the kinds of problems that might happen in later life. Some work places offer pre-retirement courses but probably not enough, and not everyone has access to these opportunities. In addition, this study suggest that people are not keen to go to their employers for information.

It is interesting to note that the methodology developed for this project proved useful, not just in terms of conducting this research. Many found it helpful and interesting to hear others' experiences and share information and views, which suggests that there is potential to develop this format to help people think through issues in their 50s, if not before.

Some would say that we are in the midst significant social change. As life expectancy increases and the demographic change that goes with this shifts perceptions of the ageing process, people no longer feel they understand what being old will be like for them, neither can they anticipate the range of possibilities, and, without some model of what to expect, people do not know quite what to do. Others would argue that we are always in the midst of significant social change and the thing that does not change quickly enough is the public policy response to social change. Which ever view one takes, we know that there is a significant change in the policy agenda, presaging an enormous shift in the way social care is delivered. In turn this creates opportunities for involving people in planning their lives as never before, because, whether people have plans or not they certainly have expectation and aspirations of their lives at all ages and these will not necessarily be met if they are not aware of and able to act on the possibilities available now and in the future. For their part public services can play a part by helping support life planning activity.

This project has generated some very rich data. However, as time was limited it was not possible to do more than note the issues that people raised in the discussion groups. The broad brush approach of this work has mapped out the territory, so to speak, but each policy area would benefit from an in depth exploration in separate focussed discussions. This would help us to understand the nuanced experience that feeds and shapes people's aspirations, expectations, and decisions, and hence help those implementing policy to find better ways of working with people to deliver the new personalisation agenda.

APPENDICES

1 discussion guide

2 workbook

3 vignette

1 discussion guide

ARRIVAL ARRANGEMENTS (15 mins)

Meeting and greeting; incentive payments [recruiters will host event]

Checking basic information to validate sample (anonymous)

Reminder re consent

Settling down with refreshment if wanted

GENERAL INTRODUCTION (10 mins)

Facilitator and note taker introductions

Arrangements 2-2½ hours, refreshments - ad lib, loos, alarms, mobile phones

What to do if you want a break

Individual introductions – first name only

Reason for discussion group

What will happen to the information you give; report; anonymity (not identified by name in reports and publications); how to get a copy of the report

Outline of session: discussion in several stages with variety of activities to allow breaks to stretch and refresh

Discussion ends no later than 165 mins to allow for wrapping up

Scribe 1 will make notes; scribe 2 will check checklist

The discussion will be recorded for checking purposes only

DEPARTURE ARRANGEMENTS (15 mins)

NB All timings approximate

1. YOUR QUALITY OF LIFE NOW [35 mins]

Think about your life now.

What is important for your quality of life?

What helps you to maintain / develop your quality of life now?

What makes it difficult for you to maintain / develop your quality of life now?

Overall, are you satisfied with your current quality of life?

jot down notes [workbook]

checklist / notes

discussion [group]

discuss specific policy areas as necessary [group]

three things exercise [workbook]

if you have problems or you need to know something *now*, where do you go for information that might help you? [group]

information re preparing for retirement / preventing problems: activities / money / housing / health / dementia / osteoporosis / help & coping with caring

day to day activities (*incl. day services, leisure, life long learning*)

What do you do day by day, and occasionally, that gives you the quality of life that you enjoy now?

What kind of social life do you have?

Hobbies? Leisure activities? Involvement and activity within your community?

Do you do voluntary work?

What is your social network like?

Who do you see regularly? Family? Friends?

At what sorts of occasions do you see family and friends?
How often?

How do you get around at the moment?

housing

Where do you live?

What's your house/flat like?

What do you like about where you live that enhances your quality of life?

What detracts from it?

money, choice & control

What about your finances?

How financially healthy are you now?

Can you do the things you **need/want** to do?

Who decides how you spend your money?

What financial plans have you made for the future?

health (*if not raised in discussion earlier*)

How do you look after your health now?

What do you do to stay fit and healthy, mentally and physically?

How do you know about the things / activities / services that help you stay healthy?

checklist / notes

day to day activities:

- making a contribution to the community
- volunteering
- *travel:*
 - car?
 - public transport?
- rural transport
- *access* to facilities, events
- anyone caring for someone?

housing:

- type of accommodation now
- benefits of living where you are now
- detractions:
 - location
 - housing type

money, choice & control:

- pension provision
- types of pension
- where to go for *information*/advice re money

health:

- activities for health:
- *information* re healthy living
- nutrition
- getting *information* re preventing health problems
- *access* to health care: people / places / services / prevention

2. YOUR QUALITY OF LIFE WHEN YOU RETIRE [35 mins]

Now that you have reflected on your current quality of life, think about what you expect your life to be like when you retire.

To what extent have you made plan for your retirement?

Will your quality of life change? Will it improve? Will it diminish?

How will you maintain or develop your quality of life in retirement?

What do you expect to be doing when you retire?

What might happen that would make this difficult?

Overall, do you think you will be satisfied with your quality of life when you have retired from paid work?

jot down notes [workbook]

checklist / notes

discussion [group]

discuss specific policy areas as necessary [group]

three things exercise [workbook]

if you have problems or you need to know something *when you retire*, where will you go for information that might help you? [group]

*information: activities /
money / housing /
health / dementia /
osteoporosis / caring*

day to day activities *(incl. day services, leisure, life long learning)*

Do you think your day to day activities will change? Your hobbies? Your leisure activities? If so, how? If not, why not?

How will you find out about activities available when you retire?

If you already do voluntary work will you continue doing it. If you don't will you think or have you thought about doing voluntary work?

What kind of social life do you think you will have?

What is your social network like? Who will you see regularly? Family? Friends?

At what sorts of occasions do you see family and friends? How often?

How will you get around? What sort of travelling do you expect to be doing?

housing

Where will you live when you retire?

Will your housing change? Will you move?

If so, where to? How will you make this choice? Why? If not, why stay where you are?

money, choice & control

What about your finances?

How will your finances change?

How will you organise yourself financially to do the things you **need/want** to do?

health *(if not raised in discussion earlier)*

Are you expecting your health to change?

What will you do to stay fit and well, mentally and physically?

checklist / notes

day to day activities:

- making a contribution to the community
- *information* about volunteering
- *access* to life long learning / cultural events
- *travel:*
 - car
 - public transport
- rural transport
- *access* to facilities, events
- anyone expecting to care for someone?

housing:

- planning to change?
- reason to change or not?
- *information* on housing choices

tenure choices:

- own
 - rent
 - managed lease
- ### **money, choice & control:**
- perceived consequences of earlier financial / type of pension provision
 - where to go for *information* & advice?

health:

- staying active
- *information* re healthy living / prevention / coping with problems
- nutrition
- *access* to health care: people / places / services / prevention

3. YOUR QUALITY OF LIFE IF LIFE EVENTS LIMIT YOU [70 mins]

Life events happen to everyone. They can improve life or they can make life temporarily or permanently difficult. There tend to be more of them, and more negative ones as we get older. The sorts of life events that might limit us are:

- you / your partner becoming ill or disabled / developing physical or mental health problems
- caring for a physically or mentally dependent relative
- being bereaved

Have you thought about these sorts of life events? Made any plans? If so, how have you gone about preparing for the possibility of these life events? What contingency plans have you made? If you haven't thought about it or made plans, why not?

How would these events change your life?

Is it important to you that you stay independent? Why?

What sort of help or support would you need to maintain your quality of life?

Where do you see gaps in your own resources? How would you expect to fill them?

With what sorts of things would you expect to get help? From whom?

jot down notes [workbook]

checklist / notes

discussion [group]

three things exercise [workbook]

discussion [group]

discuss specific policy areas as necessary [group]

information preference exercise [workbook]

information preference exercise [group]

do you want to be involved in shaping services and policy that might affect you when you are retired? If so, how? If not, why not? [group]

Use vignettes as discussion flags

if life events limit you
and you have problems
or you need to know
something, where will
you go for *information*
that might help you?
[workbook/group]

involving the public

how to communicate
change

type of involvement

- information giving/getting
- questionnaires
- events
- groups like this one

day to day activities *(incl. day services, leisure, life long learning)*

If life events begin to limit you:

- How would your day to day activities change? Hobbies? Leisure activities? Adult education activities? Community work? Voluntary work?
- What activities would you be reluctant to give up? Why?

- Which will happen to your social life?
- What will happen to your social network?
- Who will you see regularly? Family? Friends?
- At what sorts of occasions will you see family and friends? How often?

- Who will care for you and/or your partner?
- What resources do you, your family and friend have to help you deal with physical and mental health problems?

- What if you can't drive anymore or use public transport? How will you get around?

checklist / notes

day to day activities:

- making a contribution to the community
- *information* about volunteering
- *access* to life long learning / cultural events

- getting *information* and help

- *travel*:
 - car
 - public transport
- rural transport
- *access* to facilities, events

Use vignette as necessary

housing *(incl. expectations of extra care housing)*

If life events begin to limit you:

- Where will you live?
- How well suited is your current or expected housing to managing the issues arising from physical and mental health problems?
- Will you move?
- If so, where to? Why?
- What sort of housing might you need?
- How will you find out what's available?
- If not, why stay where you are?
- What sort of help would you need to stay in your own home?
- If, because of physical or mental health problems, you become very dependent and need more help with *day to day living*, would you prefer to go into a residential care home or to be supported to live at home via special resource centres in the community catering for higher dependency needs?
- In each case, why?
- Would you consider using new and emerging technology in order to remain independent in older age?
- Do you know *what is available* now? eg community alarms and sensors that can be placed in your home and will trigger a response from a call centre if activated?
- What do you think of what is available now?
- Would *being aware* of what is available now help with your future planning?

Use vignette as necessary

checklist / notes

reasons to change / not change:

- suitability of accommodation for retirement needs?
- *access* to services and facilities?
- community?
- proximity of relatives?

types of accommodation available:

- sheltered
- extra care
- residential
- nursing home

tenure choices:

- own
- rent
- managed lease

staying in your own home:

- informal social networks
- formal care networks
- small repairs
- high dependency resource centres

assistive technology available:

- community alarms/sensors
- telecare

money, choice & control (*incl. expectations of self directed support*)

In thinking about your own resources (discussion should have highlighted these) can you see:

- Any gaps?
- When might you need help from health and social care or from other sources?
- What things would be most important for you to continue to do? (day to day activity)
- What kinds of help and support might you need to tackle the kinds of problems you might encounter when you are older.

Thinking specifically about money, if life events begin to limit you:

- What are the implications for your finances? Saving? Spending? Using your assets?
- How will you organise yourself financially to do the things you **need/want** to do?
- What sort of financial support or help might you need?

If you ever need more formal or professional help eg from an agency or social services:

- Which services would be so important that you would be prepared to pay for them? (money, choice, control)
- Thinking specifically about social services, how involved would you like to be in the care you get from them?

Use vignette as necessary

Self-Directed Support

Self Directed Support is the process by which a person has choice and control over the help that they need so that they can go about their daily life. For example, if you want to you can assess your own needs, make your own plans, and decide how to spend an agreed budget.

NB council has duty of care to arrange services for anyone who can't do this themselves.

- What do you think of this change in principle?
- How involved would you like to be in care of this sort?
- How would you feel about being in control and managing your own care?

Use vignette as necessary

Checklist / notes

SELF DIRECTED SUPPORT

contact by:

- a team member
- a named person

assessment by:

- professional dedicated assessor
- professional with broader range of knowledge
- you, if you are able
- you, but with a bit of help

a plan for things to help you developed by:

- the council
- 3rd party (you pay for this)
- you, if you are able
- you, but with a bit of help

choosing who will provide the things and services you need via:

- the internet
- a support line
- word of mouth
- a local event
- an advisory service
- in libraries
- other

checking that your plan is working:

- when
- how often
 - every few months
 - every six months
 - once a year
 - after 2 months then annually
 - when you ask

2 workbook

date	group no.		book no.	
your consent	yes	no		
your gender	male	female		
your age now	50-54	55-59	60-64	
your ethnicity	white	mixed	asian Asian British	black Black British chinese all Chinese not given
are you:	single	married	living with a partner	
are you working:	yes	no	if 'no' this through choice? y n if 'n' are you receiving benefits? y n	
are you:	full / part time	semi-retired	pension	retired
current income from:	salary	pension	other source	
your type of pension	State Pension	private pension	occupational pension	
your expected retirement income pa	£6,190 (State Pension)	£6191-12,380	over £12,381	
your expected savings at retirement	under £20,000	over £20,000		
your home type	owned	rented		
your home location	urban	rural	urban means Oxford & rural hub towns including fringe developments rural means village, hamlet, grouped or single dwellings such as farms or isolated houses	
where:				

Many thanks for taking part in this group discussion. The information you will provide will be very helpful to making plans for future services for older people in Oxfordshire

This work book is for you to use during the session. The group facilitator will let you know when to use it and it will be collected at the end of the session.

Your contribution to this project is anonymous. This means that neither you nor anyone you name, or any place that you mention during the discussion or in this book, will be used in the report, or handed to Oxfordshire County Council or Age Concern Oxfordshire. This book will be destroyed at the end of the project.

All information that you have provided will be treated with respect. The recording of the discussion is for checking purposes only and will be erased at the end of the project.

Tomorrow's Older People aims to find out about the expectations and aspirations of those currently approaching retirement in order to inform policy focussed on keeping people independent as possible as they grow older, preventing problems and maintaining quality of life as far as possible.

People living in Oxfordshire are taking part in a number of discussion groups like this one.

This work book is for you to use during the session, to jot down thoughts and ideas in whatever form suits you, and for particular exercises. The group facilitator will let you know when to use it.

The book will be collected in at the end of the session and used in the analysis alongside the discussion. It will be destroyed at the end of the project, although selected material may be retained to illustrate any reports and publications arising from this project.

Your contribution to this project is anonymous. This means that neither you nor anyone you name, or any place that you mention during the discussion or in this book, will be used in the report or any subsequent publications, or handed to Oxfordshire County Council or Age Concern Oxfordshire. In addition, any quotations or materials from either the discussion or this book, used in any reports or publications arising from this project, will be anonymous.

You can get a copy of the report that will be written about this project by filling in and returning the form in your pack.

If you enjoy taking part in today's discussion and would like to be asked again, by Age Concern Oxfordshire, to take part in follow on projects or related projects, remember to fill and return the form in your pack.

THANK YOU for participating in today's discussion. Your contribution will help shape future services for Tomorrow's Older People.

1. YOUR QUALITY OF LIFE NOW

Think about your life now.

What is important for your quality of life now?

What helps you to maintain / develop your quality of life now?

What makes it difficult for you to maintain / develop your quality of life now?

Overall, are you satisfied with your current quality of life?

Use this page and the white pages that follow to jot down your own thoughts in whatever way suits you... notes ...word maps... pictures... diagrams... write... draw...

YOUR QUALITY OF LIFE NOW: three things in your life *now* that you don't want to lose

1.

2.

3.

2. YOUR QUALITY OF LIFE WHEN YOU RETIRE

Having reflected on your quality of life now, think about what you expect your life to be like when you retire.

To what extent have you made plan for your retirement?

Will your quality of life change? Will it improve? Will it diminish?

How will you maintain or develop your quality of life in retirement? What might happen that would make this difficult?

Overall, do you think you will be satisfied with your quality of life when you have retired from paid work?

Use this page and the white pages that follow to jot down your own thoughts in whatever way suits you... notes ...word maps... pictures... diagrams... write... draw...

YOUR QUALITY OF LIFE WHEN YOU RETIRE: three things you hope will be in your life *when you retire* that you don't want to lose

1.

2.

3.

3. YOUR QUALITY OF LIFE *IF LIFE EVENTS LIMIT YOU*

Life events happen to everyone. They can improve life or they can make life temporarily or permanently difficult. As we get older more 'life events' seem to happen to us, they tend to be more negative and can change the way we live our lives day to day. The sorts of life events that might limit us are:

- you / your partner becoming ill or disabled / developing physical or mental health problems
- finding yourself caring for a physically or mentally dependent relative
- being bereaved

Have you thought about these sorts of life events? Made any plans?

If so, how have you gone about preparing for the possibility that these life events might happen to you?

What contingency plans have you made?

If you haven't thought about it or made plans, why not?

How would these events change your life?

What sort of help or support would you need to maintain your quality of life?

Where do you see gaps in your own resources. How would you expect to fill the gaps?

What would you expect to get help with? From whom?

Use this page and the white pages that follow to jot down your own thoughts in whatever way suits you... notes ...word maps... pictures... diagrams... write... draw...

YOUR QUALITY OF LIFE: three things you hope you don't want to lose *if life events begin to limit you*

1.

2.

3.

4. IF YOU HAVE PROBLEMS LATER IN RETIREMENT...

WHEN WOULD YOU WANT INFORMATION THAT MIGHT HELP YOU? tick one

Before there is a problem

When I have a problem or become a carer but while I can still manage

When I have been managing for a while and know what help I need

Never. I prefer to manage without help

SPACE FOR NOTES

WHO WOULD YOU PREFER TO GET INFORMATION FROM?

put these options in order of preference

most preferred = 1; least preferred = 9

- Employer
- GP
- Nurse
- Priest
- Social Services
- Citizen's Advice Bureau (CAB)
- A specialist organisation like Age Concern
- Family and friends
- Nobody. I won't need information

SPACE FOR NOTES

WHAT FORM WOULD YOU PREFER INFORMATION TO TAKE?

put these options in order of preference

most preferred = 1; least preferred = 5

In person / face to face

Telephone

Leaflets picked up in a public place

Unsolicited direct mail / door drop

The internet

SPACE FOR NOTES

WHERE ARE YOU MOST LIKELY TO GO TO FIND INFORMATION?

- tick the THREE places you are *most likely* to go to find information
- cross the THREE places you are *least likely* to go to find information

- Place of work
- GP surgery
- Hospital
- Church
- Social Services offices
- Citizen's Advice Bureau (CAB)
- A specialist organisation like Age Concern
- Specially organised events
- The library
- Community Centre / Village Hall / community building
- Local shop windows
- Family and friends
- The internet

SPACE FOR NOTES

3 vignette

day to day activity:

Maria is 76. She lives in an isolated area of Oxfordshire where she grew up. She and her husband returned there and bought a small cottage when they retired. Two of her children live in the nearby town but her other 3 children and their families live in other areas of the country and one lives abroad.

Maria was fit and healthy although finding it hard to do some of the stuff she enjoyed. She used to do embroidery and continued a life long passion for Scottish dancing. When her husband died 5 years ago, she started creative writing classes. However, recently she stopped going to the evening classes because because she didn't like the long drive home from the town where the classes were held. She only went if someone available to take her.

Maria suffered a minor stroke 9 months ago. Since then she has found it hard to remember things and she can't drive anymore. Scottish country dancing is a thing of the past. She is now completely dependent on others to take her to her embroidery group, to see family and friends, and go shopping to the super market and for clothes and other things.

If you were in similar circumstances how would you life change? What would happen to your social life? Who would care for you? If you couldn't drive any more, how would you get around?

independence and housing:

Maria's family wonder how she will maintain her independence. Maria herself is wondering whether to stay in the cottage or move. This is not an easy choice. She is very attached, socially and emotionally, to her home and the small community where she lives. If she stays she would be dependent on friends and people coming in to help with the housework, house repairs and garden. If she moves she would have to relocate. It would be like starting all over again and, inevitably, she would have much less contact with her friends. She could move to a property that's easier to maintain and live in, or into sheltered accommodation, to a specially designed retirement village. She could own, rent or have a managed lease.

day to day activity:

Maria is physically quite limited but, having decided to stay in her own home, she still wants to get out and about and do some of the things that give her pleasure and sustain her, such as going to church and to see her family instead of expecting them to come to her. She is thinking about who can help her or whether she should give up doing things?

money, choice, control & services:

Maria's neighbour, Susan, has been helping her to have a bath once a week. Susan is going back to work full time and with her own family to attend to, she will not have time to help Maria on a regular basis. In any case, Maria would rather have Susan's company in the

sitting room than in the bathroom. However, her weekly bath is important to her, and she has decided to find someone else to help with this.

high dependency resource centres and extra care housing:

Maria has suffered another stroke. She needs help now to get up, washed and dressed. She can get herself simple meals but only if someone else has prepared them. She is still living in the cottage but, once again, is trying to decide whether or not to move. If she stays she can go to the high dependency recourse centre in the local town. There she can get a bath, lunch, activities, and the company of others. If she wants to stay in her own home she has been told that she can also get help with community alarms or sensors that will summon help in an emergency. But should she be considering residential care? All her needs would be met here. The sale of her house would cover the cost.

self directed support:

Maria is now very limited. She is still living in the cottage but relies on social services to help her now. A carer visits her twice a day to get her up and dressed, make sure she has her meals, and then to help her to get to bed.

However, things have changed recently. A new government initiative, allows Maria and her family to decide what help she needs, and to decide how she gets it. A professional care manager helped them to do this. Having decided what help Maria needed, she and her family were given a budget and made their own decisions about how it was best spent to get Maria the help she needed. Between them, they decided to employ Jenny, a trained carer, to help Maria on a daily basis. When Jenny has a holiday, members of the family take over temporarily, and the whole plan is reviewed from time to time to make sure that things are still working for Maria.

This arrangement is better for Maria. She was not encouraged to walk by her previous carer and had come to spend long periods of time alone. Now, Jenny is able to spend time with Maria. Maria is walking again as a result of Jenny's gentle encouragement, and she does some of the things that she had given up, and visits friends, goes on outings, sees the rest of her family regularly, and goes to the theatre and cinema.



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