

# In Focus

Experiences of older age in England

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# Foreword from our Chief Executive

Older age can be a fantastic time. It can bring a new lease of life, freeing us up to pursue old interests and ignite new ones; to spend time with friends and family, and forge new connections; to teach others from experience and learn something new.

As our population ages, we need to maximise the opportunities and positives older age can bring. There is a huge amount of potential contained within this growing age group, and tapping into this should be a priority for any 'ageing society'.

But the reality is that many older people are struggling – struggling with their health, struggling with their finances, struggling with the responsibilities of caring or grandparenting, and struggling with loneliness and isolation. I have heard this first hand from the many conversations I've had with older people up and down the country since taking up this role.

To address these challenges and maximise the potential of later life, we first need to move beyond ageist stereotypes of what we think 'older people' look like. We've heard it all before: wealthy baby boomers with big pensions, big houses, big savings and big families falling over themselves to support them. Unfortunately, nothing can be further than the truth for many people. These larger-than-life stereotypes are having a negative impact on older people. Too often, policies aimed at older people are based on a fundamental misunderstanding by politicians and policymakers that this is a largely homogenous group, when the reality is very different.

This report aims to help tackle this narrative by taking what is a very fuzzy understanding of who makes up 'older people' and bringing it into focus. It puts a spotlight on groups of older people whose voices often go unheard and, through their stories, shows how unhelpful assumptions of what it means to be an 'older person' can be. I want to give my thanks to all the research participants who gave up their time to be interviewed for this project, opening up about subjects that can be painful and taboo. Your experiences will inform our work now and in the future and are at the heart of this report's recommendations.

At Independent Age, we want to ensure that, as we grow older, we all have the opportunity to live well with dignity, choice and purpose. The recommendations in this report set out the action the Government and public sector need to take to ensure that this is a reality. For too long, key policy decisions that affect older people have been kicked down the road. This must end if we are to face head on the opportunities and challenges our ageing society will bring.

Musice

**Deborah Alsina Chief Executive** 





" At Independent Age, we want to ensure that, as we grow older, we all have the opportunity to live well with dignity, choice and purpose.

# Executive summary

The way that society talks about older people and debates the impact of our ageing population is often couched in extremes, and based on assumptions about the millions of people who are aged over 65 in the UK today.

Later life can be a fantastic time. Every day at Independent Age we hear about the positive experiences people are having of older age.

But the evidence also shows that many people aged 65 and over are facing significant challenges and major inequalities exist. Many of the assumptions about older people simply do not apply to everyone over 65.

This project set out to explore the reality of life for older people whose voices can be less often heard in debates about ageing, and what is important for people in this age group. It has focused on the experiences of specific groups of older people: people with mental or physical health conditions; people providing informal care; black, Asian and minority ethnic (BAME) groups; people on low incomes; and people without children. Additional aspects were considered, such as sexuality and gender differences. The project focused on older people in England.

### The research consisted of:

- a scoping review by the National Development Team for Inclusion
- in-depth interviews with 45 older people across England, conducted by Humankind Research
- analysis of data by City, University of London, including an in-depth exploration of the Understanding Society survey.

### What needs to change

While there are many older people living a good life – the kind of life everyone would want in their later years – there are many who are facing the sorts of challenges our research highlights.

At Independent Age, we want to ensure that, as we grow older, we all have the opportunity to live well with dignity, choice and purpose. Achieving this vision will require action on many fronts and we will continue to advocate the changes we need to see in key areas of people's lives, such as their experiences of health and care, their level of financial security and their emotional wellbeing.

Alongside the specific changes we will be campaigning for, we will drawing on the issues identified through this research – apply the following tests in all our work to drive change for older people. This will ensure we keep the stories we have heard through this project at the heart of our work. These tests are, of course, not exhaustive but provide a baseline for what 'good' should look like.

We urge others with a role in achieving positive change for all older people to look through this lens as well, and ensure we are all seeing the whole picture of what it is to be an older person in the UK today.

### Key findings

We have grouped the findings from the research into six main themes:

1. Overarching assumptions and stereotypes about older people persist and can have a significant negative impact. Across the older people who shared their stories, there was a widespread feeling that they weren't regarded as individuals. There was also a sense that they were hemmed in by society's expectations of how older people should behave and what their limitations are.

### 2. People can have limited expectations of their own lives, and of the support they are entitled to.

The research highlighted a range of points around people's expectations – about whether older age was what they had envisaged, about their future and about what was 'due' to them.

3. Vital social connections that can combat loneliness and ensure people are supported in many different ways are often fragile.

The vital importance of social connections came through in all the interviews. For many people, having strong social connections was the number one indicator of living a good life. But, in many cases, these connections weren't in place or were diminishing, and there was a sense that this was just something that would happen as people get older.

### 4. People often experience a disempowering and damaging lack of choice and control in their day-to-day lives.

There was a strong sense of a loss of choice or control in aspects of people's lives, and there were examples of how precarious people felt their lives were.

### 5. The challenges older people face overlap and are interconnected, with one problem often leading to another.

It is well established that difficulties in a person's life can have a knock-on effect and create other problems. This project has provided a chance to consider the issues lying behind - and often driving people's vulnerability or poorer outcomes, and how certain events and challenges can combine to create considerable difficulties for people in later life.

### 6. Certain protective factors can help people to build and maintain their resilience.

The research highlighted a number of factors that could be seen as protective – helping people to stay resilient and more able to cope with challenges - or that could potentially slow a decline in how resilient they are.

	Themes from our research	
	Older people aren't seen as individuals and ageist assumptions persist about their needs, capabilities and preferences.	ls of ar
	Older people can find it difficult to navigate changes in their lives and access the support they are entitled to.	A ad
	The complexity of systems and processes can be overwhelming and reduce any sense of choice, control or agency.	A pe
	Older people's opportunities for social contact can be fragile and can be hindered by factors such as limited public transport.	A in of
	The challenges people face can reinforce or create more difficulties.	A
	Older people often contribute actively to society and manage their own resilience.	A

And, cutting across all of these, are older people defining what success looks like and how it is measured?

### The tests we will apply to policies and programmes

s there a clear and comprehensive understanding of what older people need, want and are capable of, and that looks beyond the average or majority?

Are people getting the right information, advice or advocacy at the right time?

Are approaches being redesigned to be more person-centred, and to see people as active participants rather than passive recipients?

Are joined-up approaches being taken, and the mpact of decisions on all groups and all aspects of their lives being considered?

Are opportunities to prevent issues developing or escalating being seized?

Are people's assets being recognised and nurtured?

# Introduction

Bed-blocker. Baby boomer. Behind the times. The way society talks about older people and debates the challenges posed by our ageing population is often couched in extremes. And it is often based on assumptions about the 12 million people who are aged over 65 in the UK today.

But do these assumptions really reflect the reality of life for older people? And, in particular, do they reflect the reality of life for older people whose voices are heard less often in these debates? What are the risks of those voices continuing to go unheard? And what are the potential opportunities of having the best possible understanding of the hopes, needs and circumstances of all older people?

These are some of these questions we have set out to answer in this project.

### Assumptions that do not echo reality

People are, as a whole, living longer and experiencing good outcomes across a range of areas. Those in their early to mid-70s are more satisfied with life than any other age group<sup>1</sup>.

But the evidence also shows that many people aged 65 and over are facing significant challenges and major inequalities exist. In terms of the issues that Independent Age focuses on, we know that, for example:

Health and care More than half of people over 65 have at least two chronic health conditions<sup>2</sup>.

- Financial security Some 1.9 million older people are living in poverty and this is more likely to be the case for single women, ethnic minorities and the over 80s<sup>3</sup>.
- Emotional wellbeing There are 1.2m chronically lonely older people in the UK<sup>4</sup>.

Many of the positive assumptions about older people – that they are living longer, are comfortably off and are well-supported by their extended families – simply do not apply to all over-65s.

### Contrasting outcomes in later life

Given the apparent mismatch between the variable outcomes for older people and some of the entrenched generalisations about this age group, we wanted to explore:

- the extent to which insight and data relating to older people at risk of experiencing worse outcomes is being captured
- what older people in groups that may not have enough representation in policy and research think and feel about their lives and the barriers/ enablers they experience, and how this compares to older people in general
- how a better understanding of these issues could potentially lead to better service design, better policy making and ultimately better outcomes.

### Our findings are based on three main strands of research:

1. A scoping review by the National Development Team for Inclusion, which explored the extent to which specific groups of older people appear to be represented in research and policy thinking. This stage of the work also informed our decisions about which specific groups of older people we would focus on.

- 2. In-depth interviews with 45 older people across England, which focused on health and care, financial security and social connectedness. This gualitative workstream was delivered by Humankind Research.
- University of London, which included a review of the representation of older people in national statistics and in-depth exploration of the Understanding Society survey. This provided specific insight on the groups we focused on and comparisons across the life-course.

Full details are available in our

3. Analysis of data by City,

methodology section. This section also summarises how we worked with older people to shape the project. Apart from the scoping review, the research has focused on England.

### • The way older people are often

Change is needed

This report brings together the

findings from this work as well

on what needs to change.

from older people that:

as the implications and our view

Overall, we have heard directly

- labelled or stereotyped is not only frustrating but limits their choices and can mean they don't access the support they need and are entitled to.
- The challenges they face for example, because of financial problems, health issues or the lack of a social support structure - can have major knock-on effects and opportunities to prevent worsening outcomes can be missed.
- While their lives can be very difficult and precarious – and very often are getting harder - they are making important contributions, for example, as family members, as friends, as volunteers and as engaged members of their local communities.

### Our work has also highlighted how:

- Older people facing challenges that aren't generally experienced by all over-65s are often not represented in research or reflected in data and statistics.
- Older people are often viewed through specific lenses - for example, by focusing on the social care needs of people in care homes rather than considering wider aspects of their life. This means that research, services and policies may be at

one problem without considering what the 'whole person' needs or wants, and missing opportunities to significantly improve overall outcomes.

None of us lives a life that is exactly the same as someone else's. We all have our own hopes and fears, likes and dislikes, frustrations and moments of joy (see Figure 1). And this is no different as we age. We all need different levels of support at different times, and want that to be provided in a way that makes us feel understood and regarded as an individual.

In the next chapters, we set out what we heard from older people in the groups we focused on, and what needs to change as a result.

All of the photos included in this report were taken by the older people who were interviewed during the research. The photos were taken to show a range of things, including things that mean a lot to them or frustrate them in their daily life.

contented less pain live abroad lottery-winner stronger healthy happier groups good wise **Wealthy** outgoing fun family independent more sleep nobile mobile go-go-go manageable happy pain-free sociable worry-free accepted social younger lucky positive accepted soci freedom food

When asked what words they would use to describe their ideal life. this is what our research participants said.

1 Office for National Statistics, (2018), Estimates of personal well-being in the UK from the Annual Population Survey by sex and age, year ending September 2012 to year ending September 2017.

2 A Kingston et al (2018), Projections of multimorbidity in the older population in England to 2035: estimates from the Population Ageing and Care Simulation (PACSim) model, Age and Ageing 47(3). Available at: www.ncbi.nlm.nih. gov/pubmed/29370339

3 Department for Work and Pensions, (2019), Households below average income time series 1994/95 to 2017/18.

4 CtEL The facts on loneliness, from Age UK 2016 No one should have no one.

risk of understanding or solving

### *My* pain in my legs will be very different to anyone else's... People's lifestyle support, financial and personal situations will all determine how they cope and live with the condition

day to day.

Charlie, 69

### Figure 1: Older people's ideal life

# Bringing our groups into focus

### We focused on a number of specific groups of older people in this project (see page 8):

- people with physical health conditions that limit everyday activities, such as washing and getting dressed
- people with mental health conditions, such as anxiety and depression
- people providing informal care for others
- black, Asian and minority ethnic (BAME) groups
- people on low incomes
- people without children (or whose children had died).

People in these groups often face particular challenges or experience worse outcomes than older people as a whole, and we wanted to explore this further. We, of course, recognise that people don't fit neatly into specific, discrete categories and, in many cases, the research participants belonged to more than one of these categories – and also to additional groups that aren't listed above. Equally, we did not assume that everyone would be found to be experiencing challenges – we wanted to understand the positives in people's lives as well as the frustrations and difficulties.

We also considered broader demographic issues, such as sexuality, rural vs urban locations and gender differences.

Forty five older people within the age range of 65 to 95 were interviewed in 2019, at locations in and around Birmingham, Bristol, Leeds and London. Each fell into at least one of the groups listed above. The findings from the qualitative research were compared with population-level data from the Understanding Society survey, to explore the extent to which issues identified in the interviews are reflected at a larger scale. Unless otherwise indicated, all figures used in the report are based on this analysis. The threshold for statistical significance was a p value measured at less than 0.5.

Over the course of this report, we set out some more information about these subgroups of older people and summarise some of the key issues identified through the research.

All names have been changed throughout the report to ensure anonymity.

### Questions asked in the interviews included:

- How do you feel about life at the moment?
- What most affects your health and wellbeing?
- What are your hopes or plans for the next few years?
- Do you feel part of your community?
- How do you think society sees people of your age?

### An observation on under-representation of these groups in research and statistics

The first stages of the project highlighted that, in general, there appears to be a *relatively* limited understanding of the life experiences of older people in these groups.

The scoping review conducted by the National Development Team for Inclusion looked at a sample of research, policy reports and other grey literature published in the UK in the past five years. The review found that:

- Some groups appear to be particularly under-represented in research and policy thinking in comparison with others such as BAME older people and older people with mental health conditions.
- There appears to be a tendency to view older people through particular lenses for example, it was found that where research was being carried out on the experiences of or outcomes for people in care homes, the primary focus was often on their care needs rather than other aspects of their lives, such as their financial situation or contact with friends and family.

This impression of underrepresentation of certain groups of older people was also reflected in a review of national statistics conducted by City, University of London.

This looked at more than 30 official and national statistics relating to different aspects of older people's lives, such as access to social care, receipt of benefits, housing tenure, volunteering and internet usage. In general, these statistics weren't presented in terms of subgroups and were often only broken down by age band. While this often provides useful information on the 'oldest old', it may mask key differences between subgroups of older people.

Where statistics were broken down by subgroup, again we found the 'lens' to be limited. For example, there was health data for those with health conditions and financial data for those on the lowest incomes, but less of a sense that people's whole lives were being considered.

While these were both lighttouch reviews and not fully representative of the literature or statistics available in relation to older people, the findings suggest that there may be a tendency to view older people in terms of just their age or very specific aspects of their lives, rather than creating a more rounded and joined-up picture.

More work would be needed to assess this in more detail.







### The groups this work focused on

### 1. People with physical health conditions

### Approximate number in England

- One in five older people has a severe physical health problem (a condition that limits everyday activities, such as washing and getting dressed, or restricts mobility).
- Limited options for getting out of the home, affecting mental health.

**Key issues** 

**Key issues** 

• Struggle to manage

geographically).

and emotional needs.

Missing out on social

and seeing friends.

activities, volunteering

• Not always receiving the

financial support they are

**Key issues** 

entitled to.

administrative load and

connect with authorities

that may be able to help. • Lack of someone to confide in.

Struggle to communicate

financial problems, as well as

a lack of access to wellbeing options (financially and

- Additional costs, for example, equipment, needing taxis to appointments.
- For care home residents, a sense of having 'checked out' of society.

### Example

Omar, 82, has a range of conditions, including diabetes and osteoarthritis, and was living on the seventh floor of a block of flats.

" It's easier to stay inside and not be a burden on people. **Omar**, 82

# Older people with severe physical health issues 5% All older people

### 2. People with mental health conditions

### Approximate number in England

in total

One in 10 older people has moderate or severe anxiety or depression.

### Example

Frances, 95, started feeling depressed when she had a nasty fall and became housebound.

" I fall just above the threshold for pension credit but can't really afford to live... I am in no man's land. Betty, 86

# **1.2m** in total

### 3. People providing informal care

Approximate number in England One in five older people in England is a carer. Some 400,000 of these

care for more than 35 hours a week.

1.9min total

### Example

Michelle, 90, lives in social Physical and mental wellbeing is compromised by the inability housing and her son manages to prioritise their own health her finances.

"

Your focus is totally looking after [your partner], your depression doesn't manifest itself. George, 65





### 4. Black, Asian and minority ethnic (BAME) people

### Approximate number in England

200,000 older people in England are Asian, and approximately 100,000 are black.

### **Key issues** • Often struggled with housing issues, particularly in social

• Felt that they benefited from a strong sense of community centred around shared heritage.

### Example

Freddie, 72, lives in social housing. He represents his tower block as a spokesman and, following a recent attack on a resident, is concerned about people's safety.

### " I've found a lot of comfort and support through the black community. Linda, 75

Black older people 19% Asian older people 9% White older people

### 5. People on low incomes

0.3m

in total

### Approximate number in England

16% of older people in England are living on a low income.

### **Key issues**

**Key issues** 

housing.

- Unable to pay unexpected expenses and get behind with bills.
- Unable to stay connected with friends/family without a tablet computer, access to the internet.
- Financial situation can cause stress and anxiety and have impact on mental health.

### Example

Mary, 69, lives in Bristol and lives with her husband, who is disabled. Her husband suffers from COPD and arthritis, which limits his mobility and what he is able to do around the home.

" I feel as if I'm idle because I can't get up and do what I've always done. Frances, 95



# **1.6m** in total

### 6. People without children

### Approximate number in England

15% of older people are without children (including those who have never had children, and those whose children have died).

1.5min total

### Example

- Fear they may struggle in the future without children to provide a level of informal care.
- They also miss out on help with simple practicalities such as a lift after an operation.
- Some people were worried that they had no 'back up' to turn to if things went wrong financially.

Ron, 66, worries about getting older and having no kids to support him.





# Key findings

In this section, we summarise the themes from the qualitative research that broadly apply across all the groups. We have also highlighted where the findings from the qualitative research are reflected at a more population-level scale, based on analysis of the Understanding Society survey. There are six main themes, which appear to influence and be influenced by each other.

# The six main themes 2. Limited expectations 1. Assumptions about older people 5. Interconnected challenges Resilience and protective factors Overarching assumptions and stereotypes 1 about older people persist and can have significant negative impact. These assumptions can in turn create or contribute to key problems that people face. 2 People can have limited expectations of their own lives, and of the support they are entitled to. 3 Vital **social connections** that can combat loneliness and ensure people are supported in many different ways are often fragile.



# **1.** Assumptions about older people

### Overarching assumptions about older people persist and can have significant negative impacts

Across the older people who shared their stories, there was a widespread feeling that they weren't regarded as individuals. There was also a sense that they were hemmed in by society's expectations of how older people should behave and what their limitations are.

### Labelled with stereotypes

People felt that simply because of their age they were seen as incompetent and a nuisance, no longer fitting into the community they once were a part of. Instead they felt 'othered' and pushed aside, and no longer seen as being able to make a contribution.

"

Yes, there are stereotypes: old, sick, crocheting, holding on to their houses, keep the kids out, house stockers, bedblockers – or that's the media at least. Ron, 66

# "

People think you get to a certain age and should go home, a woman should be knitting cardigans and old men should watch telly. We've got an awful lot of life experience that could be tapped. George, 65

as a priority in society. 'Needy', 'slow', 'incompetent' were just some of the negative stereotypes people felt they were labelled with. There was a sense that they had been reclassified without their knowledge or consent.

People living in care homes particularly felt that they were seen as having 'checked out' of society.

They believed they weren't seen



25% of adults below retirement age worry 'a lot' about feeling lonely and isolated in older age.



40% of older people do an arts activity, such as playing an instrument or painting at least once a week, the highest of any age group.

# Individuality not recognised

People often felt that the expectations society has of older people, and how services are set up, constrained them and made it hard for them to express their personality.

People talked about the importance of being able to express themselves - often through hobbies or interests - and the positive impact that could have on their sense of wellbeing. Often these were things they had grown up doing and were an important part of their identity. They wanted practical ways of doing the things they loved, which would bring a sense of satisfaction and enjoyment as well as maintaining or strengthening their sense of identity.

"

I had issues with the NHS occupational therapist who came to the house to assess my needs... most people do not understand disability, and how personal it is. She looked at the stairs and said I needed a great big clunky disabled person's handrail up the stairs. Yes, I am disabled, but I do not want it to ruin the look of my house, so instead we got the builder to make us a special one that was more subtle and looked nice and blended in with the house. I don't want choices for my physical disability to make me feel depressed and miserable too. **George, 65** 

Because of their age, however, people felt it was often assumed that there were only certain activities they should enjoy or ways in which they should behave. If they felt unable to express themselves or maintain their interests, it could make people feel deeply unhappy. This could particularly be the case in certain settings – for example, in care homes where activities can

A specific example that people had concerns about was the way in which equipment that could help them was off-putting because of its medicalised appearance and how intrusive it was in their home.

be limited.

I want to always improve my dancing, my singing, myself. Marco, 67



# **2.** Limited expectations

### The consequences of casual assumptions

The casual assumptions that are often made about older people's capabilities, needs and preferences were seen to play a role in the other challenges highlighted in the research. They could feed into:

- a narrowing of what people felt they were entitled to or could expect out of life
- a lack of consideration of specific needs in the planning or delivery of services
- diminishing opportunities to make meaningful choices
- silo-based approaches that, by failing to consider the whole lives of older people, miss vital chances to prevent problems developing.

### Case study: Kathryn

Kathryn, 77, has been in a care home for around five years and is one of the younger residents there. Kathryn was previously living in sheltered accommodation but, after breaking her back in an accident, Kathryn and her family decided together that it would be best for her to go into residential care.

Kathryn has always been a positive person and coped well with her sudden change of lifestyle, despite missing her old flat. There is a small variety of activities at the care home, including bingo, poetry and crafts, but Kathryn prefers to spend her afternoons by herself. *"I prefer to come back here* y'know. I like my own space in the afternoon. I don't like to be there all day. And I find the people downstairs... they're older than me."

Although Kathryn is fairly contented in the care home, she can feel under-stimulated because most of the activities on offer are either not of interest to her or are no longer available. She is close to her family and she has visitors at least twice a week, but she'd like to have more visits. She has a couple of good friends who she describes as "bright as a button".

Her days are quite structured, and in between meals and chatting to other residents she watches television and reads magazines and newspapers. Kathryn often finds that she is sitting in a chair all day and in the mornings there isn't anything to do. Kathryn is unable to get out and about on her own and would like to be able to go on the bus to take in the views. "It would be nice to go and look out everywhere. I used to go shopping."

### Age – just a number?

Research or policy thinking can, at times, look at older people as one single group but, as this report underlines, there is a huge diversity within this age range and it can't be assumed that as soon as people hit retirement age they will experience the same issues or have the same needs.

Analysis of the Understanding Society survey found relatively few straightforward linear relationships where prevalence of a particular issue or challenge increased with chronological age. Indicators relating to physical health were the main exception to this. And the qualitative research highlighted instances of people in their late 80s experiencing better quality of life than those who were 20 years younger.

The qualitative research also highlighted older people's own perceptions of what 'old' is. One person commented: "an old person is someone in their 80s. To young ones today, I'm an old person at 66."

### People can have limited expectations of their own lives, and of the support they are entitled to

The research highlighted a range of points around people's expectations – about whether older age was what they had envisaged, about their future and about what was 'due' to them.

### Older age not as expected

For many people, older age is not what they imagined it to be, with unexpected challenges such as health problems coming on suddenly and not having the income they expected to have when they retired. There was a sense that there was more 'admin' involved – such as booking and juggling appointments – and many people were also poorer than they had expected to be. Life was generally seen to be getting harder as they aged.

### Reluctant to plan ahead

People showed a reluctance to plan ahead or think too far. One of the things that made it hard for people to do this was the fact that their circumstances could change very quickly. The research process – whereby people were interviewed and also had a follow-up call a few weeks later – highlighted how much people's lives could change in a short space of time. In some cases, health conditions had dramatically worsened, loved ones had passed away, or people important to them had moved home.

The challenge of unforeseen expenses can make it difficult for older people on low incomes to plan ahead. While they often budgeted very carefully, previous experiences meant they tended not to make too many assumptions about the future. This is a particular issue for older BAME people who, according to the data, are more likely to say that they would not be able to pay an unexpected expense and be behind with some or all of their household bills.

What am I looking forward to? What am I planning? What will I be doing? Nothing. I don't like to think more than one day ahead. Sometimes a week ahead if I have to book friends into the diary, but not more than that. Michelle, 90

# "

I thought I'd be wealthier as I got older, but it's going the other way. I never thought I'd go downhill as I have health-wise. I walk bent over now. because of my back. I would have thought it'd happen later than it has. Joan, 75

### 'Mustn't grumble'

Many people were reluctant to complain about, or even fully acknowledge, serious problems in their lives, and did not say that they felt they needed support. This was especially true of certain health or financial challenges they faced, where they were comparing their situation to others who had worse health/finances and therefore didn't feel able to complain. Carers, for example, were particularly hesitant to complain because they felt the person they were caring for had bigger health problems and they didn't want to appear insensitive.

of people in difficult situations adopting a positive mindset and finding meaning in what they were still able to achieve. This included volunteering once a week to help others in need, focusing on small things, such as getting up in the morning to write in a diary, or finding solace in motivational quotes.

There were also several examples

There was more of a tendency to be accepting of their lot among the oldest people. This was often based on memories of tougher times they had experienced in their past - for example, growing up after the war or in a different country.

### Alienating language

The language used to engage people in services or other forms of support didn't always reflect how people saw themselves or their situation, and therefore didn't create an expectation that this was something they could benefit from.

A large proportion of the participants described challenges with their mental health, but didn't identify themselves as having a mental health condition. Instead, they referred to having 'low days'. And where people were in difficult financial situations, they didn't see themselves as being on a low income, but 'getting by'.

### It appeared that this gap between the language used by the 'system' and how people talk about their own lives was deterring people from accessing support with the potential to make a big difference to their lives.

### An alternative glossary

Some of the common phrases older people used:

Money aware, living within

### Mental health

Low mood, feeling low, my bad days, stress, worry, low, sad, getting by a bit quieter, not coping, struggling, not managing life.

### Physical disability

Pain, niggle, my 'insert condition'.

# Low income

### means, cautious, we get by. Carer Wife, husband.

every day between 8.30 and 9am I write in my diary – no matter how much pain I am in, no matter if I feel like it or not, no matter if I have or have not got anything to say. I have done this little ritual for 15 years after my husband died, and it's always given me a purpose, a reason to get up and out of bed and make me appreciate the little things in life and realise all the goodness. Betty, 86

Yes, I am in pain all day, every day, but

Of all adults in the poorest income group, people over 65 are significantly less likely to say that they are struggling financially.

### Older full-time carers are less likely to have a holiday away from home.



Older people, particularly 65–74 year olds, are more likely than any other age group to worry about their future financial situation.



# **3.** Fragility of social connections

Vital social connections that can combat loneliness and ensure people are supported in many different ways are often fragile

The vital importance of social connections came through in all the interviews. The positive impact included emotional support and friendship, as well as having someone to help navigate complicated systems or issues. For many people, having strong social connections was the number one indicator of living a good life. But, in many cases, these connections weren't in place or were diminishing, and there was a sense that this is just something that will happen as people get older.

### Shrinking social circles

For many people, older age had brought with it reduced social circles and decreasing opportunities to engage with the friends and contacts they still had. In some cases, this was because their close connections had died, while for others their mobility had become restricted and they were unable to go out and see their friends and family. There were often limitations on how long people could spend away from their home or the type of place they could go to because of the needs they had.

In many cases, feelings of loneliness arose from a sudden change in circumstances, such as becoming housebound. A lack of purpose also contributed to these feelings, especially during times such as Christmas or New Year.



"

Loneliness. It's in this alone period that the clouds start coming in. That is the biggest problem. When you are alone. Akwasi, 91

# Women aged 85+ are more likely than men to say they

don't go out to visit friends, and are more likely to say it's a health condition that stops them.

# "

I've spoken to the family over the road but I don't bother them. I don't go in people's houses. It's not neighbourly like it used to be. It's been terrible since [my old neighbour] died, he was always there. I've got no neighbour there. Shirley, 73

# "

Mostly in the evenings, it's when I hear people going out, and that's when I feel 'why can't I do that?' When you are old and you don't have a partner, people are more likely to exclude you. [You are] more included when you are in a couple, you are excluded if you are single. **Doreen, 92** 

### Navigation and advocacy

There was also a strong sense that having someone to help navigate through systems and processes – such as benefits or social care – could make a huge difference. Having someone alongside them to help fill in forms or source information was invaluable in making the process less daunting, even if that person had no particular expertise.

### It's quality not quantity

Some older people said that even if they had close ties with others and lots of contacts, they could still feel lonely and 'disconnected'. This was because their sense of loneliness came from not having anyone to confide in openly and honestly a feeling that could still occur even with regular contact with family and friends. This was particularly the case for some who had spouses or partners, but where the relationship had broken down and the open communication that once existed between them was gone.



My children and my grandchildren are my life... I can ask them to help me with things like filling in forms, or take me to places, and they stop me from worrying. If I didn't have them I would be utterly lost. Karen, 70





The likelihood of having no or very few close friends (including family as friends) increases with age, and rises sharply for people aged 75+.



Approximately three in five older people aged 85+ live alone. Of this age group, women are almost twice as likely as men to live alone.

### Access to transport and other enabling factors

Access to transport was a vital factor in being able to maintain friendships and other social contact. Where this wasn't available, or when people's health issues limited their ability to get out and about, people found that their world was getting smaller.

Without suitable and affordable transport, people could find it difficult to access vital services. Everyday things such as attending a GP appointment could require significant amounts of planning and take up a lot of time.

buses, and if a bus stop was moved - or removed altogether - it could have a major effect. This issue was magnified in rural or suburban areas. In inner city areas, older people felt like they could move around more easily due to better provision of public transport, but in rural or suburban areas just one bus stop closing or moving could greatly affect an older person's freedom of movement.

There was a particular reliance on

Aids and adaptations that help people to be mobile, such as ramps, were also key. People who didn't have these in place, or were struggling to get them, could be effectively imprisoned in their own home, and extremely reliant on assistance. People reported the intense frustration and stress they experienced as a result of delays in getting aids or adaptations put in place and the complexity of the process.

The bus stop opposite got vandalised and, instead of fixing it, the council just took it away. I don't think they realise what a big impact this has had on my life. I now cannot go down to the main shops in that direction because there is no bus stop and the buses are unreliable and I cannot stand for long. It also means I cannot go and see lots of my friends who live down that way - and my friends cannot come up and see me here, because it would mean they too would need to get the bus back in that direction. Who knew one bus stop could serve so many purposes for so many? Linda, 75

Adults aged 65+ travel by bus more frequently than any other age group, other than 16-24 year olds.

### Likelihood to not go out socially or visit friends



### Use bus service three times a week or more



White older people

# **4.** Lack of choice and control

People often experience a disempowering and damaging lack of choice and control in their day-today lives

There was a strong sense of a loss of choice or control in aspects of people's lives, and there were examples of how precarious people felt their lives were.

### Feeling disempowered

People's sense of disempowerment could be caused by a range of issues, including:

• a low income making it hard to pay for the things that would make life easier or even cover the essentials

### frustration over limitations caused by health conditions or disability

• decreasing opportunities to access services in person, due to the shift to online approaches.

Many older people had needed to stop working earlier than they would have liked due to physical health issues, which meant they had few savings or had not built up an adequate pension. Health problems could also lead to high one-off costs, for example, the need for specialist equipment, or regular, smaller costs, such as needing to get taxis to medical appointments.

### Case study: Betty

Betty, 86, has lived alone since her husband's death in 1999. She used to work in an agency teaching shorthand, before becoming a business teacher at a college. She rents a onebedroom flat because she doesn't qualify for social housing. "...this means that most of my pension money goes on rent. I'm lucky I get (about) £50 Attendance Allowance a week – but this has to be used to buy food."

Money is a struggle for Betty and she tries to make do with what she has. Her income is just above the threshold for Pension Credit. which means that she cannot qualify for help that could go towards her living expenses. She described it as living "in no man's land".

As well as the challenges that come with living on a low income, Betty has also found that older age has brought a lot more commitments and 'admin' than she expected, including having to do all of her banking online.

"Everything is internet. We haven't got a lovely local bank with a manager we knew well. We're back to bottom of the *pile. Frightening."* Despite these concerns, Betty tries very hard to remain positive and is involved in various clubs and activities, such as book clubs and coffee mornings. "You want people to benefit from you being there. I love teaching and motivating."

Fewer than one in five people aged 85+ uses the internet every week. In this age group, women are significantly more likely than men to say they never use or have no access to the internet.



Older people with severe physical health problems are more likely to be behind with some or all of their household bills.

Likelihood to feel dissatisfied with health



All older people

### Carrying the cognitive burden

One of the main challenges people faced was the need to summon a lot of energy and willpower to access the formal support or services they needed.

Many of the processes individuals had to go through, such as benefit applications or asking for council support, involved many long, complicated elements that tested individuals' capacity to remain optimistic. Systems and processes were often felt to be complex, confusing and stressful.

At times, people felt defeated and they would give up or, because of other experiences, would choose not to start the process of getting help at all.

Some people highlighted the importance of having a positive mental attitude to cope with these challenges – but also felt that not everyone would be able to summon the energy or determination needed.



Just over half of people aged 85+ say they rarely, if ever, had a lot of energy.

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Approximately 60% of people in their 70s and 80s feel that they have 'no say in what the Government does', the highest percentage of any age group.



### Disconnection from politics

Many people felt completely disconnected from both local and central government and had low expectations that their voice would be heard. There was a sense of resignation, including where they had a poor experience of a service or felt they had been let down by the authorities.

Many spoke about negative interactions in the same way they might talk about the weather: a natural phenomenon that could not be avoided or changed.

### Case study: Cynthia

Cynthia, 66, has lived on her own for two years since the death of her husband, and her health has declined during this time. She has spent a lot of time in hospital in the past couple of years with osteoarthritis, lymphedema and kidney problems. Cynthia has three adult children and she relies on her daughter, who is her carer, to help her with tasks such as showering, housework and shopping. However, help is not always readily available.

Although Cynthia has an electric scooter, she is unable to go out freely because she can't get it over the doorstep on her own. This is frustrating for her because it means she has to wait for someone to come and help. There are times when Cynthia does not leave her house for almost a week because of this. She rents her bungalow through the council and she is currently trying to get a ramp fitted through the council. However, she describes this is as "like getting blood out of a stone" because it's a long, drawn-out process that hadn't yet been arranged.

Even when Cynthia is able to get and about on her scooter, she still comes up against challenges and she finds herself constantly

needing to apologise to people if they walk in front of her. "They look sideways at you and tut, it puts you off going out when you get attitudes like that because you feel like you're being a nuisance. They make you feel like you're in the way."

This isn't the first time Cynthia has struggled to get an adaptation or an aid to help her at home. She has a small, deep shower that she struggles to stand up in. The council supplied her with a shower seat but it's too big and the wrong shape, which means that she is unable to use it. Cynthia has explored the possibility of a walk-in shower with the council, but they have told her that she would need to be doubly incontinent to qualify. Although this would make her life so much easier, she has given up on it becoming a reality.

The two years since her husband's death have taken their toll on Cynthia's emotional wellbeing and she frequently experiences periods of low mood and hopelessness. However, she doesn't wish to tell her children how she's feeling because she wants to avoid being a burden to them. "Sometimes I just don't want to be here...I do keep a lot

### of things to myself, how I feel and how I am."

Although she admits that talking to someone she doesn't know could be easier, she hasn't sought emotional support elsewhere because she feels it would be a sign of weakness. Cynthia feels she cannot talk to a GP because there isn't time during a 10-minute appointment and because she believes that medical professionals will judge her. "It's not that they don't want to listen to you, they just can't."

Because Cynthia is unable to do what she wants to, she feels like she's not living up to her potential. She also feels that unless you are better off financially, it's hard to access activities in her community, and activities such as arts and crafts are difficult to join or do not exist like they used to. She often sees people older than her walking freely down the road and wishes she could have the same freedom. "I know I'll never be free of pain, but if I could get out a bit more freely, I'd love that. If they make it easier and more accessible to get out and go places, you'd be surprised the way it lifts you."

# **5.** Interconnected challenges

# Problems often have multiple causes

It is well established that difficulties in a person's life can have a knock-on effect and compound other problems. This project has provided a chance to consider the issues lying behind – and often driving – people's vulnerability or poorer outcomes, and how certain events and challenges can combine to create considerable difficulties for older people in later life.

The difficulties people shared through the research were often not a simple case of being caused by one circumstance or event in their lives.

### The issues they described included:

- a problem or challenge directly causing another
- a problem or challenge increasing the risk of another issue emerging
- a problem or challenge negatively affecting someone's ability to cope with another issue.

Examples of these are set out within this chapter.

### The stress of caring affects these groups as it does many others

The interviews with older people underlined the strong links between being an informal carer and experiencing mental health challenges.

Carers were under a great deal of pressure – and had high expectations of themselves – frequently juggling their caring role with administrative and household tasks, such as dealing with social services. The stresses these activities involved created feelings of anxiety and depression.

Many people were less able to manage these stresses because their caring duties meant they lacked a close contact to confide in. For some, their caring role meant they were unable to go out to socialise and attend groups where they could build and maintain relationships. This prioritisation of their loved one's needs risked a build-up of negative, overwhelming emotions, which had a damaging knock-on effect

Women were more likely to have a role as an informal carer, and so were more affected by these challenges.

on their own mental wellbeing.



Older people who are full-time carers are less likely to feel calm and peaceful.



Older people who are full-time carers are more likely to be at risk of mental health issues.

### Having a physical health problem can make caring doubly difficult

In addition to providing care and having a mental health condition, a number of people also faced the challenge of having a physical health problem.

People who provided regular care for a loved one explained how this could be very physically demanding, often exacerbated by physical constraints they associated with ageing, such as arthritis, weakening muscles and low cardiovascular fitness. Many said that as they got older and these conditions developed, their ability to provide care in the way they wanted to decreased. This often created more stress and frustration, with no means of expressing it.

Many people who were providing care felt unable to communicate any distress of their own, because they felt it would be selfish to do so when comparing it to the situation of their loved one. Their priority was the person they cared for and not themselves, and this had a direct impact on their willingness to seek help.

### Being on a low income and having poor mental health can lead to a vicious cycle

Among people who were in challenging financial circumstances, those with depression or anxiety found it harder to deal with their situation.

Some people avoided engaging with support mechanisms that were theoretically available to them, because they feared the process or interaction would be too stressful and worsen their existing mental state. And some relied heavily on family members for help and even sought to hand over full control to others.

People also described how being on a low income made it harder to manage their mental health. Being active and taking part in group activities such as exercise classes were seen as good ways to help manage anxiety and depression – but where these weren't available for free, the cost of attending them was prohibitively expensive.

I suffered with mild depression for quite a while, I took Sertraline... Your focus is totally looking after [your partner], your depression doesn't manifest itself when you have lived together for that long. George, 65



Approximately one in 10 full-time carers over 65 has both a moderate or severe physical health problem and moderate or severe anxiety or depression.



Older people with the lowest incomes are more likely to be at risk of mental health issues.

### Living without children can limit support options

While many people without children were content with their choice or situation, there was a concern that this would change if their physical health worsened.

People felt that children provide a vital source of support when faced with difficulties, including:

- help travelling to GP and hospital appointments
- providing informal care
- help navigating often complex health and social care systems.

Without this help, people felt that they could potentially be at a disadvantage, especially if they didn't have other family or friends to support them.

children, so I don't miss having them. I suppose they could help with things, but at the moment I don't really need much help! Ask me

again in 10 years.

Arthur, 66

I've never had

### Physical and mental health are closely intertwined

Physical and mental health were often raised as interconnected issues, many times mentioned together.

For some, there was a direct causal relationship – for example, anxiety and depression caused by a sudden fall, and the physical health problems resulting from that. However, for many people, they did not describe a direct link but talked about how one issue fed into the other.

People also talked about the physical manifestations of their mental health conditions - such as experiencing panic attacks - and how, as they aged, they felt too weak to cope with these symptoms.

### Case study: Ron

Ron married his husband in 2006 after being together for 10 years. He accepted early on that he would never have children and saw various positives to this - having more money, fewer worries in life and the ability to be more "selfish".

However, Ron has a number of health conditions that are worrying him. His diabetes has affected his mobility in the past six years, which has limited his ability to get out, and he has also struggled with eye issues. "I feel like I'm about 90 – my physical health is poor and only going to get worse."

Ron has noted that other older people with children do rely on the help and support they can give, which he knows he will not have. "One of the 90-yearold ladies in the church has five children and many grandchildren and great grandchildren and she always has people around, calling her up, sorting things out and doing things for her. I won't have that, but I've had benefits earlier on in life so it's a trade-off".



Whether it's difficulties around money, finances, physical health or mental health, many of the challenges people face can be interlinked - with one challenge bringing about or exacerbating another.



Approximately half a million older people have both a moderate to severe physical health problem and moderate to severe anxiety and depression.

### Housing issues can exacerbate other challenges

People's housing situations could have a significant impact on their wider situation. Some people, for example, had been forced to move because of health or mobility problems. Others were concerned that this would be something they would have to do in the future, particularly if they didn't live on a ground floor.

Stress and feelings of isolation could be magnified by concerns about noise and antisocial behaviour, particularly in properties with shared access. Delays in repairs and problems such as damp in rented properties could be not only frustrating and stressful for tenants, but also dangerous to their health.

Omar, 82, has lived in council housing. He lived in a block of flats on the seventh floor where the lift had been out of order for a long time. Due to his numerous health issues, having a broken lift meant Omar did not leave the house for 16 months since he could not get up and down the stairs. This severely affected his mental health, as he was confined to his home with little connection with the outside for more than a year. Omar's family also felt this was a fire risk. After 16 months, he got the council to agree he needed a ground-floor flat.

Since moving to the UK in 1967.



Older people in the lowest income groups, and BAME groups, are more likely to live in rented accommodation, and to experience serious housing issues, such as damp.

### Case study: Joseph

Joseph was fit and healthy and walking 30 miles a day until he suffered an asthma attack in 2002. While he was in hospital, his organs began to shut down, causing kidney and breathing issues. The impact on Joseph's life since his health problems began is extensive: "I take 65 tablets a day, 21 tablets in the *morning"*. Joseph's wife is now his carer and she often worries about him because he is unable to do the daily tasks he once did with ease. Joseph told us: "Everything you face is with a brick wall in front of you. It gets depressing."

Joseph receives Disability Living Allowance, including the mobility component that goes towards their car. This is a great help

when they go shopping because they are able to travel with his wheelchair. However, he finds that just because I can't do things any although he has a Blue Badge, it is more." He experiences periods of still difficult to find parking spaces and he is often ignored or judged when he uses his wheelchair or oxygen mask in public. "People just don't take any notice of you.. when I'm wearing my oxygen, people drag children away."

Unfortunately, Joseph has an untreatable eye condition that means that he will need to give up his driving licence in the future, get out and about as much as he a prospect that he does not like to think about because it will change their lives considerably.

The marked changes in his life have affected Joseph's mental health. "I get annoyed and angry

with myself and get angry with my wife. I hate myself for that. It's low mood and takes medication for this when needed. He has a supportive doctor that he is able to contact when he has had a bad week and finds the reassurance they provide extremely helpful.

Joseph finds joy in going to the rugby once a week, but he has seen his circle of friends get smaller now that he is not able to once did. "Your world gets smaller and smaller as you get older, it disappears on you."

# **6.** Resilience and protective factors

### Certain protective factors can help people to build and maintain their resilience

The research highlighted a number of factors that could be seen as protective - helping people to stay resilient and more able to cope with challenges, or that could potentially slow a decline in how resilient they were.

Social connections and good physical health - the foundations for wellbeing

Many people described how the challenges they faced could often be managed or minimised if certain other aspects of their lives were stable. This was especially the case for those with either good physical health or strong social connections - these appeared to be key protective factors. These two elements had the biggest impact on people's wellbeing and, where they had lots of strong connections or good health, they were often in a better position to cope with challenges in their lives.

For example, some identified the positive effect family members would have. Knowing that they would be popping in and providing social interaction, as well as helping with practical things such as filling in forms, gave individuals a sense of reassurance and happiness.

### The benefits of volunteering

can help people to retain their resilience. The interviews highlighted that many older people - including those with physical health conditions – were continuing to give back to their communities through volunteering. Many spoke of how volunteering was a big source of happiness and life satisfaction, even when they themselves were struggling or had other major commitments, such as caring for a partner. The value appeared to come not only from the social aspect of volunteering, but also the contribution they were making and the sense of control they had over that aspect of their lives.



Being alone gives you more stress and less oomph to be yourself. Together is strong. Ava, 80

It also appears that volunteering

### Mostly or completely satisfied with life



when they feel like it

Older people who do not go out socially when they feel like it

### The benefits of volunteering

It also appears that volunteering can help people to retain their resilience. The interviews highlighted that many older people – including those with physical health conditions – were continuing to give back to their communities through volunteering. Many spoke of how volunteering was a big source of happiness and life satisfaction, even when they themselves were struggling or had other major commitments, such as caring for a partner. The value appeared to come not only from the social aspect of volunteering, but also the contribution they were making and the sense of control they had over that aspect of their lives.

### A positive mental attitude

People often talked about how important a positive mental attitude was. This could be seen as being open to new ideas or approaches, being optimistic, or feeling and showing gratitude. The research did not explore what led to people having a positive attitude - for example, previous life events or personality type or whether it was directly linked to improved outcomes, but it did appear to enable people to feel more resilient.



Approximately 680,000 older people with a physical health issue volunteer once a week or more.

# lack Elders Association

### Case study: Linda

A mother of three, Linda had to take early retirement 20 years ago because of a problem with her knees that couldn't be repaired through surgery.

Since she retired, Linda has immersed herself in voluntary work in her community, which she describes as being a really important part of her life. She felt strongly about getting involved because she believes the Government and local authorities do not support the community in a way that people actually want and need. "I am going to fight for my needs. These MPs are supposed to represent us, they are representing themselves. Nobody is listening."

Linda has spent 25 years in a senior role for the Leeds Black Elders Association and has had significant involvement in projects such as opening the Mandela Centre in Leeds, which provides a variety of youth services. "I am happy myself because I am independent. I do my own things, I have friends but I don't depend on them. I'm a proud black woman – that is one thing I know."

# Conclusion

It is well known that the number of older people in the country is set to grow and that older people will make up an increasing proportion of the population. Within this, the number of people in the groups this report has focused on will also increase – for example, we estimate that the number of older people without children could more than double to four million by 2040. We are likely to also see significant growth in other groups, for example, among those that currently have larger numbers in late working age than in older age, such as the BAME population. People are living for longer with chronic health conditions and complex care needs, and pensioner poverty is on the increase.

### The here and now

The stories we have heard through this research project remind us all of the challenges older people are facing in the here and now. While there are many older people living a good life – the kind of life everyone would want in their later years – there are many who are facing the sorts of challenges our research has highlighted. And their voices aren't always heard in important debates or as key decisions get made.

People are struggling financially, not getting the support they need in terms of managing their health and doing day-to-day activities, and experiencing loneliness and isolation. They often feel frustrated, hemmed in and disempowered by the attitudes they face in society. They often don't feel they are seen as individuals with multifaceted lives.

### Enabling a good later life

There has, for some time, been a widespread acceptance about what 'good' should look like in terms of helping people to live full and healthy lives, including:

- focusing on wellbeing and the whole person
- the need for services and support to be joined up, integrated, personalised and more focused on prevention
- recognising the assets that people have – such as their own knowledge or expertise or the communities they are grounded in - and giving them agency.

Our research confirms the importance of all these elements, but importantly highlights the gap between the rhetoric and the reality for many older people. While there has been some welcome progress, as a society we need a renewed effort to realise these aspirations for all older people.

### **Tackling** assumptions

Achieving this progress will, at times, require a shift in how decisions are made - about policies, programmes, services and other support. It is vital that decisions – such as what support people might need and how it should be delivered – aren't based on assumptions about people's needs and capabilities or a sense of what will work for the 'average' older person.

Through our research, we have seen evidence of casual assumptions or generalisations about what it means to be an older person negatively affecting the individuals on the receiving end of them. This can have a number of damaging consequences, including:

- feeding into and perpetuating a narrowing of what people feel they are entitled to or can expect out of life
- driving a lack of consideration of specific needs of different older people in the planning or delivery of services and support
- diminishing opportunities for older people to make meaningful choices
- reinforcing siloed approaches that, by failing to consider the whole lives of older people, miss vital chances to prevent problems developing.

As a society, we need to collectively move away from crude assumptions about what life is like for older people and develop a more nuanced understanding about the diversity of people's circumstances and prospects. A lack of understanding or will to act on the varied needs and preferences of older people is, of course, not the only factor behind the challenges shared through this project. The pressures on public services are well understood, for example, and have contributed to a false economy where short-term savings are prioritised over longerterm preventative investment.

### The change we want to see

At Independent Age, we want to ensure that, as we grow older, we all have the opportunity to live well with dignity, choice and purpose. We want to see national government taking the lead in driving this positive change by empowering and resourcing organisations, agencies and communities to deliver the following:

 A clear plan on social care reform, ensuring that older people are able to get high quality support with their dayto-day lives when they need it.
We want to see personal care available free at the point of use and protection from the vast costs that some older people and their families are currently faced with. The Government must deliver on its promise to set out the way forward on social care.

- A comprehensive workforce strategy to ensure we attract and invest in the individuals who are the key to delivering high-quality care. The vital role that informal carers perform must also be recognised and supported.
- Older people lifted out of and kept out of – poverty. It is unacceptable that older people have to make choices between heating and eating. As part of the action needed on this, the shockingly low take-up of Pension Credit must be urgently addressed. At just 60%, the takeup rate means that more than a million pensioner households are missing out on this vital benefit. The Government must set out an action plan to ensure every older person entitled to Pension Credit receives it.
- Consistent availability of highquality, personalised, accessible bereavement support for older people experiencing partner bereavement. Losing your partner of many years can be one of life's hardest transitions, and not having the right support to deal with the emotional, health and financial impacts can exacerbate this. Currently, support can be difficult to find or navigate.
- A strategic approach to tackling and preventing loneliness and social isolation. The Government should build on its promising foundations, including rolling out social prescribing and making sure that these services understand loneliness and evaluate the impact they are having. The Government should also include loneliness in the Family Test, and train officials so that policy across government takes every opportunity to tackle loneliness.

- A clear focus on prevention that recognises the importance of understanding the whole of people's lives and the impact that different policies and programmes can have on older people. Following the green paper, the Government must take action to meet its own target of people gaining an extra five healthy years of life by 2035.
- Older people in the most precarious housing situations having more stability and certainty. Around 500,000 older people live in privately rented accommodation in England alone, and this number is growing. The Government must deliver on its commitment to abolish so-called no fault evictions, whereby people with shorthold tenancy leases can be evicted without a reason.
- Ageism in healthcare should be addressed. People should be treated on their fitness for treatment not on chronological age.
- Older people's mental health needs should no longer be overlooked. Everyone should be able to access the treatment and support they need to ensure they can live well.

# Looking at the whole picture

Alongside the specific changes we want to see, we will – drawing on the issues identified through this research – apply the following tests in all our work to drive change for older people. This will ensure we keep the stories we have heard through this project at the heart of our work to drive improvement – whether on the issues set out above or on other priority areas we will focus on. These tests are, of course, not exhaustive but provide a baseline for what 'good' should look like. We urge others with a role in achieving positive change for all older people to look through this lens as well, and ensure we are all seeing the whole picture of what it is to be an older person in the UK today.

Themes from our research	The tests we will ap
Older people aren't seen as individuals and ageist assumptions persist about their needs, capabilities and preferences.	Is there a clear and o people need, want a the average or majo
Older people can find it difficult to navigate changes in their lives and access the support they are entitled to.	Are people getting t at the right time?
The complexity of systems and processes can be overwhelming and reduce any sense of choice, control or agency.	Are approaches beir seeing people as ac
Older people's opportunities for social contact can be fragile and can be hindered by factors such as limited public transport.	Are joined-up appro on all groups and al
The challenges people face can reinforce or create more difficulties.	Are opportunities to being seized?
Older people often contribute actively to society and manage their own resilience.	Are people's assets

And, cutting across all of these, are older people defining what success looks like and how it is measured?

### pply to policies and programmes

I comprehensive understanding of what older and are capable of, and that looks beyond ority?

the right information, advice or advocacy

ing redesigned to be more person-centred, and ctive participants rather than passive recipients?

roaches being taken, and the impact of decisions all aspects of their lives being considered?

o prevent issues developing or escalating

being recognised and nurtured?



### Scoping review

We commissioned the National Development Team for Inclusion to conduct a scoping review, to provide an indication of whether specific groups of older people appear to be under-represented in recent research and policy thinking in the UK. The review informed our decisions about which subgroups this project should focus on.

### Qualitative research

We commissioned Humankind Research to conduct in-depth qualitative research with 45 older people from specific groups. Individuals were aged between 65 and 95 and lived in urban and rural areas in and around Leeds. Bristol, Birmingham and London.

The research consisted of three stages:

Stage 1: 30 people were given a disposable camera and, over a period of one week, were asked to take 18 photos of different things in their lives. They were given topics, for example, 'something that frustrates you', and the photos were then used as a stimulus for discussion in the later stages of the research.

Stage 2: In-depth interviews were conducted with all 45 older people who had been recruited. These were completed in person in the individual's home or in a convenient location of their choosing. The interviews lasted around one to two hours and covered individuals' feelings and experiences relating to their health and wellbeing, financial security and social connectedness.

**Stage 3:** Follow-up interviews were conducted over the phone with around half the individuals recruited, to explore issues that had been identified in stage two of the research.

### How we involved older people in shaping the approach to our research

As well as engaging with older people in the qualitative research, we wanted to achieve meaningful co-production during this project wherever possible. We involved a group of six people as expert advisers to help us shape and plan the project. This included:

- sharing views on how the approach to the research could best gather the views and experiences of older people
- helping us make decisions about which research organisations we would work with
- providing views on the findings of the qualitative research and what they felt were the most important or interesting discoveries we should present.

### Quantitative analysis

City, University of London, was commissioned to conduct the quantitative work, which consisted of a statistical review, as well as the main body of analysis, which looked at data from Understanding Society survey. The full methodology can be found in their report (to be published in 2020).

In their review of official and national statistics, City trawled published statistical compendiums to assess the extent, availability and quality of data relating to health and wellbeing, financial security and social connectedness. Alongside this, City investigated how the specific groups we had identified were represented in these compendiums. City reviewed more than 30 different sources of official and national statistics, as well as data produced by other organisations.

In the second phase City used the Under Society survey datas new statistics on sp of older people. The large-scale househo repeated annually w households from ac countries of the UK study only looked at survey first took pla (wave 1), and the ma used in City's analys 2016-17 (wave 8), w 6,955 adults in Engl and over.

### Group

Older people from Asian, and minority (BAME) groups.

Older people with health condition.

Older people with health condition.

Older people with lowest incomes.

Older people with

Older people who

The 'oldest old'.

- 1 'Mixed' ethnic background was judged to be too low a sample size to evaluate as it is <100. 2 The SF-12 is a multipurpose suite of 12
- guestions designed to measure mental and

health focus on limitations on daily activities of living, mobility and pain. The questions on mental health focus on feelings of anxiety or

e of the project,
rstanding
set to create
ecific groups
e survey is a
old panel survey
vith 40,000
cross all four
(although City's
it England). The
ice in 2009–10
ajority of data
sis is from
vhich contains
land aged 65

Questions in the survey cover a broad range of areas, including income, family composition, health and social relationships. City looked at more than 50 indicators across the themes of health and wellbeing, financial security and social connectedness, such as:

- satisfaction with life
- ability to pay an unexpected expense
- number of close friends.

The definitions used for each specific group of older people is set out in the table below.

	Subgroup definition
n black, ty ethnic	Older people who describe themselves as Asian or black <sup>1</sup> .
n a physical	Older people with a severe physical health problem as measured by the SF-12 questionnaire <sup>2</sup> .
n a mental	Older people with a severe mental health problem as measured by the SF-12 questionnaire <sup>2</sup> .
n the	Older people in the lowest total net household income quintile.
nout children.	Older people who do not have any living children.
o are carers.	Older people who care for someone else inside or outside their household.
	Older people aged 85+.

# Acknowledgements

### **Authors**

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We would also like to thank everyone who spoke to Humankind Research as part of this project. This work would not have been possible without them. Our expert advisory group members included:

### Maggie, 65, London

Maggie was interested in this project because she wishes to challenge misconceptions people have about the older generation.

### Jeff, 71, London

Jeff wanted to take part in this project because he feels that people over a certain age can feel invisible and he would like to debunk negative views of older age.

### Tony, 81, Luton

Tony was interested in taking part because he feels that he's got a lot of practical experience of older age and he's passionate about helping other people.





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