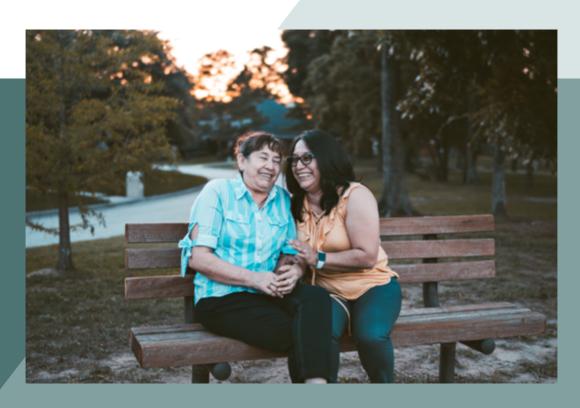
# Future of Ageing Public Dialogue

Research by BritainThinks on behalf of the Nuffield Council on Bioethics

August 2022





NUFFIELD COUNCIL™ BIOETHICS

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#### **Foreword**



**Bella Starling**Director, Vocal; Wellcome Trust Engagement Fellow, Manchester University NHS Trust

Increasingly, our UK population is ageing. Forecasts predict that by 2032, around 22% of the UK population - 13 million people - will be over the age of 65, up from 11 million in 2022. These trends will have significant implications for the wellbeing of individuals in later life, and for wider society. Many people will have more

complex health needs and circumstances in older age than in previous generations. How science and technology, as part of wider society, can help to address these concerns and help shape the future of ageing, is a hugely important question. As someone who specialises in bringing different voices into scientific research and ethical debates, I was thrilled to be a part of this public dialogue and to help explore important public perspectives on this issue.

This dialogue took a creative, inclusive and people-centred approach. Carried out in different locations, with people from all walks of life, and combining online and in-person discussion, the dialogue explored people's experiences of ageing, science and innovation, and asked people to come up with their own recommendations for the future of ageing. I particularly valued this approach of not constraining dialogue into pre-determined subject areas. The sessions were variously deep, fun and informative. A huge thanks to the team at BritainThinks for their expertise and analysis, to all of the people who took part, and to the Nuffield Council team who supported the work.

Here are my top five take home messages from the dialogue:

- Everyone is ageing. Perhaps an obvious statement, but not an easy one for us all to get our heads around. I was glad to see the dialogue endorse a holistic view of approaching ageing across the life course from birth to death. This mirrors our findings in the inquiry, and calls for a new framing of how science, technology and policy might address how to age well.
- People's experiences of ageing, and what it means to age well, are not universal. Deep and
  troubling inequalities persist and must be addressed the need for equity, fairness and
  accessibility has come out strongly as part of this dialogue. I have been shocked though
  perhaps I should not have been surprised to hear first-hand some of the "burden" that older
  people can be labelled with, and instances of institutional ageism.
- Ageing is everyone's business. We have heard loud and clear from people in this dialogue that
  everyone, whether younger or older and irrespective of background and life experience, needs to
  be involved in thinking about ageing well. It's heartening to hear a desire for collaboration which
  extends further to a pressing demand for all organisations to work more collaboratively in ageing
  research and innovation.
- Ageing can sometimes be big business. People involved in the dialogue were not naive to the
  crucial role of industry/the commercial sector in supporting research and innovation into ageing.
  But there is an urgent need to balance profit and people's needs who is research for?
- Finally, as much as ageing is everyone's business, so too is research on ageing. People felt strongly that a range of voices should be heard in research and innovation, from the bench to the bedside, including in the prioritisation, design and delivery of research, and that a more diverse range of people should be supported to take part in research. No doubt I'm biased but I can't help but agree.

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<sup>&</sup>lt;sup>1</sup> Office for National Statistics (2022) *National population projections: 2020-based interim*, available at: https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/bulletins/nationalpopulationprojections/2020basedinterim#changing-age-structure.

#### **Executive Summary**

#### **Background: The Future of Ageing Inquiry**

Increasingly, people in the UK are living longer than ever before. In the UK, the number of people aged 85 years and over was estimated to be 1.7 million in 2020 (2.5% of the UK population) and this is projected to almost double to 3.1 million by 2045 (4.3% of the UK population). This shift in population will require us to adapt many areas of our society, including how we work, care for, communicate with and interact with each other. Without significant improvements in health, the ageing UK population will also mean an increase in the number of people living with ill-health and disability. This in turn, will increase pressure on health and care systems, as well as on personal care responsibilities and unpaid carers.<sup>3</sup>

The Nuffield Council on Bioethics (the NCoB) is an independent body that informs policy and public debate about the ethical questions raised by biological and medical research. The NCoB is currently running an in-depth inquiry exploring the ethical questions around how science and technology can help older people live better lives. Throughout the inquiry, the NCoB have run a series of creative engagement workshops to hear directly from older people about their experiences of science and health technologies and their values in later life. Following the engagement workshops and other evidence gathering activities, the NCoB has developed recommendations for how science and technology can be more effective, ethical and responsible when it comes to ageing.

The NCoB commissioned BritainThinks to design and deliver a rapid public dialogue to engage with the public on these recommendations. The aim of the dialogue was to ensure the recommendations are inclusive of the values of members of the public.

#### About the dialogue process

24 members of the public from two locations (Kent and West Yorkshire) took part in the public dialogue, over two weeks, during June 2022. Half of participants were aged 18-64 and half were aged 65 or over. The older age group included people with different support needs for daily tasks, to ensure we heard from people experiencing some of the challenges common in later life. We wanted to hear from people with a range of different views, so included people with different attitudes to health and wellbeing technology, those who are currently using more technology, and those who aren't. You can read more about who took part in the appendix of this report. We met the participants three times, once in person, and twice online, spending a total of seven hours with them.

#### What we heard

We started the dialogue by discussing participants' own experiences and expectations of ageing, and how ageing might change in future. Participants interacted with scenarios introducing the concepts of geroscience research, technological developments and changing

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<sup>&</sup>lt;sup>2</sup> Office for National Statistics (2022) *National population projections: 2020-based interim*, available at: https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/bulletins/nationalpopulationprojections/2020basedinterim#changing-age-structure.

<sup>&</sup>lt;sup>3</sup> Government Office for Science (2016) *Future of an ageing population,* available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/81 6458/future-of-an-ageing-population.pdf.

attitudes towards older people in society to help build a picture of what this future might look like. Participants feel they want to see a future of ageing which takes a holistic view of living well in older age. They see physical and mental health, financial security, family, and a social circle as important and interconnected aspects of living well in older age. Participants want to see developments in research and technology that can help them live independently for longer, while protecting their privacy. Participants see a role for products and medicines or treatments in helping older people to live independently, but want to have a choice about what steps to take in their own lives.

We then asked participants to tell us what is important for research and innovation to consider, to help reach the future of ageing they want to see. Participants highlight four principles to inform research and innovation processes:

- Fairness: assurance that the outputs of research will benefit the public, not just commercial organisations or government. Access to products should be fair, with universal access to products and treatments that support older people to live healthier lives for longer.
- **Informed choice and consent:** it is important to be transparent about research processes. Transparency about how the research will/has taken place ensures participants are able to give informed consent to take part, and to make educated decisions about products, medicines and treatments they might choose in the future.
- Accountability: appropriate protections should be in place for those involved in research, and clear accountability is required in cases of mismanaged research.
- Safety: for medical research in particular, regulations need to be in place to ensure the safety of medicines and treatments for end-users. This includes safety at the trial and testing stage of research, as well as at the outputs stage.

After discussing their own priorities for research and innovation processes, participants then fed back on the NCoB's eight emerging recommendations:

#### 1. Role of the national government

**Recommendation**: Involve the public in shaping policy to support current goals and create an intergenerational advisory group (made up of diverse older generations now and into the future) to challenge ageist assumptions that are deeply embedded in society.

Participants see the role of government as making a real commitment to challenging ageist assumptions in society. They imagine this will take the form of government funding, policy positions and setting priorities for research in this area.

Participants also like the idea of the intergenerational advisory group, and feel it is important that people from different generations are given the opportunity to feed into this, to ensure the views of older people and 'future older people' are equally considered.

#### 2. Role of the research field

Recommendation: Expect meaningful collaboration with older adults in the studies they fund, review, or publish, and ensure public contributors (members of the public who help to design research studies) reflect the diversity of the population who may be affected by the proposed research.

While the scope of this recommendation is seen to have less reach than others, participants support measures to ensure meaningful collaboration with older adults is a key part of research studies. The complexity of this recommendation and a lack of familiarity with research processes means many participants struggle to imagine how actors in the research field can ensure the studies they fund, review, or publish actually do engage with a diverse population of older adults in a meaningful way.



#### 3. Including older adults in research

**Recommendation**: Collect suitable information about those that are included in research, e.g. what access to support do they currently have? and work with older adults to design studies that will help more older adults to be

included in research.

Participants are enthusiastic about including older adults in research and feel it is important to include the voices and perspectives of older people in research that will impact them. This feels a realistic goal to achieve, and they can see how it will work in practice, based on their involvement with this dialogue. However, participants feel less sure how researchers will work with older adults to *design* studies, and feel they are more likely to be included once the research has already been designed.

Participants are interested in seeing research that looks at the wellbeing of older people as a whole, not specific conditions or needs, reflecting their experiences of multiple conditions. They are less focused on the part of the recommendation about collecting suitable information, but when prompted, agree it is important that diverse audiences are represented in research.



#### 4. Support for researchers

**Recommendation**: Use the reflective framework to guide individual research teams, funders, and ethics committees to think about supporting flourishing in older age, challenging ageist assumptions, promoting equity and fostering

empowerment.

This recommendation is difficult for participants to engage with. Low familiarity with the research environment and technical language contribute to this. However, themes of flourishing in older age, challenging ageist assumptions and promoting equity are all seen as extremely important, for researchers and society as a whole.



#### 5. Development of a kitemark or set of standards

**Recommendation**: Develop a kitemark system to indicate technologies that have been ethically developed.

This recommendation receives a lukewarm reaction from participants. They struggle to imagine how this kitemark will be distinguished from other product standards that are already in place. 'Ethically' developed is felt to be ambiguous, with participants assuming that technological and especially medical products are already heavily regulated. Emphasising that the kitemark could include values that are important to participants, for example the involvement of older people in the development of products and equitable distribution to end users, will likely help build support for this recommendation.



#### 6. Flexibility with budgets

**Recommendation**: Promote flexibility with budgets so that key players (e.g. those in health, social care, housing, transport etc.) are able to work together and pool budgets to better focus on meeting the needs of older adults.

Participants feel this recommendation has huge potential and support the suggestion to pool budgets and work collaboratively across sectors to lead to a richer understanding of older people's needs and better outcomes for older generations in the future. However, this recommendation is felt to be particularly difficult to achieve, with participants interested in learning more about who would organise and drive forward this approach.

#### 7. Working at the grassroots level

**Recommendation**: Support small community-led projects that are aimed at helping diverse older adults.

Participants emphasise the importance of supporting community-led projects and believe they are more likely to have a better understanding of local communities and lead to real impact in their own area versus bigger scale projects. This is largely due to the perception that community-led projects can account for local people's needs and behaviours in their design and scope, as well as having better capacity to address challenges specific to the local population.



#### Encouraging different disciplines to work together

**Recommendation**: Encouraging people from different disciplines to work together (interdisciplinary working), and welcoming better collaboration across the research sector.

Participants support a more joined-up and efficient approach to understanding the needs and behaviours of older adults. They feel that different disciplines should already be collaborating together to reach richer understandings of the needs of older people. However, participants feel it will be difficult to encourage changes to ways of working and wonder how competing priorities will be managed. Clarifying specific disciplines will make this recommendation feel more realistic for participants.

#### Our conclusions

Reflecting on the discussions participants had across the whole dialogue, we have drawn out six themes describing what is most important to participants when considering the future

of ageing. They show where participants see potential for research and innovation to support living well in older age, as well as concerns about how these processes may work.

- 1. A holistic approach to living well in older age. Participants tell us that physical and mental health, financial freedom, a support system, and social interactions are all important to living well as they age. These values are closely connected: it's difficult to enjoy one without the others. Researchers should use the same broad definition of 'living well' and take a holistic view of what living well in older age looks like, beyond solely living healthier for longer in later life.
- 2. Feeling listened to. Participants are overwhelmingly supportive of recommendations for including older people in research. Older participants reflect on societal expectations holding them back and are eager for outlets to share their views and experiences and be listened to. Participants are looking for older people to be involved in research processes broadly, not just for products specifically aimed at older people, but for innovations that anyone might use.
- 3. Working together across generations. While participants think it's important to involve older people in research processes, such as in the design and testing phases of new products, they want to see involvement of a wide spectrum of age groups, including younger adults. They see intergenerational interaction as an opportunity for all age groups to share knowledge and learn from each other, as well as for researchers to learn from a wide range of age groups. This diversity of perspective is seen as strengthening the research process and ensuring the views of older adults, as well as future older adults, are considered. Opportunities for intergenerational interaction are seen as key to changing attitudes towards older people and challenging ageist assumptions.
- 4. Supporting independence in later life. Participants are looking to research and innovation to support older people to live independently for longer. This might mean staying in good health and so being able to live without additional care, new technology that supports people to continue to do daily tasks for longer, or potential treatments that may help manage pain from chronic conditions. Participants are enthusiastic about all developments that might help older adults stay independent for longer, which in turn may contribute to maintaining their dignity as they grow older.
- 5. Making your own decisions. Independence also extends to being able to make informed decisions about whether to use new products, technologies, medicines, or other developments. Participants are wary of products that might threaten their privacy or feel like surveillance. While this is primarily felt to be a risk with new technologies, participants are also looking for education about advancements in medicine to enable them to make informed decisions about new treatments.
- 6. Equitable access and fair distribution. A key concern throughout the public dialogue was about cost and equitable access to new treatments and products. Participants often assume that developments in geroscience and new assistive technologies will be very expensive and contribute to greater inequalities. Fairness in the distribution of outputs will be key to building trust and support in the research process.

#### 1. Introduction

#### 1.1 Context: The Future of Ageing inquiry

The Nuffield Council on Bioethics (the NCoB) are currently running an in-depth inquiry, exploring the role that science and technology may play in helping people live well in older age, and helping society navigate and support an ageing population. The inquiry – titled *The Future of Ageing* – involves a range of different interactions with members of the public, scientists, and researchers. Within the inquiry, the NCoB have run a series of creative engagement workshops to hear directly from older people about their experiences of science and health technologies and their values in later life. Additionally, the NCoB have brought together an interdisciplinary working group, to develop recommendations for policymakers and other stakeholders on how science and technology can better achieve the aims of more people living well for longer. The NCoB want to make sure these recommendations are reflective of the views and values of citizens as well as experts, and commissioned a public dialogue to test the emerging recommendations. Following a competitive tender process, the NCoB appointed BritainThinks to deliver this dialogue and write this report.

#### 1.2 What is a public dialogue?

At its heart, public dialogue is a conversation between the public and people working on a complex topic. Public dialogues recognise the value that members of the public can bring in terms of their insight and experience and gives the opportunity for exploration of the values that underpin people's views and opinions. Key aspects of a public dialogue include:

- **Open discussion**: Discussions should be open, with members of the public able to discuss the topics they are most interested in;
- Access to accurate information: People should have access to accurate information about a topic, and to different perspectives and views on the surrounding issues:
- Purposeful collaboration: Working closely with the people commissioning the dialogue (in this case the NCoB) to ensure they take into account the findings that emerge from the research;
- **Widely shared**: The results (this report) should be made freely available and shared widely with people who can act on that they hear.

The design of this dialogue was based on three key principles:

- **Inclusion**: We wanted to hear from as wide a range of people as possible, and ensure that participants were a cross section of society, selected to reflect a diversity of characteristics and views;
- Creativity: We wanted to give participants as much information about current and future ageing research and technology as possible without overwhelming them. We used creative tools, like immersive scenarios, to achieve this;
- **Focused**: We wanted to get as much feedback as possible on the topic of ageing well, and on the emerging recommendations made in the inquiry.

#### 1.3 Aims and objectives

The NCoB commissioned the dialogue with three key objectives in mind:

- To help the NCoB ensure its draft recommendations are inclusive of public values and considerations with respect to ageing;
- To gain an understanding of how members of the public feel the report recommendations can be refined and developed;
- For members of the public to help identify potential points of consensus and disagreement on the issues raised by the NCoB's recommendations.

#### 1.4 Methodology

We wanted to hear directly from people living with low, moderate, and high health needs. We worked with professional recruiters (accredited by the Market Research Society) to free-find a total of 24 people from two areas in England, Kent and West Yorkshire, who were broadly reflective of the populations in each area. All participants were paid for their time, to ensure that nobody was excluded from taking part because of their financial circumstances. The dialogue took place across three weeks, starting with separate three-hour in-person workshops in two locations in Leeds and Kent, followed by two additional combined two-hour workshops hosted on Zoom. Further information on how dialogue was designed and delivered is included in Appendix 1. This includes the recruitment process, the materials used, workshop content, details of the public dialogue participants and process of analysis and reporting.

Workshop 1: Saturday 11<sup>th</sup> June & Sunday 12<sup>th</sup> June. 9:30am-12:30pm: This first workshop introduced participants to each other and the dialogue process and got participants thinking about the concept of ageing through a series of 'games'. Participants then explored three immersive scenarios about geroscience research; assistive technology and technology research; and changing attitudes and culture around ageing. Participants shared their hopes and concerns for each vision of the future and discussed what is important to them in thinking about the future of ageing.

**Workshop 2: Thursday 16<sup>th</sup> June. 5-7pm**: This workshop introduced the current process of research and development within scientific and technological fields through short presentations from expert speakers. Participants then shared their thoughts on the way they feel these processes could be developed in the future, including what would be the best and worst ways for research processes to be run at each stage of research, including the research input, process, and output.

**Workshop 3: Thursday 23<sup>rd</sup> June. 5-7pm**: This workshop began by summarising what was discussed in the second workshop, allowing participants to comment, reflect on or challenge our summary. Bella Starling, Chair of the NCoB Future of Ageing inquiry presented the NCoB's draft recommendations and opened discussion for questions and clarifications. Participants then discussed the recommendations further in small groups, conducting ranking exercises to prioritise them and doing a deep dive into the detail.

Throughout the dialogue, information was provided to participants about current research on ageing. We used lots of different formats to immerse participants in scenarios, generate discussion, and share information about different aspects of research in relation to healthy ageing. A list of the materials and further details can be found in the appendix.

#### 1.5 About this report

This public dialogue generated a rich set of data. Each workshop was recorded, with notes made by the BritainThinks research team throughout the sessions. These notes were analysed thematically; meaning the research team read through all the comments made by participants and through internal analysis sessions, developed a set of overarching themes around the public's views, as well as their reactions to the recommendations that the NCoB put forward. This analysis is the basis for this report, along with the reflections of the facilitators, for example where they noted strong agreement or disagreement among participants about an issue. The report also draws conclusions based on what participants said and clearly indicates where we have done this.

This dialogue involved a small number of people (24) who had in depth discussions and were carefully chosen to represent a wide range of backgrounds. However the findings don't necessarily represent the views of the general public as a whole, and so references to some or all participants are merely indicative. This report also includes direct quotes from participants, to illustrate the points they made in their own words.

# 2. The future of ageing: participants' hopes and concerns About this chapter

What does it mean to age well? This chapter focuses on participants' hopes and concerns for the future of ageing and the role biomedical research and innovation might play. Dialogue discussions on this topic were prompted by questions, in the form of simple games and future scenarios, on experiences and expectations of ageing.

#### 2.1 Expectations and experiences of ageing

#### How old is old?

In game one, participants wrote down the age that they think of being the beginning of 'old age', then compared notes and discussed the reasons for their choices. This helped us to explore societal norms around 'old age' and the key milestones and events participants associate with ageing, before discussing how ageing could look in future.

In their answers, participants focus on either key events such as retirement (age 66) or the onset of health issues associated with older age (ranging from age 60-80). Participants aged 60 and over feel that their perception of 'old age' is continuously changing, the older they get. Many participants aged 60 and over reflect that when they were in their 30s and 40s, they expected to feel 'old' by their 60s but in practice when they reached this age they didn't and old seems just as far away. In contrast, many of the younger participants are more likely to pinpoint retirement age as a fixed point for the start of 'old age'.

"Age 66. There's a reason there's a retirement age, that's when you're old.

It gets ingrained in our heads."

(Female, 38)

"I would say age 80 but it's flexible and always changing. 10 years ago I would have said 70 but now I'm in my 70s and I don't feel old so now I think 80! People are living a lot longer now so that's what I mean when I say it's flexible. You can't put a number on when you'll feel old."

(Male, 70)

#### How old are you?

#### **Adhar**

Chronological age: 67

Biological age: ?

- · This is Adhar, his chronological age is 67.
- Adhar spends most of his time indoors. While he can go outside, he find that he suffers from aches and pains if he is active too much and would prefer not to.
- He used to be active in several social and sports clubs, however he now finds he either can't take part, or has lost interest.
- He also needs to write down reminders to complete tasks like taking out the bins and paying bills, otherwise he often finds he forgets.



Do you think Adhar's biological and chronological ages match?

Britain**thinks** 

Game two explored chronological versus biological ageing. Chronological age is the number of years you have been alive, whereas biological age is an estimate based on any health conditions and how your body functions<sup>4</sup>. In this game, participants reviewed three case studies of people whose chronological and biological ages differ, like Adhar in the example shown above. Participants were given the person's chronological age and asked to estimate their biological age.

"You have to be lucky not to have any health conditions or pain in older life, but it's also a result of being active and healthy in younger life."

(Male, 70)

Participants find this idea familiar and consistent with their own experiences and are quick to reflect on whether or not they felt older or younger than their own chronological age. Some participants feel that being active and healthy in younger life leads to better health in later life and point out that many different factors contribute to biological age. Others talk about the importance of mental wellbeing and attitude in living well in older age. They feel that someone with a positive outlook on life would be more likely to have a biological age that is closer or even younger than their chronological age.

"All the aches and pains I have definitely make me feel older than I am."

(Female, 73)

"Your mentality is really important to being healthy in later life."

(Female, 36)

<sup>&</sup>lt;sup>4</sup>Hamczyk MR, Nevado RM, Barettino A et al. (2020) Biological v chronological aging: JACC focus seminar Journal of the American College of Cardiology 75: 919-30.

#### How fast do we age?

In game three, participants were asked to draw a line on a chart showing how fast they felt they were ageing during each decade of their life and discuss why.

Many older participants feel that time goes quickly after the age of 60, due to being kept busy with grandchildren and hobbies. They reflect on the years in which they were working and raising a family as moving at a medium pace due to having lots of things to juggle.

"Age 20-50 it was at a medium pace when you're working and have a family, 50-60 slowed down as I was waiting for retirement and then 70-90 is speeding up as you no longer have those responsibilities."

(Male, 68)

Younger participants share that they anticipate life slowing down after retirement, as they will have less to do and expect to experience more health problems. Some participants recall stories from grandparents or other older relatives about a decline in health that now looms in their expectations of what living in older age may be like.

"It's gone very fast in my 30s and with the birth of my son. I expect there'll be a gradual decline to slower when I'm older because there won't be much to do during the day and when you're older you're in God's waiting room."

(Male, 31)

#### When were you born?

In game four, participants were asked to find their birth decade on a chart that plotted predicted life expectancy at birth.

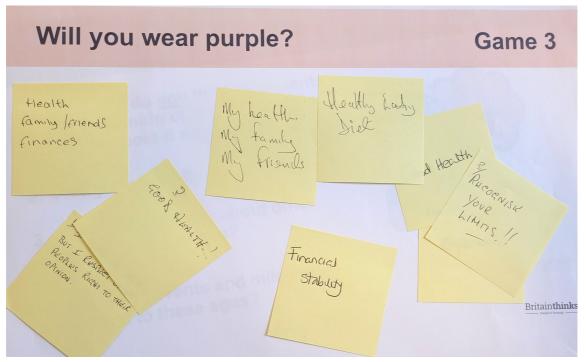
Participants debate the extent to which a healthy lifestyle is always in the control of the individual and the impact of where you live, both in different parts of the UK as well as globally, on your life expectancy. Some participants argue that the development of new medicines to treat common diseases and conditions is also seen to have a significant impact in increasing life expectancy. Participants feel comfortable with the idea that life expectancy is going up over time and tend to expect that this will continue in the future.

"There's a massive different in life expectancy [from 1930 to 2020]. I suppose people used to die of things you don't die of any more like childbirth and tuberculosis. It should go up – that's what you expect, progress."

(Male, 66)

#### Will you wear purple?

The title of this game is inspired by the poem Warning by Jenny Joseph, in which she describes wearing purple when she grows older. Purple has since come to represent older age in the UK. In this game, participants each wrote down three things they value for themselves in later life. This prompted a discussion on what 'living well' in later life looks like and what might help or hinder people to live well in older age.



Participants feel it is important in later life to have good physical and mental health, a support system of family and friends, financial stability, remain active and have hobbies to enjoy. This list of values are connected, and make up part of the holistic picture of 'living well.'

"You need things to do when you retire, or you'll get bored. It's not good for you to have nothing to do, you can only walk the dog so many times. People tend to age when they retire and have nothing to do, you need to keep busy."

(Female, 63)

Some participants give examples that while being in good health is critical to living well, family and housing security are also important factors in this overall picture.

"My family is most important to me, they're my purpose. I've also been lucky with my health, but I try and stay active. My home is also important to me, I've strived all my life to have my home and the security that brings. I have a sister in a care home, and I don't want that."

(Male, 68)

#### 2.2 Longer, healthier lives: Participant views on geroscience

Participants then explored three immersive scenarios set in a future where technology, medicine or societal change has altered the experience of ageing. In each scenario, the scene was tailored to the topic with props, multimedia displays and guided exploration led by the facilitator.



Image 1: Participants in Leeds exploring the scenario on geroscience.

In the scenario focusing on geroscience, the scene was set for participants with this message:

It's 2050 and geroscience research has delivered medicines, treatments and diagnostics that have improved health in later years by targeting the underlying causes of ageing. They have also spotted, prevented, or mitigated some of the most common illnesses associated with older age, such as dementia, cardiovascular disease and cancer.

Participants then explored five case studies showing individuals who had benefited from advancements in geroscience, but also experienced some of the potential downsides:

### Case study: Ife, open doctor's office door

#### This is Ife.

At age 34, Ife saw her mother and grandmother both suffering from multiple conditions, including arthritis, diabetes and heart disease. Ife became used to seeing her mother and grandmother take many different medications and go for many treatments in their later life to manage their multiple conditions.

At age 69, Ife had begun to see early signs of arthritis, diabetes and heart disease in herself. However, after visiting her doctor, Ife was told that geroscience had led to the development of a new medication that targets the underlying causes of arthritis, diabetes, heart disease and even other conditions associated with older age, such as Alzheimer's in a single pill. Ife began to take one pill a day.

Now age 74, Ife has been taking this pill for 5 years and has seen significant improvements in her health and the delay of conditions she saw affect her mother and grandmother. This has meant Ife is able to keep up her favourite pastime of singing and dancing with her local choir. Ife plans to continue to taking this drug in the coming years.



Image 2 Example of a case study shown to participants

#### 2.2.1 Are the benefits worth it?

Participants are open to the idea that geroscience may help people live longer, healthier lives. However, many wonder, what will the trade-offs be? For example, they ask:

#### You might be living longer, but can geroscience really ensure you are living well?

Participants see 'living well' as more than just good physical and mental health.
 While they acknowledge that health is important, they also look to later life as a time for enjoyment. As a result, approaches to living healthier for longer in later life that feel restrictive, like specific diets, aren't always felt to enable 'living well'.

### You may be able to prevent disease, but will the side effects of treatment be just as debilitating?

Participants below the age of 40 are particularly likely to be wary of preventative treatments that would need to begin before experiencing symptoms. These participants want to see robust research about potential side effects and long-term implications before starting a long-term course of treatment. The majority of participants aged 60 and above, or those with experience of ill health and/or long-term health conditions, are more likely to be open to taking preventative medications

and trust that the side effects have been researched if their GP is telling them that the treatment is safe.

"I would be worried about the side effects and how you'll then need treatment for the side effects."

(Female, 38)

#### People may be living longer, but can the UK's infrastructure and services support this?

Participants are concerned that more people living longer could put pressure on the UK's resources, whether that's housing, health services or the pension budget. Some participants give examples of news stories they have heard about the challenges associated with an ageing population. As many participants are sceptical about the potential for side effects from geroscience treatments, some aren't convinced that geroscience would really lead to people living healthier in later life for longer, but could just lead to living longer, with other health concerns. These participants feel that demand is therefore unlikely to decrease on health services.

"But will we end up with too many people? What about pressure on housing and health services?... And how can we guarantee that people won't get stuck with health problems for longer if we can't really cure [the health problems] but people do live longer?"

(Female, 34)

#### 2.2.2 Key benefits and concerns

Participants see some key benefits to geroscience, including:

- A holistic approach to health that treats multiple conditions at once will be easier for the user to manage and may reduce negative interactions and side effects from competing medications (something that older participants in particular describe having had experience of);
- Preventative treatments could lead to a more positive outlook on life if you know you are less likely to develop health conditions in later life;

"You'd have a more positive outlook on life if you weren't worried about being ill when you're older"

(Female, 73)

 A healthier generation of older people could relieve some younger people of caring duties, as some younger participants expect to care for their parents as they get older. Some participants aged 60 and over also comment on feeling reluctant to put the responsibility of caring for them on their children. Participants also express concerns about geroscience, including:

Equitable access to new treatments. Participants readily reference news stories
and anecdotes about those with more money already being more likely to live healthy
lives for longer and are concerned that developments in geroscience could widen the
inequalities gap;

"It's already the case that people who have more money live longer. It costs more to look after yourself and to eat well."

(Male, 66)

- Participants from ethnic minority backgrounds are also more likely to question
  whether developments in geroscience will be shared globally and how countries in
  the Global South will be supported in accessing new treatments and medicines.
- Concerns about financing a longer life. Participants are concerned about state
  pensions "running out" and feel the state pension age would have to rise if people
  were living longer. Some question if this would mean having to work for longer, even
  if they would prefer not to. Others questioned whether people would need higher
  pension contributions, putting a good pension out of reach of those on lower
  incomes.

"People who are living longer are going to have to pay in [to their pensions more]. What you pay into your pension already isn't enough to pay out for the length of time people are living and it will only get worse if people live longer."

(Female, 63)

Participants spontaneously discuss the benefits of geroscience, especially when it could tackle the root causes of illness, not just individual diseases related to ageing. They want to see the field of geroscience develop as part of a broader approach to health and wellbeing, with more support for people to live active and healthy lifestyles. But before they can support geroscience treatments being made available to the public, they want to know how treatments will be rolled out so that cost will not be a prohibitive factor, and how treatments will be made accessible to everyone.

## 2.3 Better health and wellbeing through technology: Participant views on assistive technology

In the scenario focused on technology, participants were introduced to the topic with the following message:

It's 2050 and although people aren't living longer, technology research has delivered devices and services that improve the lives of older people and contribute to healthy ageing, allowing for greater independence, mobility, and access.

Participants explored examples of assistive technology, including an Amazon Alexa and remote monitoring webcam, and watched videos highlighting both positive and negative impacts of technological developments.



#### 2.3.1 How technology can both support and hinder independence

A key tension for participants when discussing future technological developments is assistance versus independence. On the one hand, both younger and older participants see the potential for technology to support them to live more independently, from daily tasks such as using smart technologies to regulate their heating or remember shopping lists, to larger tasks such as robotic technologies that could support older adults in using the bathroom or washing themselves. Use of technology in this way is seen as supporting people to stay in their homes for longer with dignity. Participants aged 60 and over identify increasing dignity as a benefit of assistive technology and imagine technologies that can support them with activities as they age, like using the toilet or washing themselves, that they do not necessarily want another person to help them with. Living independently with dignity is seen as a key part of 'living well' in older age, particularly by participants with family members or friends in assisted living or care, as well as those without family members nearby to help with tasks.

"Anything that can help you stay in your own home is worth looking into, especially if you don't have family nearby. [Technology] could help with things that are embarrassing, like going to the bathroom."

(Female, 73)

However, participants across age groups are also cautious about the ways in which technology could limit independence. Some feel that the increasing presence of technology in our lives could make people dependent on it, where it replaces a task people could manage with assistance. Others are concerned about privacy, including both those who admit to feeling less confident with technology already, and those who feel well-versed on data sharing. Participants bring up issues of monitoring and sharing of personal and health information with private companies, or with family members and carers. In most cases, participants expect information about their health to be shared with their GP's and the NHS and are happy for this to continue. However, with the introduction of assistive technologies, many worry there's a risk the companies who produce and operate the technologies may share, use inappropriately or sell on their health data to other private companies.

For many participants a better understanding of how new technologies work and how their personal data is shared and stored will help them feel more confident using new technology.

#### 2.3.2 Key benefits and concerns

Alongside supporting independence, participants see the following <u>benefits</u> of developments in technology research:

- The potential for relief from chronic pain, either long-term or when waiting for a diagnosis or treatment. Participants imagine that technology can provide interim support to older people. For example one participant spoke about his wife's arthritis and imagined she could be provided with a pair of gloves, similar in style to the image of the exoskeleton suit showed to participants, to assist her with daily tasks and reduce her pain while she waits for further treatment:
- A few participants suggest the NHS could loan out technologies to help both with waiting times for treatment and also alleviate the costs of what many assume will be expensive products.

"It would be great if you could use tech to ease pain while you're waiting to be treated. My wife is waiting for treatment on some extremely painful arthritis on her hands. I'd like to see the NHS loan her some gloves that would reduce the pain in her hands while she waits for treatment."

(Male, 70)

Diagnostic technologies that could alert you to minor or emerging health issues
before they progress are seen as offering benefits in improving health in the long
term. For example, one participant imagines a 'preventative Fitbit' that could not only
monitor your vital signs, but also run regular tests and alert the user to potential
changes in activity and health that might need further clinical investigation.

"I'd like to see a preventative Fitbit that does check-ups on your body and sends you alerts if you should get something checked."

(Male, 59)

Alongside questions around privacy, participants also express the following <u>concerns</u> about future developments in technology:

- As with geroscience research, participants are concerned that future technologies
  may contribute to health inequalities, with only those who are able to afford the
  expected high cost of technologies having access to them.
- Some older participants express a lack of confidence in using technology in its
  current state and worry that future developments will leave them even further behind
  those who are already confident with technology.
- Some participants are sceptical about the reliability of technology and potential
  for user error and describe difficulties with use in the past. For example, multiple
  participants reference smart home technologies not working properly, and one
  participant gave an example of a relative consistently having difficulties enacting their
  personal alarm.

"I had an aunt with dementia, and we got her a personal alarm and she never remembered to use it when she fell. It would have been more useful if it was advanced enough to alert someone something was wrong without her having to do it."

(Male, 68)

Whether increased use of technology in the future may lead to increased social
isolation of older people. While participants support the development of
technologies that can help older people live independently for longer, there are some
concerns that this might begin to replace human care and leave some older adults
more isolated.

"It could mean less human contact and less socialising. You might become dependent on technology."

(Female, 38)

Overall, participants are open to learning more about how technology research may impact the future of ageing and see a clear role for technology in supporting independence in later life, easing chronic pain, and assisting with early diagnosis. However, participants feel that future technology rollout will need to be accompanied by sufficient education and information on how to use the technology safely and to its fullest potential. Some participants suggest that it would be helpful to have easy access to explanations and tutorials available for those less confident in using technology. As with geroscience, participants see assistive technologies as one piece of the puzzle of living well in older age and feel technology research is most likely to have an impact where there is an equitable roll out and it is part of a larger societal shift in which older people can more easily remain active and be supported by family and social circles.

# 2.4 A society of valued older people: Participant views on changing attitudes

In the scenario focused on changing attitudes towards older people in society, participants were introduced to the topic with the following message:

It's 2050 and the way society thinks about older people has changed, leading to a greater focus on their valuable contribution and improved circumstance for many, including living healthier for longer in later life.

Participants explored case study examples of how shifts in employment, media and infrastructure could support changing attitudes towards older people (please see the appendix for further detail on these case studies).

Participants then explored an imagined workplace called Sprytely that prides itself on inclusive hiring and working practices. Participants heard the stories of four employees at Sprytely who are working in later life and how workplaces can support this, for example:

#### Improving society's views on older people in action

It's 2050 at Sprytely, a medium sized business in London.

Let's meet Rachel, aged 77, and her co-worker Lauren, aged 29





Having retired from her job as an English teacher six years ago, Rachel started to think about returning to work, but not as a teacher. Rachel saw an advert for 'Sprytely' online, looking enthusiastic workers over the age of 59 as part of a Government initiative. After applying and having an interview, Rachel was offered the role – working closely with the brand strategy team for 20 hours a week.

Rachel now works with Lauren on wording menus for new cafes and restaurants. Rachel has developed good relationships with the other staff, particular the younger staff who look to Rachel for advice on other aspects of their lives. Rachel has enjoyed developing intergenerational friendships and feel she and her colleagues have a lot to learn from each other.

Britainthinks

Image 4 A Sprytely employee

#### 2.4.1 Can attitudes towards older people really be changed?

While received positively, participants find it difficult to imagine how this scenario can be achieved. Participants aged 60 and over in particular are enthusiastic about this idea and discuss the lack of positive representation of their generation in the media, for example dating shows rarely highlighting older adults. Others are eager to discuss supportive work environments for older adults, that utilise the skills older adults have developed over time and offer flexible working arrangements. Participants feel that keeping active through employment is likely to lead to better physical and mental health outcomes for older adults.

However, participants across age groups struggle to imagine how society will overcome biases towards older adults. These biases are seen as embedded in all parts of society, meaning a multi-pronged approach will be necessary. While changes in media

representation of older adults seems plausible, participants feel that without accompanying education of younger generations, this is likely to have little impact. Participants are most likely to feel sceptical that changes in infrastructure to make spaces more accessible to older adults and conducive to an active and healthy lifestyle will occur.

Additionally, a minority of participants under the age of 40 feel that society is *already* at this point and old age has been destigmatised. These participants cite seeing older adults in their own workplaces and/or their own positive attitudes towards older adults as evidence of this.

#### 2.4.2 Key benefits and concerns

Participants identify the following key <u>benefits</u> as a result of changing attitudes towards older people in society:

- Participants feel an important aspect of changing attitudes will be encouraging
  intergenerational interactions and learning. This is seen as having the potential to
  be a learning experience for both younger and older people, both of whom can share
  skill sets with the other.
- Changes to infrastructure and opportunities to work are both seen as supporting
  physical and mental health in later life. Participants feel that keeping active and
  having a purpose are both key to staying healthy as you age.

Participants also discuss the following concerns:

Some participants, across ages, initially express concern that in this future society,
 older people would have to work for longer, due to an increasing pension age and
 difficulties saving for retirement. Younger participants in particular feel that retirement
 is an ever-moving goalpost and one that is likely to increase in their lifetimes. For
 these participants, it is important that working in later life is a choice and not a need.

"I don't want to be working at [age 72]. It doesn't sound appealing." (Female, 34)

- Others express concern that older people staying in work for longer may 'block'
  opportunities for younger people in earlier stages of their careers. These
  participants hypothesise that this then might lead to resentment among younger
  generations and is unlikely to foster more positive attitudes towards older people.
  - Participants who hope working in older age is a choice and not a financial need suggest that more volunteering opportunities could be provided for older people. They reason this would allow job opportunities for younger

people, while still providing opportunities for purpose and social interaction for older adults.

"This might end up with older people job blocking opportunities for younger people who now can't move up because older people are staying in the jobs. Older people could volunteer instead. It would still give you purpose and it's social."

(Male, 68)

- Some participants are sceptical that changing attitudes towards older people
  will lead to better health outcomes for older adults. The effects of changing
  attitudes, such as in media and employment, on health is difficult for some to grasp.
- Participants also struggle with the idea that changing the way people live can lead to better health outcomes for older adults. The idea of improving housing, local neighbourhoods, green spaces and transport systems is appealing in itself, but participants are sceptical that it will make a real difference to healthy lifespan (as well as being sceptical about changes being achieved). As a result, participants are unlikely to make the link between changing attitudes and how this might change other facets of society, such as housing or neighbourhood development.

Overall, changing societal attitudes towards older people feels out of reach for some participants, despite being the most attractive of the scenarios for many. It is difficult for participants to imagine changing the status quo in a significant way. However, encouraging intergenerational interactions is felt to be a step in the right direction. Across age groups, participants can see the value in creating opportunities for generations to come together and feel this is likely to be a good starting point in changing the attitudes of younger people, who otherwise may not have much interaction with older people outside of close family members.

# 3. Participant recommendations for reaching a better future for ageing

#### About this chapter

Having explored the future of ageing that participants want, we moved on to thinking about how research and innovation might help us get there. Participants heard three presentations about geroscience research, assistive technology development, and public contribution to ageing research. Participants then discussed how research and technology development works currently and could be improved. We broke the topic down into three stages:

**Input:** Wider factors that influence ageing related research and development

**Process**: Carrying out ageing related research and development

**Output**: Deploying the results of ageing related research and development

In this chapter, we present the **principles** that participants developed and referred to in the discussion, and the recommendations they made.

#### 3.1 Key principles

**Fairness** is the most important principle for participants in discussions of research and technology development. Participants feel strongly that the outputs of research should benefit everyone, not just those who are lucky enough to live in the right place, or can afford the latest developments. Participants are keen to see processes in place to support this principle, and to protect against commercial interests limiting access, whereby researchers and developers may be unwilling to share their thinking for the wider benefit of the sector.

**Informed choice and consent** are also key principles for anyone taking part in research or using new medicines or technologies. Many participants feel it is important that they not only be properly informed about the process stage of research (as participants or future users of outputs), but also receive information on new technologies or medicines when they are developed. This would allow participants to retain their autonomy and to make an informed decision.

Other key principles that emerged are **efficacy**, particularly in deciding what to research, **transparency and accountability** as research and development are carried out, and **trust** in the deployment of new developments. Participants feel instinctively that there are risks to taking part in research which need to be carefully managed, whether that's about data protection, penalties for any misconduct, or clear information to build trust. Adhering to these principles will ensure the **safety** of everyone involved.

# 3.2 The research context: participant recommendations for a supportive ecosystem for ageing research

When thinking about the ecosystem or context for research and technology development, participants focus largely on how the *right* projects can be commissioned, by which they mean projects that benefit as many people as possible. To make choices about which

projects are commissioned, they expect the research and technology ecosystem to consider what's fair and what's effective.

With regards to **efficacy in the research ecosystem**, participants want to see:

- Robust assessments of the potential benefits of research (participants often talk about using statistics to make these assessments, as a sort of shorthand for objective measures). Assessments should consider the number of people who would benefit and how big an impact any development could have.
- Joined-up thinking in the commissioning of research. Research shouldn't be duplicated in different places, and funding should be shared across the UK to make sure the necessary mix of skills and experiences are brought in.
- Decisions about research funding being free of political or social influence and not influenced by short term trends – participants are concerned that this isn't the case currently.

"I think the way forward would be for companies to do their own research about what are the predominant conditions among older people with ailing health, and then work in that direction."

(Male, 84)

With regards to **fairness**, participants emphasise that:

- Issues affecting a minority of people should not be ignored. Participants emphasise
  the needs of people from ethnic minority backgrounds, living in different regions of
  the UK, from different socio-economic backgrounds, and of different genders, should
  all be considered in deciding what research to pursue.
- Research should not be carried out only with commercial profit in mind, but also with the purpose of helping people. As with political influence, they feel that commercial interests may have too much sway currently.
- Research questions should be based on what's important to individuals not what's important to researchers. Research should start from the perspective of the people who will benefit, understand what is important to potential beneficiaries, and why, avoiding assumptions and preconceptions.

## 3.3 The research process: participant recommendations for equitable and inclusive ageing research

When it comes to the research process, participants tend to focus on the role of research participants, thinking about who needs to be involved to ensure research is fair and inclusive. They are also keen to see processes in place to keep research participants safe from harm through informed consent, transparency, and accountability. In an ideal world, participants want researchers to minimise risk for those taking part, participants to be fully informed of the risks, safety to be guaranteed as much as possible, and that problems are remedied in the future should participants encounter harm.

With regards to **fairness in the research process**, participants emphasise that:

- Both older and younger people need to be included in research processes as
  participants and public contributors. Participants of research should be diverse, in
  terms of age, location, socio-economic background, ethnicity, gender and religion, as
  well as health conditions, mobility and care needs.
  - Participants tend to focus on inclusion as a general principle. While they are aware that people experience a range of levels of poor health, they are less familiar with the specific concept of *health inequalities* (i.e. avoidable and unfair differences in health status between different groups of people or communities), and so this is rarely cited as a motivation for more inclusive processes.

With regards to **informed choice and consent**, participants want to know that:

 Research participants are given clear information ahead of time so that they are aware of the process they are signing up for. Participants feel that efforts must be made by those conducting the research to minimise the risk of harm, both during and after the research process, particularly when discussing sensitive topics.

With regards to transparency and accountability, participants expect:

- Accountability on the part of those conducting research and developing innovations.
   This means taking responsibility for any errors. Some participants specifically mention compensation for any person who experiences harm during the research process.
- At an individual level, research participants should be kept up to date with the
  research process, its outcomes, and the next steps. Wider transparency about
  research processes is needed to allow participants to give informed consent, and to
  ensure that those conducting research can be held to account.

Participants also discuss **efficacy and safety of research processes**. While still important, these recommendations are mentioned by a smaller number of participants.

#### For research to be **effective**:

- Duplication of work should be avoided, and effective communication between those that carry out research should be ensured.
- Research processes should seek to understand individuals on a more holistic basis. This is opposed to trying to understand someone's health on a condition-by-condition basis. Participants across different age groups reflect on their own experiences of the healthcare system where they feel their health concerns are often looked at and treated in isolation from one another. Participants with these experiences feel this same approach may lead to research and development that doesn't meet the needs of older people since it will be limited to understanding only a part of their experience and needs.

"My question for the professors is: Is what you are doing here also taking place in Australia, America, or wherever? Are you doing the same thing or are you working with them?"

(Male, 71)

For research to be **safe** participants want to feel confident that:

- For medical advancements in particular, appropriate regulation is in place. Specific recommendations include ensuring the safety and efficacy of medicines and treatments by trials and testing with e.g. placebos, control groups.
- Researchers are acting in the best interest of research participants, and are considering their individual needs. This means that potential risks are thought about in advance and mitigated against.

# 3.4 The implementation phase: recommendations for deploying the outcomes of ageing research

The implementation or output stage, of research and development, where new approaches to improving ageing are ready to be used, is felt to be the most important. Participants have strong views about ensuring that advances are rolled out fairly, but also that individuals maintain the right to choose which measures they take for their own health and wellbeing. Participants are especially mindful that the successful implementation of new medicines and technologies is heavily reliant on public **trust**. Trust and willingness to adopt innovations means that genuinely beneficial products will be used for helping people, and ensuring research isn't wasted.

With regards to **fairness**, participants recommend:

- That new medicines and technology are accessible and shared equally throughout society. Accessibility is a key element of fairness for participants, including price (e.g. being cheap enough for the NHS to purchase and prescribe), how the product or service is accessed (in person, online, etc.), and availability across the country.
- Ensuring that the benefit of development isn't just limited to the company or country
  where it was developed. Developments should be of benefit to the general public in
  the UK and internationally. Participants want to see the deployment of new medicines
  to help prevent diseases and redress inequalities in the Global South, working
  towards a net global economic benefit, and ensure that people do not need to cross
  borders to be able to access treatment.
- That companies should be committed by regulation to share their developments in an
  ethical manner so that older people can benefit, and companies are unable to keep
  developments to themselves. Participants feel this is not how developments in
  research and technology work now and will be difficult to implement.

"New medicines and technologies should be available for everyone regardless of their situation. It can't just be a postcode lottery"

(Male, 77)

With regards to **informed choice and consent**, participants recommend:

- The public must have an informed choice about which innovations to use. In promotion of innovations to the public, information must be clearly presented and verified.
- The ability to maintain 'human options' instead of technological alternatives is important to many and should be facilitated.

This leads into the final key priority for implementation, **trust**:

- Products and services must be delivered by trusted sources to ensure uptake.
   Specific examples include NHS sources such as GPs. Sources must be seen to have people's best interest at heart, and not solely profit-driven (although participants feel that making *some* profit is okay).
- Engage with people through common forms of communication such as social media, and TV ads, or public engagement such as open displays of new technology in trusted environments such as hospitals or surgeries. Participants recognise it is important to avoid bad press that would put people off trying innovations.

"If a glossy leaflet or something comes straight through the door, it goes straight in the bin. So all I can think of for reaching out to people here is social media to hear about what is new on the market and in the health system."

(Female, 43)

Other recommendations are more general, or concern **transparency and accountability**, and future development:

- Quickly share and act upon the results of research, and ensure they are benefiting the people they are designed to help.
- Provide transparency such as the publication of statistics regarding innovations' benefits and potential risks. Disclose who will profit as a result of purchasing or using new medicines and technologies.
- Products and medicines should be constantly refined to incorporate user feedback.
   This includes conducting research to continuously understand more about longer-term consequences of products and medicines and resolve issues which weren't predicted.
- Ensure that technological products are subject to rules regarding privacy. This
  includes data protection. Regulations should be kept up to date to allow products and
  medicines to be rolled out without hold ups.

### 4. Participant views on the Nuffield Council on Bioethics' recommendations

#### About this chapter

The main purpose of this dialogue is to understand how well the NCoB's recommendations align with the public's hopes and priorities for what ageing could look like in the future. This section describes the feedback heard from the public after being shown eight emerging recommendations developed by the NCoB.

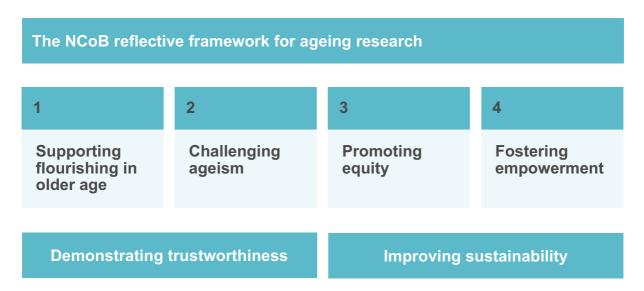
#### 4.1 NCoB's emerging recommendations

Bella Starling, Chair of the NCoB's Future of Ageing working group, joined the third and final online workshop to present the NCoB's recommendations for discussion. Participants were shown eight recommendations in total. To make this information as digestible as possible, recommendations were grouped into categories and presented in batches, with pauses throughout so that participants could provide their initial reactions and ask questions. This was also the first time that the NCoB's reflective framework was introduced to participants.

Section 4.2 discusses what was heard from participants in relation to the eight recommendations, considering for each recommendation:

- How important it is to implement
- How much of an impact it could have for older people
- How easy it would be to implement
- How well it is aligned with participants' own priorities
- How it could be made more ambitious or effective, to achieve better outcomes for older people in future

# 4.2 Participant feedback on the draft recommendations and emerging findings



Simplified diagram of the ethical framework presented to participants

Participants are strongly supportive of the NCoB's reflective framework, with all four principles felt to be important and worth promoting among researchers and technology developers. While promoting equity (or fairness, to use participants' preferred language) was the most consistent priority for participants in earlier stages of the dialogue, the three other principles of challenging ageism, supporting flourishing in later life, and fostering empowerment were also felt to be important. Participants told us that these principles are lacking in the UK today and were pleased to see an organisation like the NCoB taking action to address this gap.

"I think a lot of the ideology is very commendable, certainly supporting flourishing. Ageing is inevitable, and I'm probably the oldest guy here, so for me I won't see it. But I'm hoping that your efforts will produce good results for the older generation that will follow."

(Male, 84)

The NCoB's set of draft recommendations makes participants feel optimistic, enthusiastic, and hopeful about what growing older might look like in the future. Participants can see that the recommendations match up with some of their own priorities, such as increasing the frequency and diversity of older people in conversations about ageing and advocating for more cross-sector and interdisciplinary working to increase efficiency and depth of knowledge. The following tables review each recommendation in turn.

	<ul> <li>Recommendation #1: Role of the national government</li> <li>We recommend involving the public in shaping policy to support current goals set by the government.</li> <li>We recommend creating an intergenerational advisory group (diverse older generations now and into the future) to challenge ageist assumptions that are deeply embedded in our society.</li> </ul>
Overall takeaway:	Increasing government commitment to shaping what ageing will look like in future is seen as a crucial step in setting an example for the private and public sector to follow. However, the recommendation currently doesn't go far enough in outlining what will be needed from government in order to ensure this happens.
Rankings:	High importance, high impact, high difficulty
Participant feedback:	<ul> <li>All participants see the role of government as pivotal in determining the success of the ageing field.</li> <li>However, most participants see the role of government as being more directive and stretching much further than the current</li> </ul>

recommendation does. There is significant doubt about whether the current draft recommendation sets out with enough granularity what will be needed from government to drive progress.

"The researchers do a brilliant job, but the government have got to work harder. I'm not saying fund the research, but the government needs to stand up and help determine how other organisations behave."

(Male, 66)

- All participants want to see real leadership from government with concrete action as without this, they are sceptical that change will happen. For example, in addition to involving the public and creating an intergenerational advisory group, participants want to see government responsible for:
  - The creation of timely legislation that supports goals across the field.
  - Ensuring that appropriate **funding** is available and is released to the suitable groups.
  - Driving forward the implementation of the other NCoB recommendations such as numbers six (flexibility with budgets) and eight (inter-disciplinary working) where the private and public sectors are expected to be reluctant to changing their current processes and styles of working.
- The idea of an intergenerational group is supported since collaboration between older and younger generations is seen as key for developing a future that will benefit those that are older today as well future older people.
- There is concern among a small minority of participants about possible future disruption to progress within the field as new governments come into power, as well as a minority of participants who are concerned that too much government involvement could lead to too much regulation and the slowing of progress within the field.

"The role of the government is crucial. Older people do need to be involved at the outset and I agree that things like policy need to be involved, not just research. I do wonder if they could be doing more."

(Female, 61)

#### Potential builds:

To overcome some of these concerns and to strengthen this recommendation further, participants want to see:

- Measures built into the recommendation to hold government to account. For example, participants want to see:
  - The addition of a **timeline** for the creation of the intergenerational group.
  - A review process built-in so that government are responsible for determining progress against these goals every 'X' number of years.
- Clearer account of the powers of the intergenerational group and more detail on the processes for challenging ageist assumptions. For example, participants want to know if the group will be able to make decisions or set standards for the wider field.
- A small group of participants across the sample want to see the
  government stretching overseas and building relationships in this
  field on an international scale. The main benefits of this are
  avoiding duplication of costly and lengthy research and improving
  the level of understanding in the UK by drawing on a wider set of
  experts from around the world.



### Recommendation #2: Role of the research field (researchers, regulators, ethics committees and funders)

- We recommend that researchers, funders, journals should <u>expect</u> meaningful collaboration with older adults in the studies they fund, review or publish.
- Importantly, public contributors need to reflect the diversity of the population who may be affected by the proposed research.

### Overall takeaway:

While this recommendation is seen to have less reach than others, this does not diminish its' importance. All participants strongly support better and more frequent collaboration with diverse groups of older adults. However, it is hard for participants to imagine the functions and processes for making this work across the academic research field.

#### Rankings:

Low importance, medium impact, low difficulty

### Participant feedback:

 The public has little understanding and experience of the academic research environment. Despite seeing a range of expert speakers and information during the dialogue, participants find it

- very hard to imagine how this ecosystem operates. As a result, **only small parts of this recommendation resonate**.
- However, the parts of this recommendation that do stand out to participants have strong support:
  - Participants across age groups strongly believe that older adults need to be included within studies on a far greater scale and that more studies need to be carried out.
     Older adults are seen as an important group to collaborate with on a consistent and frequent basis to ensure that new technological products and medicines are developed to meet their actual needs.
  - Participants also strongly agree that it is important to
    ensure a diverse range of people are included in studies
    so that better representation results in products and
    medicines that are suited to as wide an audience as
    possible. This needs to include people of different ages.

"40- and 50-year-olds will be 'old' by the time some of this tech comes to the marketplace. For that reason, they should be involved in the process of designing it!"

(Male, 61)

Most participants have not heard of a public contributor before
and find it difficult to understand what this term could mean.
Once the role is explained, many see it as unrealistic for members
of the public to be involved in shaping research processes,
despite taking part in this process. For this reason, the call for
public contributors to be more diverse was not discussed much.

#### Potential builds:

- While participants agree that including older adults in research should be the priority, participants aged 60 and over are also particularly likely to also see an important role for younger generations or "future older people" to be included in developments that may more strongly shape their future given the timescales involved in research and the expectation that some older participants have of being unlikely to see the benefits of the recommendations in their lifetimes.
- Participants also feel this recommendation could be strengthened by stating explicitly that older people will be involved throughout the full course of research studies, reflecting concerns that participation may be sporadic and therefore less influential.



#### Recommendation #3: Including older adults in research

- Collect information about who is included (gender, ethnicity, access to support etc.).
- Working with older adults to design studies in ways that help include older adults in research.

### Overall takeaway:

As with recommendation two, participants across the sample strongly support involving older adults in research. Regarding the information that is collected about those taking part, the public is particularly keen to see greater focus on understanding individuals living with multiple health conditions.

#### Rankings:

High importance, high impact, low difficulty

### Participant feedback:

A consistent theme when looking at the NCoB's
recommendations is how important the public feels it is for the
target audience of a new product or service to be a part of its'
development. For this reason, this recommendation has very
strong buy-in across the full research sample.

"You need to include the people it's targeted at. So, if it's finding a cure for cancer, it's about researching people who have cancer. If it's about older people, then older adults need to be included."

(Female, 60)

- While older adults are seen as one of the most important groups to include in research, participants feel that including older adults in research alongside other relevant stakeholders will help to develop a deeper understanding of different individuals' needs. For example, making processes accessible for GPs to contribute to, as well as third sector organisations who understand hard-to-reach and marginalised groups, scientists that develop the products, and informal carers who may be better equipped to comment on the practical needs of those they care for.
- There is particular support for individuals' medical needs to be understood on a more holistic basis, focussing specifically on individuals who are living with multiple long-term health conditions.

Participants equally highlight the need for building an understanding of what individuals' priorities are when it comes to health. One of our speakers posed the following question to help display the benefits of public contributors – How do the conditions people have affect the way they live their lives? This helped participants see more clearly how involvement of the public can lead to concrete improvements.

"We're not so much looking at age, but at what age does to you. We're an ill-er generation. We get diseases and problems because of old age. It is all about achieving a better life. We need to be talking to people from a medical point-of-view to understand what their main priorities are."

(Male, 70)

 Participants want involvement in research to be intergenerational, particularly where people might already be suffering with conditions they will carry into older age.

#### Potential builds:

- This recommendation raises questions about how old 'older adults' are – participants feel it is important to be clear about this point within the recommendation itself.
- Several participants across the sample also want to know more about when exactly older adults will be included within research processes, e.g. if they will play a role in the full research process or a smaller part of it.
- Several participants also feel this recommendation could be made more realistic by giving an idea of what mechanisms will be used to bring new participants into these processes.



#### Recommendation #4: Support for researchers

• We recommend the **use of the reflective framework**, with prompts and questions to guide individual research teams and funders, ethics committees etc.

# Overall takeaway:

Because few participants are familiar with how individual research teams work, they find it hard to imagine the impact of this recommendation. However, the principles of the reflective framework feel familiar and are supported by participants, particularly those aged

	60 and above. Some of the language within this recommendation is difficult to interpret and it would be helpful to make it more accessible for readers.		
Rankings:	High importance, high impact, medium difficulty		
Participant feedback:	<ul> <li>All of the principles laid out by the reflective framework are strongly supported by participants who describe these as things which are missing for older people living in the UK today.</li> <li>The principle of challenging ageist assumptions prompts</li> </ul>		
	an emotional reaction for many older participants who recognised it as an issue they face. These participants tend to feel oppressed by society's view of older people and their perceived lower capabilities. Many reflect on how long stereotypes about growing older have been around for, and how deeply engrained assumptions about older people are across society. For them, this part of the reflective framework is the most important but also the most difficult to achieve.		
	"I think challenging ageist assumptions, which are deeply embedded in society [is important] – These are what we need to change, but it won't be easy. Years and years of building assumptions, you can't get rid of easily."		
	(Female, 38)		
	<ul> <li>Supporting people to flourish in older age and fostering empowerment amongst this group are principles which are also strongly supported by participants. These concepts feel new and inspiring, and the language used (i.e. flourishing, empowerment) sits in direct contrast with many of the assumptions that older participants feel held down by.</li> </ul>		
	<ul> <li>Promoting equity is a theme which is consistently important to the public, and came up throughout the dialogue. However, participants tend to frame it more in terms of 'fairness', and the other principles of the framework feel more exciting and new.</li> </ul>		
	<ul> <li>Despite overwhelming support for these principles, the 'reflective framework' is hard for the public to relate to as the language, concept and practical application is not easily comprehensible for a layperson. For that reason, they also presume it must be a difficult recommendation to achieve.</li> </ul>		

"What's a 'reflective framework'? I am not sure what they mean by that. It must be important because they've underlined it [on slides]!... This one must be the hardest [to achieve] because we don't know what it means."

(Male, 70)

#### Potential builds:

- Participants want to understand more about both who will be responsible for driving forward implementation of the framework as well as what impact the NCoB hope the framework will have.
- Reflecting on how little participants know about the research process, and how this framework would apply, several participants suggest a need for researchers to do more to understand the public's priorities when it comes to deciding what research to carry out. Several participants believe that researchers frequently focus on issues which are not important to individuals nor address their needs, and that more should be done to get public input.



Recommendation #5: Development of a kitemark or set of standards to indicate technologies that have been ethically developed.

A set of requirements for the kitemark could include:

- ⇒ Has it been tested with diverse audiences?
- ⇒ Is it evidenced based?
- ⇒ Does it do harm?
- ⇒ For whose benefit is the technology aimed at?

# Overall takeaway:

Participants across age groups struggle to understand exactly what a kitemark could achieve, and so tend not to prioritise this relative to other recommendations. They feel it would be helpful to explain how 'ethical development' differs from other standards which are in place e.g. safety standards or optional schemes like fair trade. The NCoB should emphasise aspects that are known to be important to the public, for example the involvement of older people in the development of such products as well as equitable distribution of benefits to end users.

Rankings:	Low importance, low impact, low difficulty		
Participant feedback:	<ul> <li>The development of a kitemark system is well supported in principle. Participants have an appetite for a system which allows them to know which products have been developed ethically and which haven't. However, at the moment, this recommendation doesn't resonate with participants due inaccessible and unfamiliar language.</li> <li>Participants approach the NCoB's potential kitemark system with other product safety standards in mind. For this reason, they find it difficult to know what this specific kitemark system might add.</li> <li>This is particularly the case when considering medical</li> </ul>		
	products. Participants assume these products are already strictly regulated, meaning a kitemark system that designate the ethical development of such products would add little to the perceived integrity of a product.		
	"What do kitemarks mean? How many times do you buy a product that's damaged or needs to be recalled? It doesn't actually mean anything does it? It's supposed to, but does it?"  (Female, 34)		
Potential builds:	The most commonly raised concern about the NCoB's kitemark recommendation is not knowing who would issue the kitemark. Participants feel strongly that an independent body needs to have responsibility for this versus a specific researcher or developer in order to maintain impartiality and the resulting trust.		
	"To me the kitemark system has to be made by an outside body and has to be checked if it's correct, not by anyone who has anything to do with the research."  (Male, 66)		
	(, 55)		



#### Recommendation #6: Flexibility with budgets

 Importance of key players (health, social care, housing, transport etc.) having the flexibility to work together and pool budgets so that they can focus on meeting the needs of older adults.

# Overall takeaway:

Despite some overlap with recommendation eight, participants believe this recommendation has huge potential (if achieved). Participants across age groups strongly support the suggestion to pool budgets and work more collaboratively across sectors as they feel this will ultimately lead to a richer understanding of older people's needs and better outcomes for older generations in the future.

#### Rankings:

Medium importance, medium impact, high difficulty

# Participant feedback:

- To the public, it is critically important that teams from across a range of sectors (e.g. health, social care, transport, housing) are able to help increase researchers' understandings of what ageing is like. However, given the tight budgets that these sectors are known to operate on, any strategy which fosters greater efficiency from either a time or financial perspective is met with great support.
- Participants also have a specific desire to see the reduction of duplication of work, which they suspect is happening in the UK and internationally. The pooling of budgets within this recommendation is pulled out as having substantial potential to ensure working is more joined-up and that processes are more efficient.

"Budgets are tight these days – you have got to get something collaborative between different areas. Don't duplicate work."

(Male, 59)

 Despite the public's strong support for this recommendation overall, it is also met with significant concern about feasibility and organisations' willingness to cooperate with each another. This scepticism is particularly high regarding sectors where profit is a key goal, e.g. housing. Participants across the sample feel leaders in these sectors are less likely to want to split funding and possibly take away from the successes of their own outcomes.

"It will be difficult for health and social care because their budget is so limited. I don't think people pull together nowadays, everyone wants to make sure their own house is in order."

(Female, 71)

#### Potential builds:

• The scepticism from participants about the feasibility of this recommendation means they are particularly interested to know who will be organising and driving forward this new approach. The perceived rigidity of many business processes means the government are seen as a necessary proponent of ensuring flexibility with budgets is possible via legislation, and that teams across sectors do work together.



#### Recommendation #7: Working at the grassroots level

• **Support small community-led projects** that are aimed at helping diverse older adults.

# Overall takeaway:

Participants across age groups strongly support this recommendation, suggesting that local level projects often have better on-the-ground outcomes than larger scale projects. Participants feel that local organisers and smaller-sized projects are better able to understand local people's needs and behaviours, and that local projects will bring about wider benefits for local communities, particularly those like West Yorkshire and Kent which aren't traditionally associated with research.

#### Rankings:

Medium importance, medium impact, low difficulty

# Participant feedback:

 On an issue as complex and varied as ageing, the public want older people to be understood as much as possible. Projects led at a national scale, while impressive, are seen as less able to accommodate the individual needs of specific groups of people. This recommendation is seen to bridge this gap by working at a closer level with local communities, leading to more tailored and effective outcomes for older people overall.

- Participants also feel that this recommendation has potential to have wider positive impacts over and above adding to inclusive research practices. Small community-led projects are thought to:
  - Improve the mental wellbeing of older generations by bringing people together, helping individuals to form new connections and tackling the huge issue of loneliness and isolation.
  - Facilitate intergenerational community-building and help to foster greater understanding between varying age groups.
  - Increase awareness of the wider aim of creating a better future for older people by having community projects happen in visible locations, helping to break down ageist assumptions as a result, e.g. that older people are no longer 'capable' or that older people 'have nothing to offer'.

"I think it's a good idea because here in my small village, once a month, we have tea/coffee mornings funded by the local council. There are 20/30 people that come, and we talk and you're meeting people you would never see, and I think it's a good idea because its informal. It gets you out."

(Female, 71)

 Participants raise some concerns about community-led projects being funded via a postcode lottery, participants want reassurance that projects will be funded equitably across the country.

> "I do get worried that this could be a bit like a postcode lottery. How will they ensure that projects are funded in different areas?"

> > (Female, 73)

#### Potential builds:

Participants want to know what structures will be in place to ensure these projects are carried out meaningfully and purposefully. This hesitation predominantly comes from participants who have taken part in local events that they feel were poorly organised and who want to ensure that these projects will be better run.

- There are also several participants who feel confused about the specific purpose and goal of these projects. The recommendation would therefore benefit from more explicit information about what these small community-led projects are set up to achieve.
- Some participants are already thinking ahead about how these projects will be publicised. They feel that the recommendation could be strengthened even further by detailing the types of methods that will be used to raise awareness of these projects and to ensure local involvement. GP surgeries and social media are seen as the most obvious ways to do this. However, participants across the sample voice their desire to see communication strategies that are well thought-out to reach even the most isolated within communities.



Recommendation #8: Encouraging people from different disciplines to work together (inter-disciplinary working)

Welcoming better collaboration across the research sector.

# Overall takeaway:

While this recommendation in principle is well-liked by the public, it is seen as less of a priority due to its' overlap with recommendation six. Participants tend to see the main benefits as researchers gaining a better understanding of older people, or avoiding overlap, but find it hard to move past their scepticism that individual teams will work together in this way.

#### Rankings:

Low importance, low impact, high difficulty

# Participant feedback:

 Participants across age groups see joined-up working as fundamental to achieving change on a topic as broad as ageing.
 Older people and their needs are extremely diverse, and understanding this diversity requires many different skills.

"You do need to include healthcare partners and social care – they are not working together as well as they could. And also primary and secondary care sectors, as well as companies doing tech and research."

(Female, 61)

 However, participants are concerned that there will be reluctance from researchers to change current ways of working, and the public feels there is a role for government in setting the expectation for disciplines to work more collaboratively together.

> "There is no chance ever of different drug companies working together for the same goals unless they're forced to, which they won't be. No chance of this ever happening."

> > (Male, 61)

#### Potential builds:

Participants feel there will be some benefit to clarifying which
disciplines are being referred to in this recommendation so as to
ensure accountability amongst those sectors to put this
collaborative way of working into practice.

# 5. Conclusions and next steps

## **About this chapter**

This chapter aims to build on the dialogue findings reported in previous chapters, to draw conclusions, and suggest how the NCoB's draft recommendations could be developed further in order to align more closely with what is important to the public.

Over the course of the workshops, we learnt a great deal about what is important to the public when thinking about growing older in future. The previous chapter (Chapter 4) reports directly on the views that were shared by participants themselves when reviewing the NCoB's draft recommendations. In contrast, Chapter 5 reflects on the bigger picture of what we know is important to the public, and where applicable\* the implications this has on further development of the NCoB's draft recommendations.

\*Reflections on recommendations have been included below only where the wider context and feedback from participants suggests the recommendation could be developed further. This means not all eight recommendations are included in this chapter.

## 5.1 Reflections on the NCoB's emerging recommendations

#### 2: Research field (researchers, regulators, ethics committees and funders)

We recommend that researchers, funders, journals should <u>expect</u> meaningful collaboration with older adults in the studies they fund, review or publish.

Importantly, public contributors need to reflect the diversity of the population who may be affected by the proposed research.

Workshop three highlighted how little known and poorly understood the role of the 'public contributor' is to members of the public. Most participants have not heard of a 'public contributor' before and find it difficult to imagine what this role entails from the title alone. Once the role of a public contributor is explained, some are sceptical about how involved a member of the public could be in shaping and designing research processes, despite performing a similar role during the dialogue. To encourage more people to get involved in research (something participants feel is important), it is important to publicise these roles and the value the public can bring to research.

"How would a member of the public ever be able to say how a research process should be designed? That sounds incredibly daunting to me."

(Female, 55)

#### 3: Including older adults in research



Collect information about who is included (gender, ethnicity, access to support etc.).

Working with older adults to design studies in ways that help include older adults in research.

This recommendation asks for more information to be gathered about members of the public getting involved in research processes. Through all stages of this public dialogue, members of the public, particularly those aged 60 and above or those with long-term health conditions, express how poorly they feel individuals living with multiple health conditions are understood. This is based on their own experiences with the health and the social care system, e.g. only being able to discuss one condition per appointment, or the effect of one condition on another rarely being addressed. This is an area where participants feel there is a real gap in professional understanding, and would like to see the NCoB (and research) focus on and fill this gap. In contrast, there is much less discussion of other types of health inequality, for example different health outcomes experienced by people from different backgrounds. This is consistent with other research which shows that health inequalities are poorly understood by the majority of the public, and therefore seen as a low priority<sup>5</sup>. If health inequalities are an important part of the NCoB's recommendations, this will need to be explained carefully to the public.

"I have three different health conditions that all affect me in different ways, but no one has ever asked me which one has the greatest impact on how I live my life. Those are the types of questions I think people carrying out research should be asking."

(Female, 43)



#### 4: Support for researchers

We recommend the use of the reflective framework, with prompts and questions to guide individual research teams – and also funders, ethics committees etc.

Despite overwhelming support for the principles of the 'reflective framework', members of the public find it difficult to relate to the language used. Participants find it difficult to understand and think accessible and familiar language should be used to make the framework easier to engage with, for example referring to it as a set of 'Guiding principles'.

The term 'ethical', and associated concepts like the 'ethics committee' referenced in this recommendation resonate strongly with the public. It is important to them that individual researchers and organisations (particularly private companies) act ethically, even if they aren't always sure what this would involve beyond general principles like fairness or equality.

<sup>&</sup>lt;sup>5</sup>The Health Foundation (2022) *Building public understanding of health inequalities*, available at: https://www.health.org.uk/sites/default.files/pdf/2022-03/2022%20-

<sup>%20</sup>Communicating%20health%20inequalities.pdf.

It may therefore be useful for the NCoB to draw on this language to make recommendations easier to understand, for example within the 'ethical' kitemark recommendation.

"I think the fact that it says the word ethical is a good thing. It's good that ethics committees are included in this."

(Female, 38)

Participants strongly support the principles of challenging ageist assumptions, encouraging flourishing in older age and fostering empowerment for older generations. They also frequently reflect that to make these types of widespread societal changes, many different segments of society need to be on board. It may therefore be worth considering how the NCoB can encourage adoption of this framework among a much wider audience including government, private and public sector, as well as individuals.

"This needs to apply to everyone, not just researchers. We're not going to change the way people think about us just through research processes, we need as many people on board as possible to make this happen."

(Male, 70)

# 5: Development of a kitemark or set of standards to indicate technologies that have been ethically developed.

A set of requirements for the kitemark could include:



Has it been tested with diverse audiences?

Is it evidenced based?

Does it do harm?

For whose benefit is the technology aimed at?

From the second workshop, we know there are a set of factors which are particularly important to the public when considering how products should be developed and rolled out to consumers. For example:

- Collaborating with older adults to develop new products
- Ensuring that products are available widely and fairly to those who need them most
- Communicating clearly and in a timely manner about the availability and potential side effects of products
- Having extensive trial processes in place (particularly for new medical products)

In order to strengthen buy-in amongst the public for this recommendation, the NCoB may want to consider aligning the requirements for the kitemark more closely with these aspects. This may also help to dispel doubt about the value of the kitemark by more explicitly distinguishing it as an 'ethical kitemark' versus a set of product safety standards.

"But how is this different to the current standards that are out there? I don't understand what value is being added."

(Male, 68)



#### 6: Flexibility with budgets

Importance of key players (health, social care, housing, transport etc.) having the flexibility to work together and pool budgets so that they can focus on meeting the needs of older adults.

The public show strong support for this recommendation but are concerned that it will be too difficult to achieve. Recommendations which call for significant changes to ways of working are felt to be particularly difficult to implement and to enforce, especially when they involve funding. As a result, it may be worth considering whether government has a role to play in delivering on this recommendation. While the creation of legislation may feel like a step too far, participants tend to see a role for government in setting the tone and encouraging researchers and organisations to change their thinking, as in recommendation one.

"How are they going to make this happen in reality? Especially when money is involved. I just don't see how it will work."

(Female, 60)



# 8: Encouraging people from different disciplines to work together (inter-disciplinary working)

Welcoming better collaboration across the research sector

While this recommendation does not call for financial flexibility (as in recommendation six), encouraging interdisciplinary working may face pushback from those that are not used to working in this way. Again, from participants' perspective it may be worth considering whether government can play a role in helping to facilitate collaboration and emphasise the benefits of working in this way.

"People are so rigid in how they work. They don't want to share anything so I don't see how to convince people to start collaborating together."

(Male, 66)

#### 5.2 Possible additional recommendations

While most of the principles that participants told us were important to them are already reflected in the draft recommendations, there are a small number of areas where participants' hopes for the future require further action. These areas are described here, as prompts for reflection on how the NCoB could influence the wider world of ageing.

#### 1. Ageing well for everyone: accessibility of new developments

Fairness, equality, equity and cost of new developments were all frequently mentioned priorities for participants throughout the public dialogue process, as part of a wider concern that developments that improve the experience of ageing might not be available to everyone. Participants see access to medical treatment, assistive devices and other developments that could improve the experience of ageing as something that should be accessible universally, in the same way that healthcare is available via the NHS. While they can see how the emerging recommendations could help make the process of research and development more equitable, they think it is just as important that the distribution of the benefits is equitable. This feels particularly important in the context of the rising cost of living, and the increasing number of older people in the UK.

#### Consideration for the NCoB

What can be done to help align industry and researchers with the public's view that measures to improve the experience of ageing are universally available in the same way that healthcare is? What measures can be put in place to ensure new developments benefit everyone across the UK and beyond?

#### 2. Changing the UK's perception of ageing

We repeatedly heard participants call out the importance of breaking down barriers between older and younger generations. Older participants describe the substantial negative impact of ageism on their mental (and to a lesser extent physical) health, and the perceptions they feel younger people hold about them. Many older participants feel that society sees them as no longer of use, difficult to relate to and vulnerable. This contrasts with their perceptions of themselves as an integral part of society, with valuable views and perspectives informed by their own life experiences. However, younger participants within this dialogue often have a different perspective and feel that they and their peers look up to and have respect for those in older generations. They describe seeing older people as a valued and knowledgeable group with much to offer. While this does not take away from the ageism that many older participants experience, it does suggest there may be a disconnect between the beliefs held by older and younger people about what it means to grow older.

#### Consideration for NCoB

In the view of many dialogue participants, there is a clear need for society's treatment of older generations in the UK to change for the better. In order to help reduce stigma about ageing, the NCoB could consider how to help raise awareness of this issue, and offer solutions. The principles of the NCoB's reflective framework are strong and impactful and the specific language used stands out to participants. Could these principles be shared widely to help other organisations across the public and private sectors to rethink communications and marketing strategies, or to challenge individuals to consider their own views? Could the NCoB advocate for opportunities to bring generations together and encourage the building of intergenerational friendships and connections?

#### 3. Maintaining social connection as technology evolves

Participants frequently tell us they feel technology is developing at a rapid pace, and many across age groups (but particularly older generations) share a mix of concern and optimism about the wider implications of these developments. In the context of 'ageing well', participants can see how some technological advances like communications networks are helping to bring people together, but are concerned that assistive devices may lead to greater social isolation if they replace human interactions. Isolation among older generations is a concern, and for many older participants it is something which is seen to be as debilitating as physical health conditions. While participants agree that maintaining independence, mobility and dignity are all incredibly important to older adults, so is maintaining social connections and mental wellbeing.

#### Consideration for the NCoB

Balancing the hopes and concerns of participants could mean advocating for the use of technology which *assists* with tasks that older people struggle with, rather than technology which replaces individuals and carries out tasks *for* them. This may help to preserve older adults' sense of independence until a task becomes unfeasible. More broadly, participants want to see greater focus from public services, the third-sector and community organisations on providing opportunities for older people to come together. They see this as an important safeguard against further rises in social isolation and poor mental health among older people as technology evolves, and think it's particularly important to support those who are most at risk of isolation and who are less likely to ask for help (e.g. older men and ethnic minority communities). How can your recommendations contribute to these wider goals?

#### 4. Protecting decision-making into older age

Participants with experience in either using assistive technology or in being helped by family members to learn about new devices, frequently mention a tension between respecting older people's autonomy and ensuring their safety. Participants who have experience using devices in particular spoke about the damaging effect on their sense of self when those

around them insist that devices are incorporated into their lives without their agreement or consent. While this is a sensitive topic to approach, there are ethical implications when older people's choices are not respected or listened to.

#### Consideration for the NCoB

Participants want everyone involved in technology development and deployment to better understand the needs of older people to make their own decisions, leading to happier and more dignified ageing. This includes adult children that support their parents as they age and formal or informal carers who support older people to adopt new technology. The NCoB is primarily concerned with the research and development of technology, but could it also consider how the same principles of empowerment and respect for older people's autonomy could be spread more widely?

## 6. Our conclusions

Reflecting on the discussions participants had across the whole dialogue, we have drawn out six themes describing what is most important to participants when considering the future of ageing. They show where participants see potential for research and innovation to support living well in older age, as well as concerns about how these processes may work.

- 1. A holistic approach to living well in older age. Participants tell us that physical and mental health, financial freedom, a support system, and social interactions are all important to living well as they age. These values are closely connected: it's difficult to enjoy one without the others. Researchers should use the same broad definition of 'living well' and take a holistic view of what living well in older age looks like, beyond solely living healthier for longer in later life.
- 2. Feeling listened to. Participants are overwhelmingly supportive of recommendations for including older people in research. Older participants reflect on societal expectations holding them back and are eager for outlets to share their views and experiences and be listened to. Participants are looking for older people to be involved in research processes broadly, not just for products specifically aimed at older people, but for innovations that anyone might use.
- 3. Working together across generations. While participants think it's important to involve older people in research processes, such as in the design and testing phases of new products, they want to see involvement of a wide spectrum of age groups, including younger adults. They see intergenerational interaction as an opportunity for all age groups to share knowledge and learn from each other, as well as for researchers to learn from a wide range of age groups. This diversity of perspective is seen as strengthening the research process and ensuring the views of older adults, as well as future older adults, are considered. Opportunities for intergenerational interaction are seen as key to changing attitudes towards older people and challenging ageist assumptions.
- 4. Supporting independence in later life. Participants are looking to research and innovation to support older people to live independently for longer. This might mean staying in good health and so being able to live without additional care, new technology that supports people to continue to do daily tasks for longer, or potential treatments that may help manage pain from chronic conditions. Participants are enthusiastic about all developments that might help older adults stay independent for longer, which in turn may contribute to maintaining their dignity as they grow older.
- 5. Making your own decisions. Independence also extends to being able to make informed decisions about whether to use new products, technologies, medicines, or other developments. Participants are wary of products that might threaten their privacy or feel like surveillance. While this is primarily felt to be a risk with new technologies, participants are also looking for education about advancements in medicine to enable them to make informed decisions about new treatments.
- **6. Equitable access and fair distribution.** A key concern throughout the public dialogue was about cost and equitable access to new treatments and products.

Participants often assume that developments in geroscience and new assistive technologies will be very expensive and contribute to greater inequalities. Fairness in the distribution of outputs will be key to building trust and support in the research process.

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- **Ann Gallagher**, Head of Nursing & Professor of Care Education, Ethics and Research, University of Exeter
- Peter Gore, Professor of Practice (Ageing & Vitality), Newcastle University
- Molly Gray, Research Officer, Nuffield Council on Bioethics
- Danielle Hamm, Director, Nuffield Council on Bioethics
- Christine Hine, Professor of Sociology and Chair of the University Ethics Committee 2015 2018, University of Surrey
- **Janet Lord**, Professor of Immune Cell Biology; Director of the MRC Versus Arthritis Centre of Musculoskeletal Ageing Research, Birmingham University
- **Bella Starling**, Wellcome Trust Engagement Fellow; Director of Vocal, Manchester University NHS Foundation Trust
- Sarah Walker-Robson, Senior Communications Manager, Nuffield Council on Bioethics
- Katharine Wright, Assistant Director, Nuffield Council on Bioethics

The views, opinions and recommendations expressed in this report are those of the authors and do not necessarily reflect the position of the Nuffield Council on Bioethics.

# Appendix 1 – Methodology

The dialogue took place in June 2022 with a total of 24 participants. BritainThinks worked in collaboration with two specialist recruiters based in the regions of research (West Yorkshire and Kent), using quotas to ensure dialogue participants broadly reflected the demographics of the UK population. Quotas were applied for age, ethnicity, gender, disabilities and socioeconomic group, location type (urban, suburban, rural) and living situation. Quotas were also applied for those with low, moderate and high health needs. To sample health needs, we provided participants with a list of 17 different health needs and allocated each to a need level, based on an aggregate of their responses across need levels. The needs were as follows:

Need level	Statement		
	Do you find it difficult to get around your house?		
	Do you have help with getting ready in the morning/your personal care?		
	Do you have someone who helps you prepare meals every day?		
High	Do you need someone to come along to help when you go out to do your shopping or run errands?		
	Do you struggle to grip, lift and/or move small objects, like mugs, toothpaste or the TV remote		
	Do you sometimes forget events or appointments, even if you have written them down?		
	Do you find it difficult to use stairs?		
Do you find it difficult to cook a meal from scratch?			
	Do you rely on lists and reminders to keep track of things you might forget?		
Moderate	Do you find that you can still get by on you own, but that some day-to-day tasks take a little longer than they used to?		
	Do you find that you get tired during the day?		
	Do you ever have a friend or family member come over once in a while to help you with big tasks like fixing things around the house, cleaning or managing the garden?		
	Do you struggle to lift large objects like a heavy suitcase, footstool or chairs?		
	Do you find you have good energy levels and are very active?		
Low	Do you exercise regularly? (e.g. tennis, cycling, hiking – or light exercise including swimming, golf, bowls, etc.)		
	Do you find that you do have some health problems but for the most part these do not have a big impact on your day-to-day life?		
	Do you feel more forgetful than you have in the past?		

Additionally, a mix of attitudes towards health and wellbeing technology<sup>4</sup>, as well as a mix of adoption of health and wellbeing technology<sup>5</sup> were recruited.

The sample was boosted to include people from a range of ethnic minority backgrounds to ensure voices that may be less frequently heard were well represented in the dialogue. Those

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<sup>&</sup>lt;sup>4</sup> Participants were provided with a definition of health and wellbeing technology as well as several examples. All participants were then screened on their openness towards health and wellbeing technology. Participants were asked to rank their openness on a scale where 1 is very cautious and 5 is very open.

<sup>&</sup>lt;sup>5</sup> Participants were provided with a list of various examples of health and wellbeing technologies and screened as to whether they personally use any health and wellbeing technologies. Those that answered 'yes' were be asked to list out any health and wellbeing technologies used, with those that use 2 or more health and wellbeing technologies being screened into the 'yes' quota and those that use 1 or less screened into the 'no' quota.

that took part in qualitative research in the previous twelve months were excluded. Participants were given a bank transfer or shopping voucher (according to preference) as a 'thank you' for the time committed. This is standard in public dialogues and means people are not excluded from taking part because of their financial circumstances. A detailed breakdown of the sample can be found below.

Table: Sample

Gender		Age	
Male	12	30 - 45	5
Female	12	46 – 60	5
Social Grade <sup>6</sup>		61 - 70	7
ABC1	12	70 +	7
C2DE	12	Openness to health and wellbeing techn	nology
Disability		Open	9
Yes	10	Neither open nor cautious	7
No	14	Cautious	8
Living Situation		Adoption of health and wellbeing technology	
Married/Partner (w/ children)	8	None	4
Married/Partner (w/o children)	5	One	11
Empty nester	5	Two or more	9
Alone	6	Ethnicity	
Location		White British	17
Rural	7	Black Caribbean	4
Rural Suburban	7 9	Black Caribbean South Asian	2

<sup>-</sup>

<sup>&</sup>lt;sup>6</sup> The NRS social grades are a system of demographic classification used in the United Kingdom. They were originally developed by the National Readership Survey (NRS) to classify readers but are now used by many other organisations for wider applications and have become a standard for market research. This definition is now maintained by the Market Research Society.

## **Analysis and reporting**

All three dialogue workshops generated a large volume of data. During the in-person workshop, the team recorded each session and took detailed notes, as well as analysing any notes or other data produced by each participant. In workshops two and three, facilitators captured visible notes on Microsoft PowerPoint templates and both sessions were recorded and transcribed for further analysis.

BritainThinks analysis approach develops themes from what we heard rather than having a preconceived hypothesis to test. Throughout the process, the research team maintained a rigorous approach and held frequent sense-checking sessions to mitigate against researcher considerations (i.e. echo chambers and bias). As public dialogues are a qualitative methodology, findings do not demonstrate statistically representative analysis. Instead, this research attempts to capture the subtleties and nuances of participants' priorities, concerns, and considerations around ageing and the part that science and technology can play in this.

## **Process summary**

This public dialogue was designed through a series of collaborative 'design sprints', which involved a co-creative process between the BritainThinks research team and the NCoB to refine the dialogue questions and tailor the methodology. Information from these design sprints were captured on 'Miro Boards', which also allowed for collaborative and iterative working.

Once the design of the dialogue was completed, it was made up of three key sessions:

Workshop	Agenda	
Session 1:	Arriving and settling in	
An in-person workshop, lasting three hours, at a location in their local area that immersed participants in three different ageing scenarios set in 2050	Welcome and introductions	
	<b>Expectations and experiences of ageing</b> : Encouraged by facilitators to reflect on what living well might look like, participants worked together at tables to play games and build creative representations of their perceptions, experiences and expectations of ageing.	
	Scenario immersion: Participants visited three different areas of the room which were set up as immersive spaces each tailored to one of the three scenarios around ageing; science helps people to live healthier lived for longer; people live the same length of time but to a better standard due to technology; people live to the same length of time but are more valued by society. Each area used props and multimedia displays to immerse participants, as well as receiving a guided exploration led by the facilitator.	
	<b>Bringing it all together</b> : Participants returned to their tables and shared their reflections on the scenarios. Key challenges were introduced to consider for the next session.	

#### Session 2:

An online workshop, hosted on Zoom, that involved participants discussing their priorities and concerns with research processes.

#### Logging on and checking in

#### Welcome back and reflections on session one

**Introducing challenges and opportunities**: A member of the NCoB team provided an overview of the challenges and opportunities the inquiry has established, helping participants orient the discussion and the goal of the workshops.

**Exploring considerations of ageing in the future, delivered by specialists**: Specialist speakers spoke for approximately 15 minutes about their specific area. After each discussion, a break-out group was held for spontaneous reactions to what had been presented.

#### Expert speakers:

- Professor Janet Lord from the University of Birmingham
   (Research and development in the medical field) gave
   participants an introduction to the research process of
   geroscience. This covered topics such as how which issues to
   address with research are decided, how hypotheses are
   developed, how research is conducted, and how drugs go
   through different stages of trials.
- Professor Christine Hine from the University of Surrey
   (Research and development within the technological field)
   gave an introduction to the process of developing assistive
   technology. This covered topics such as what assistive
   technologies are and could be in the future, how ethical and
   legal frameworks influence the research process, which
   bodies are involved in this process, and how the public and
   patients are involved in the process.
- Professor Lynne Corner from VOICE (an international organisation established to harness the experience, skills, and insights of the public to facilitate cross-generational dialogue on healthy ageing) gave an overview of experiences involving older people and public contributors on the topic of ageing. This covered topics such as the difference between public engagement, involvement, and participation, how this is systematised, and how to ensure public involvement in research is meaningful and that tokenism isn't embedded.

Participant generated recommendations: Participants were given a series of situations that researchers, technology developers, funders and other actors who the NCoB seek to influence would need to make. Participants gave their priorities and concerns at each stage of the research process, i.e. the input phase, the process phase and the output phase.

#### Session 3:

final online that workshop presented participants with the recommendations from the the NCoB 'Future of Ageing' inquiry, to garner spontaneous reactions as well as discuss how to improve/augment each recommendation.

#### Logging on and checking in

#### Welcome back and reflections on session two

**Introducing the NCoB recommendations**: A member of the NCoB team provided an overview of the recommendations from the 'Future of Ageing' inquiry with time allotted for Q&A from participants.

Stress testing the NCoB recommendations: This involved an open discussion of the recommendations, with facilitators looking out for immediate areas of support/disagreement. Participants were then encouraged to stress test the recommendations by ranking the recommendations, discussing trade-offs and decision points from the earlier sessions.

**Reflecting on the recommendations**: Participants worked collaboratively to iterate the recommendations; prioritising based on how well they performed in the stress test.

## Research materials (overview)

Workshop	Stimulus	Description
Session One: (Inperson)	Games	'How old is old?' – Exploring societal norms around 'old age'  'How old are you?' – Comparing biological and
		chronological age
		'How fast do we age?' - Thinking about the subjectivity of ageing
		<b>'When were you born?'</b> – Exploring life expectancy and life span
		'Will you wear purple?' – Considering what different people value in later life
	Scenario One Longer, healthie lives	9
	Scenario Two Better living through technology	37

	Scenario Three: Better living through change in society	A 2050 where society thinks about older people differently, with a greater focus on their valuable contribution and improved circumstances for many, including living healthier for longer in later life.
Session Two: (Online)	Speaker	Professor Janet Lord shared insight into how the research process currently works in the geroscience field.
	Speaker	Professor Christine Hine shared insight into how the research process currently works for the assistive technology field.
	Speaker	Professor Lynne Corner shared insight on her experience as a non-academic/researcher being involved in research on the topic of ageing.
Session Three: (Online)	List of draft recommendations from the NCoB's Future of Ageing	A list of eight emerging recommendations and the reflective framework put forward by the NCoB for discussion with participants.
	inquiry	Participants discuss each recommendation considering its importance, difficulty and impact, how well it aligns with their own priorities and how it could be made more ambitious.

# Research materials (selected)

## How old is old?

# Game 1

- 1. What age do <u>you</u> think represents the beginning of 'old age'? Write it on your post-it note!
- 2. Add your post-it to the chart!
- 3. What do you think about other people's responses?
- 4. What key events and milestones are related to these ages?



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## How old is old?

Game 1



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- Insight & Strategy -

# How fast do we age? Game 2 Very fast Ouite fast Outlot slowly Very slowly

# Will you wear purple?

## Game 3

- Use post-it notes to write down 3 things you value in later life for yourself.
- What do you think about each others ideas?
- What might help you to live a healthy life in older age?
- What might hinder you from living a healthy life in older age?



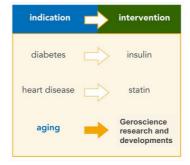
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#### Scenario stimulus (selected)

#### What is geroscience?



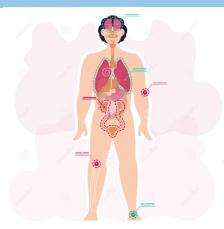
As we grow older, the biological processes of ageing put us at risk for conditions that are often associated with older age.



Geroscience aims to treat multiple conditions associated with ageing at once, with the goal of improving health in later life.

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#### **Effects of ageing**



Participants invited to place post it notes on the (large format) diagram of where they think the most significant impacts of ageing are on the body and what they think this impact is.

Pre-prepared post-its highlight some of the mechanisms:

Wear and tear: not every element of our body regenerates, some get worn out, like our joints or

ot every body that as we age our DNA accumulates more errors, effectively giving faulty instructions for new cells

ts: some e down to be sex: some effects of ageing

Cumulative effects: some effects of ageing are down to things that damage our bodies all the time, like sunlight or pollution, building up over time Differences by gender and sex: some effects of ageing may be different depending on your sex, what might these differences be?

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#### Case study: Isaac

#### This is Isaac.

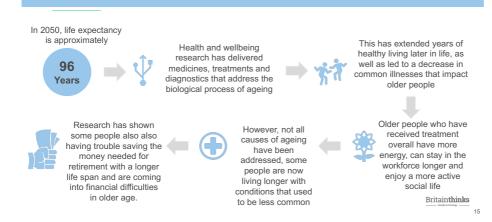
Isaac is a computer programmer for a local engineering company. Isaac loves his job and is hoping to keep working for at least 5 more years. At age 68, Isaac feels fit and healthy.

Isaac has always taken his health seriously, eaten a healthy diet and worked out. In his 40's he signed up for a new health service called 'Precision Nutrition'. He had a series of tests to determine exactly which of the effects of ageing he was most susceptible to. Isaac was then prescribed a specific diet: he only eats between 10am and 6pm every day, takes several nutritional supplements and has a list of foods to avoid – no caffeine for example. He also eats about 20% less than he used to.

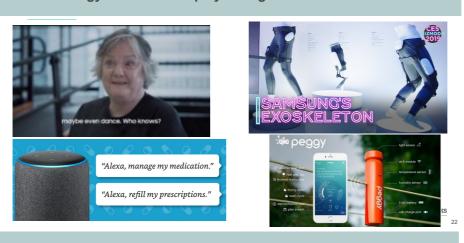
It wasn't cheap to have the tests done, and the diet can sometimes feel restrictive. But Precision Nutrition estimates that Isaac will live up to 15 years longer than he would have otherwise – plenty of time to finish that big project at work and still enjoy retirement.



#### What's changed?



### Technology adverts to display in large format



#### Assistive technologies in action

It's 2050 and although people aren't living longer, technology research has delivered devices and services that improve the lives of older people and contribute to healthy ageing, allowing for greater independence, mobility and access.

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#### IMPACT: Script for facilitator to read out (2 mins)

With assistive technology (AT), the lives of older people can be impacted in a number of ways, for example, with:

Transport: AT can help older people get from 'A' to 'B', such as a self-driving car. A self-driving car can help do long parts of a journey, such as driving on a motorway, and can help people who would normally struggle to drive, particularly for long periods of time, to reduce the burden. Self-driving vehicles can also help with public transport – providing safe, frequent and inexpensive community transport options for older people in their local area.

- Work: AT can provide:
  Screen magnification for well-defined focus,
  Text-to-Speech for audible reading,
  Complete screen reading identifies more than just text,
  Technical support from assistive technology experts
  All these AT could help older people remain in work for longer enabling greater independence and greater inclusion for older adults

Leisure: With leisure, AT is able to support older people via sports assistive technology, musical instrument playing assistance, television and radio, travel assistance and education technology

- Care: AT can:
  Provide care and support around the home, such as robots that help people rise from bed and get dressed
  Help combat loneliness by helping older people stay in touch with friends and family through tablets and smartphones that can enable video calls and have the option to have texts and emails read aloud to the user.
- Provide live health updates and information to allow people to self-monitor, or to share the information with close family members or carers

#### Safety and technologies in the home: AT can:

- Safety and technologies in the home: AT can:
  Implement automatic lights:
  Automate shut-off devices if the gas/cooker/taps has been left on;
  Fit special plugs that allow people to choose a certain level of water in the sink/bath
  Implement fall sensors in case a person has fallen over
  Telephone blockers to prevent nuisance/scam calls
  Schedule reminders

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#### What's changed?

In 2050, life expectancy Is approximately



Health and wellbeing technology research has delivered devices and services that improve health later in life



As a result, older people are increasingly independent and remain in their own homes for longer





Some older people who cannot afford human care have been forced to use assistive technology instead



However, the technology can be costly and not all older people are able to afford this, leaving potential for greater inequalities



Whilst not living longer than today, older people overall are experiencing an increase in their health and wellbeing later in life as a result of using new technologies Britainthinks

#### A society of valued older people in action

It's 2050 and the way society thinks about older people has changed, leading to a greater focus on their valuable contribution and improved circumstances for many, including living healthier for longer in later life.

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#### The road to change: Employment

In 2050, the Government releases a series of bursaries for business to hire people over the age of 59 who are either part-time employed, or unemployed, as well as keep people over the age of 59 in the workplace. Alongside incentives to hire and retain older employees, companies receive grants to make their workplaces inter-generationally friendly and provide resources and support for older employees. This is accompanied by a UK-wide ad campaign highlighting the value of older people in both the workplace and society.

Businesses report excellent results from this hiring policy, which leads to an upturn in employment opportunities for older people. Language and attitudes around older people begin to change in the workplace and the built environments of workplaces begin to be constructed to be more accessible to accommodate the older workforce

Another benefit of this policy is a reduction in the incidence of common conditions like dementia and arthritis as more older people are staying physically and mentally active for longer.



#### **Sprytely**

#### Welcome to Sprytely!

We're a hospitality consultancy company that specialises in helping new bars, cafes, restaurants, breweries, wineries and hotels grow and develop. Our core values as an employer are:

- Integrity making sure that always have the highest ethical standards
- Collaboration making sure we always work together as a team
- Opportunity making sure everyone has the same opportunity to grow

We make sure we always hire the best people for the job, regardless of any other circumstances. We value lived experience just as much as energy and ambition.

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#### Job Title: Client relations

Job Description: Look to find new clients in the world of hospitality to help Sprytely grow, as well as nurturing and maintaining relationships with current clients.

<u>About Us</u>: We're a hospitality consultancy company that specialises in helping new business flourish. Rated a top 100 employer two years in a row, we hire the best people from all backgrounds. We pride ourselves on helping you develop no matter where you are on your career path.

<u>About the Role</u>: You will use your lived-experience and know-how to build client loyalty, and bring in prospective clients Among the responsibilities of the role are:

- Opportunity Development: You will help manage the client relationship based upon new project direction at their location,
- Portfolio Expansion: For existing clients, you will liaise with our marketing team to give them the best package possible
- Maintenance Renewals: In a timely manner, you will collaborate with other team members to manage renewals.

About You: The ideal candidate will have the following skills and experience:

- 5-6 years in any field that is client facing
- Experience in creating solutions for any kind of problem
- Understanding of the needs of people and new businesses
- Strong written and verbal communication skills

If you are ready to become part of our family, apply here!



## Improving society's views on older people in action

It's 2050 at Sprytely, a medium-sized business in London. Let's meet one of the new joiners



#### This is Irene, aged 72

Eight years ago, Irene began to wind down her working hours as she felt that younger people at her company were receiving more of a voice and more opportunities. However, Irene noticed that the language and expressions used for older people began to change. She began to receive more invitations to interview for new jobs before recently taking her current role at Sprytely. Irene feels valued and happy that many co-workers are the same age as her, as well as enjoys intergenerational friendships with colleagues. She also feels there are opportunities to progress at Sprytely, and plans to reach her goal of a promotion in the next 2 – 3 years.

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# Appendix 2 – Participant feedback on taking part in the public dialogue

After the completion of the three workshops, we asked participants for feedback on how they found taking part in each of the workshops. 16 of the 24 participants provided feedback through a series of closed and open-ended questions.

Participant responses to closed feedback questions are below:

Workshop 1	
Please tell us how satisfied you were with the <b>format</b> of workshop 1?	<ul> <li>Very satisfied: 7</li> <li>Somewhat satisfied: 6</li> <li>Neither satisfied nor dissatisfied: 1</li> <li>Somewhat dissatisfied: 0</li> <li>Very dissatisfied: 2</li> </ul>
Please tell us how satisfied you were with the <b>content</b> of workshop 1?	<ul> <li>Very satisfied: 8</li> <li>Somewhat satisfied: 6</li> <li>Neither satisfied nor dissatisfied: 0</li> <li>Somewhat dissatisfied: 0</li> <li>Very dissatisfied: 2</li> </ul>
Please tell us how far you agree or disagree that your understanding of the topics we discussed increased as a result of workshop 1?	<ul> <li>Strongly agree: 8</li> <li>Somewhat agree: 6</li> <li>Neither agree nor disagree: 2</li> <li>Somewhat disagree: 0</li> <li>Strongly disagree: 0</li> </ul>
Workshop 2	
Please tell us how satisfied you were with the <b>format</b> of workshop 2?	<ul> <li>Very satisfied: 6</li> <li>Somewhat satisfied: 7</li> <li>Neither satisfied nor dissatisfied: 3</li> <li>Somewhat dissatisfied: 0</li> <li>Very dissatisfied: 0</li> </ul>
Please tell us how satisfied you were with the <b>content</b> of workshop 2?	<ul> <li>Very satisfied: 7</li> <li>Somewhat satisfied: 4</li> <li>Neither satisfied nor dissatisfied: 5</li> <li>Somewhat dissatisfied: 0</li> <li>Very dissatisfied: 0</li> </ul>
Please tell us how far you agree or disagree that your understanding of the topics we	<ul><li>Strongly agree: 5</li><li>Somewhat agree: 8</li><li>Neither agree nor disagree: 2</li></ul>

discussed increased as a result of workshop 2?	<ul><li>Somewhat disagree: 1</li><li>Strongly disagree: 0</li></ul>
Workshop 3	
Please tell us how satisfied you were with the <b>format</b> of workshop 3?	<ul> <li>Very satisfied: 2</li> <li>Somewhat satisfied: 11</li> <li>Neither satisfied nor dissatisfied: 1</li> <li>Somewhat dissatisfied: 2</li> <li>Very dissatisfied: 0</li> </ul>
Please tell us how satisfied you were with the <b>content</b> of workshop 3?	<ul> <li>Very satisfied: 2</li> <li>Somewhat satisfied: 10</li> <li>Neither satisfied nor dissatisfied: 2</li> <li>Somewhat dissatisfied: 2</li> <li>Very dissatisfied: 0</li> </ul>
Please tell us how far you agree or disagree that your understanding of the topics we discussed increased as a result of workshop 3?	<ul> <li>Strongly agree: 4</li> <li>Somewhat agree: 8</li> <li>Neither agree nor disagree: 2</li> <li>Somewhat disagree: 1</li> <li>Strongly disagree: 1</li> </ul>

Participants also gave the following feedback when asked to reflect on their experience of taking part in the workshops:

"There was a great mix of people, which for me, made it an enjoyable experience, led by your lovely team members."

"This was interesting, listening and reacting to what the speakers were talking about and working on."

"I can't speak for the others, but our breakout group was very engaged, and we didn't have a lot of pauses in communication. Everyone put across their views, and any differing views were delivered in a respectful way."

"Thought the subject was interesting especially as I am in the age group. I will be interested on where this goes from here, and hats off to yourselves; it is not easy to manage 30 people on online calls..."