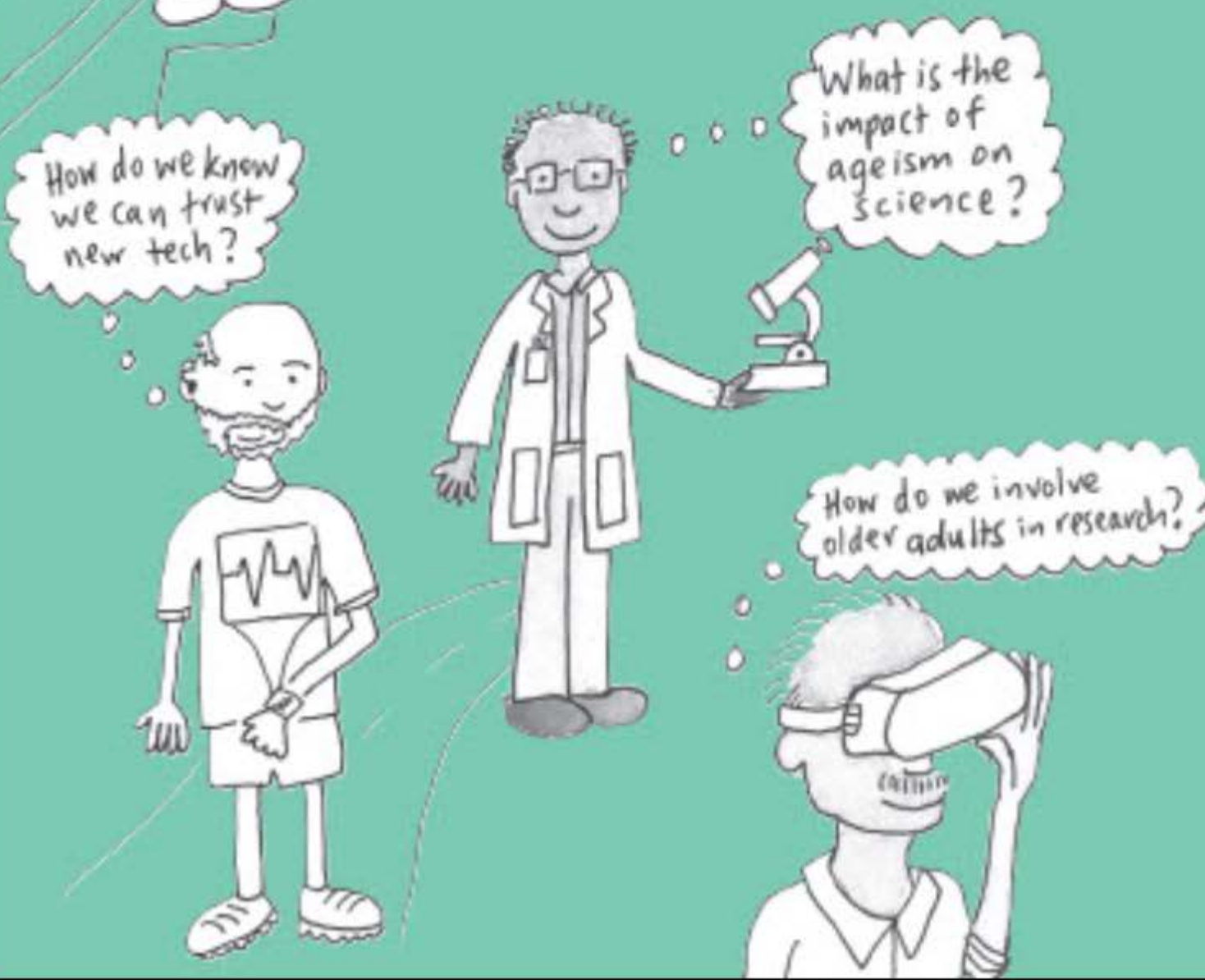




The future of ageing: ethical considerations for research and innovation

NUFFIELD
COUNCIL ON
BIOETHICS



The future of ageing: ethical considerations for research and innovation

Nuffield Council on Bioethics

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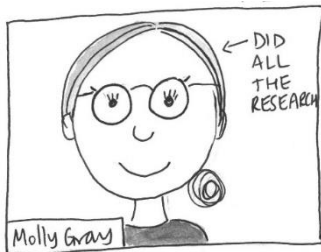
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Drawings by Muna Al-Jawad

The Nuffield Council's terms of reference:

- To identify and define ethical questions raised by recent developments in biological and medical research that concern, or are likely to concern, the public interest;
- To make arrangements for the independent examination of such questions with appropriate involvement of relevant stakeholders;
- To inform and engage in policy and media debates about those ethical questions and provide informed comment on emerging issues related to or derived from NCOB's published or ongoing work; and
- To make policy recommendations to Government or other relevant bodies and to disseminate its work through published reports, briefings and other appropriate outputs.

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Acknowledgments

The working group wishes to express thanks, in particular to the organisations and individuals who responded to our initial call for evidence and survey and to the experts who attended our roundtable meetings. These are listed in the Appendices to the report. Thanks are also due to the members of the Technology and Ageing Special Interest Group at the British Society of Gerontology for inviting us to join one of their meetings and sharing their insight and expertise. This inquiry has also benefitted from those who have generously offered their expert advice and knowledge, and patiently answered our questions and provided information (listed in Appendix 1).

The working group owes a special gratitude to all the participants who took part in the creative workshops and the wider public dialogue. The public dialogue was organised on our behalf by BritainThinks. A report of the workshops has been published separately. The participant contributions, both to our own recommendations and to the wider topic of ageing, provide a rich and continuing source of insight. We wish to express a special thank you to the individuals and teams at different organisations who helped organise and facilitate the engagement workshops including: Melanie Chapman (Manchester Metropolitan University), Monwara Begum (Manchester Metropolitan University), Bethany Jay (Manchester Metropolitan University), Arne Müller (Manchester Metropolitan University), Sarah Collins (Manchester Metropolitan University), Andy Needle (Manchester People First), Liz Jones (Greater Manchester Older People's Network), Beth Shipley (Greater Manchester Older People's Network), Jemma Tanswell (Sonder Radio), Shane Ward (West Bromwich African Caribbean Resource Centre), Ian Quaife (Bristol Older People's Forum), and Helen Smith, Chris Frankland and Ann Gallagher (Academy of Nursing, University of Exeter and Exeter College). We would like to thank the BritainThinks team, in particular Lucy Farrow, Alice Haywood, Talia Coroniti, and Tom Lusuardi for tirelessly designing and carrying out the deliberative public dialogue.

The Nuffield team is grateful to a number of organisations for generously inviting them to participate in meetings and presentations in which the future of ageing was discussed, including: Babraham Institute, Wuhan College, Jesus College at the University of Cambridge, The International Longevity Centre UK, and the Cambridge Centre for Science and Policy.

The working group also wishes to thank the external reviewers (listed in Appendix 1) who devoted considerable time and energy to engaging with an earlier draft of this report and applied their valuable advice and experience. We would like to thank our external copy editor, Jenny Cattermole and indexer, Rosie Wood. We also thank Lou Dunn who designed our covers and created an online interactive toolkit of our ethical framework. We also thank our working group member Muna Al-Jawad for drawing the cartoons featured on the front cover and early sections of this report.

While the present report has benefitted in one way or another from the valuable input of all these people, the responsibility for the final content lies with the working group listed below and with the Nuffield Council on Bioethics, which has adopted this report as a report of the Council, in accordance with its established procedures.

Foreword

It has been a huge privilege to Chair the Nuffield Council on Bioethics working group on the future of ageing.

Our inquiry started in the darkened winter months of 2020, as the COVID-19 pandemic continued to cast its shadow during a second lockdown in the UK. Against this background, our timely deliberations shone an urgent light on the role of science and technology in the future of ageing, including its important role in tackling issues of inequity and ageism. Our discussions were necessarily multifaceted and wide-ranging, bringing in the complexity of a science and technology ecosystem, working within an extensive health and social care, political and social environment that cannot be ignored.

Throughout our discussions, we have been acutely aware of our responsibilities towards the people, families, communities, and carers at the heart of our concern. Our inquiry included a strong focus on bringing 'into the room' the voices, experiences, and expertise of those who are affected by research into ageing. That is to say, all of us (though perhaps some more than others). Informed by this wider dialogue, our deliberations grappled with delicate issues of choice and control, power and equity, trust and trustworthiness, and the intricate and shifting relationships underpinning biomedical and technological research and innovation that has the potential to enable us to flourish as we age. The delivery of research and innovation to the highest ethical standards, in order to be relevant and inclusive, depends crucially upon the vital work undertaken every day by front-line research workers, health and social care professionals, and people who take part in research, as well as upon the decisions of policymakers, funders, and influencers. We hope that the recommendations and ethical framework that have emerged from our detailed and thorough investigations will be useful and illuminating to all of those involved.

Our working group has benefitted greatly from hearing from so many people as part of our inquiry, including: those who responded to our call for evidence, the external reviewers of draft versions of the report, those who attended satellite group discussions on focused topics, and all those who took part in our public engagement events and public dialogue. This included people from all walks of professional life, including researchers from diverse academic disciplines, healthcare workers, funders, policymakers, non-governmental organisations, community organisations, learned societies, charities, regulatory bodies, and industry. Thank you all for being so generous in sharing your time, experience, and expertise with us and for encouraging us to be bold and clear in our recommendations. I would particularly like to say thank you to everyone who took part in our engagement events, as well as Lucy Farrow and the team at BritainThinks, Ian Quaife, Shane Ward, Liz Jones, Jemma Tanswell, Melanie Chapman and working group members Muna Al-Jawad and Ann Gallagher for providing such wonderful facilitation, creativity, and insight to our programme of public dialogue.

I would like to close with some personal 'thank you's'. Firstly, to my colleagues on the working group. You are an awesome group of people. I'll admit to being a little daunted by the prospect of chairing this inquiry, but it has been a delightful and rewarding experience working with your kindness, intellect, dedication, and enthusiasm. A particular shout out to your good humour, patience, and resourcefulness in dealing with the logistics and nuance of working largely virtually. Secondly, I am humbled and enriched by the experience of working with Katharine Wright, Kate Harvey, and Molly Gray at the Nuffield Council on Bioethics executive. It has been a delight working with you: your analysis, creativity, energy, and insight is inspiring. My thanks

also to other Nuffield colleagues, in particular Sarah Walker-Robson and Sophia Prout, and to Council members, for constructive input along the way.

Finally, we dedicate this report to Baroness Sally Greengross. Sally was a member of the working group and an unerring advocate for the rights of older people, who sadly passed away in June 2022. We hope that this report bears testament to her passion and influence. It was an honour to work with her.

A handwritten signature in black ink, appearing to read 'Bella Starling'. The signature is written in a cursive, slightly stylized font.

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Baroness Sally Greengross OBE

Until her death in June 2022, Sally had been a crossbench (independent) member of the House of Lords since 2000 and co-chaired five All-Party Parliamentary Groups relevant to ageing. Sally was also Chair of the cross-party Intergenerational Fairness Forum and Chief Executive of the International Longevity Centre UK.

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Drawing by Muna Al-Jawad

Terms of reference

1. To explore the ethical implications of the emerging role of biomedical science and technology in helping people live as well as possible in old age, with a particular focus on:
 - the way that ageing is conceptualised, and the implications for policy and research;
 - the aims of biomedical research and technological innovation in seeking to respond to the opportunities, challenges, and implications of the age shift in the population; and the way that these aims, and any alternatives to them, are prioritised;
 - the role of diverse older people themselves in driving the research/innovation agenda, and in identifying the needs to which research seeks to respond;
 - ethical challenges specific to the conduct of research in this field, including recruitment criteria, selection of meaningful endpoints, and measures of effectiveness;
 - issues of equity, within diverse parts of the older population, and between generations;
 - issues of personal, familial, professional, societal, and state responsibility; and
 - the implications of all these factors for both research and wider social policy.
2. To draft a report and make recommendations relating to policy and practice.

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Executive summary

Introduction: scope

1. Developments in biomedical research and technological innovation offer the possibility of important future benefits, both for individuals and for wider society, but they also raise significant ethical questions, not least about how ageing is perceived, and how older adults are valued in society. There is a strong interest among policymakers in the role that biomedical science and technology can play in responding to the needs of an ageing population. This has been highlighted in UK Government initiatives, including the Ageing Society Grand Challenge, launched as part of the 2017 *Industrial Strategy*, to “ensure that people can enjoy at least 5 extra healthy, independent years of life by 2035, while narrowing the gap between the experience of the richest and poorest”.
2. This report explores these issues and aims to identify the values, principles, and factors that are most important in the context of research that seeks to influence our experience of ageing. We bring these together in a way that provides a practical guide both to policymakers and researchers and make a number of specific recommendations.

Chapter 1 – The age shift in the UK population

3. The generation of people alive today is expected to live longer than any earlier generation. However, the longstanding trend of increasing life expectancy has not been accompanied by an equivalent increase in healthy life expectancy. This means that more people are experiencing longer periods of poor health and disability in later life. Significant inequalities in both life expectancy and healthy life expectancy exist across the UK, depending on where people live and their relative wealth. The first chapter begins with an overview of the population trends and variations within the UK, focusing particularly on healthy life expectancy and the age structure of the population. It shows that the overall population structure within the UK is changing, with people who are over 85 at any given time increasing both in absolute numbers and as a proportion of the overall population.
4. The chapter provides an overview of the factors that affect how people’s bodies age, and the associated capacity to live well in later life. The promotion of good physical and mental health across the life course is already understood to be a significant driver of an active and independent later life. The crucial role of the wider social and physical environment in supporting healthy ageing and wellbeing throughout the life has also been given greater prominence. Alongside these environmental and structural factors, there is also a strong interest (in the UK and beyond), in the role that biomedical research and technological innovation might play in helping people live well later in life. This research and innovation is very wide-ranging, but in this report we focus on developments in:
 - **research into the biology of ageing (geroscience):** increasing understanding of the underlying causes of biological ageing, with the aim of actively intervening in the biological ageing process in order to extend the period of life lived in good health, and potentially the overall length of life;
 - **assistive, monitoring, and communications technologies:** the use of both specialist and general consumer technologies to help people stay socially connected

and self-reliant for longer, and/or to provide information, reassurance and support for families and other carers; and

■ **innovative predictive and diagnostic technologies:** developments in the use of data and digital tools, including the use of artificial intelligence (AI) and machine learning, to support earlier identification, diagnosis and treatment of diseases that commonly occur in older age.

5. Often the age shift in the population is presented negatively, as a challenge to society. There is a common assumption that increasing numbers of older people represent a burden on society that will become increasingly hard to afford. Such assumptions can lead to a focus on technological developments to relieve this burden by supplementing or substituting for human care and support. They also entrench negative views about older adults' capacity to manage their own lives and contribute to society. Recognising this draws attention to a critical question about the nature of challenges that biomedical science and technological innovation are being expected to address.
6. In this report we argue for an emphasis on the **opportunities offered by longer, healthier life, for all generations**, including the opportunity for people to continue to play an active role within one's community. We consider the role that research and innovation can play within this wider picture, in supporting people to flourish in older age, for both current and future generations of older adults across the whole of society. Our approach therefore also takes into account the **many non-technological ways in which society needs to change to meet the needs of older people better**.
7. In particular, **research and innovation should be concerned with addressing inequalities in health and wellbeing in older age**, experienced as a result of disadvantage and discrimination throughout the life course. The UK Government's expressed intention to be a global leader in this field reinforces the importance of ensuring that this concern to reduce inequalities is solidly embedded in the UK approach.

Chapter 2 – Attitudes to ageing

8. Chapter 2 explains why attitudes to ageing matter in research. It shows how research and innovation do not take place in a vacuum, but are influenced and shaped by prevailing attitudes to ageing, and by assumptions about the attributes and roles of older people. In order to consider what biomedical science and technological innovation can offer in this field, and what ethical considerations should shape research agendas, practice, and implementation, we need first to identify and critique these attitudes and assumptions where they arise both in research and wider social policy. This chapter touches briefly on what is known about people's preferences and needs as they get older – what 'living well' in older age might look like.
9. Some of these assumptions are embedded in how the term 'ageing' itself is understood in different and sometimes conflicting ways. The chapter describes some of the different ways in which the term 'ageing' is used, and explores how some of these can connect with ageism (negative attitudes towards people because of their age) and the 'othering' of older adults, in ways that profoundly affect the direction of research and innovation. We distinguish:
 - **Chronological ageing:** this refers to our age in years. In this sense, ageing can be experienced as positive, depending on many factors.

- **Biological ageing:** this refers to the biological changes that take place in our bodies throughout our lives which, over time, lead to functional decline and, ultimately, to death.
10. The relationship between these terms is not straightforward and whilst it is part of being human for our bodies to age and ultimately decline, this does not affect our equal moral worth as human beings. The recognition that biological ageing is highly malleable underpins biomedical research into ageing, which is reviewed in Chapter 3. Meanwhile, in Chapter 2 we highlight the importance of taking a **life-course approach** to how we understand and approach ageing.
 11. Our experiences throughout our lives affect how and at what speed our bodies age, highlighting the scope for intervening early to support better health and physical function in older age. We describe elements of a **preventative approach to good health throughout life**, by supporting healthy lifestyles and tackling the ‘social determinants’ of health such as poverty and discrimination. This includes taking account of how people’s life courses differ, for example by recognising how people with long-term health conditions or disabilities may fare differently in particular contexts compared to others. This provides a constructive challenge to those working within research and innovation in ageing, regarding how they build on what is already known when identifying research priorities, and in particular of not overlooking the importance of preventative and rehabilitative approaches. **Throughout this inquiry, we have tried to maintain a balance between considering ageing throughout the life course, which affects people’s scope for living well in older age, and a specific concern with the needs of today’s older adults. Both are crucially important.**
 12. The choice of language and terminology plays an important role in how older adults are regarded. This report uses the language of ‘ageing well’ (rather than ‘healthy’ or ‘successful’ ageing) to capture a wider sense of what is valued in later life. Health is often valued as a means to do other things (achieve personal goals, stay connected with family and friends, support others, get out and about) rather than simply for itself. Often, being able to perform valued activities promotes health and wellbeing in turn. Drawing on evidence and experience presented to the working group, the report considers what it means to ‘age well’. It recognises that while not everyone can age healthily, everyone can age well.

Chapter 3 – Research in ageing: drivers, expectations, and limitations

13. Chapter 3 provides an overview of the many different areas of biomedical research and technological innovation relevant to ageing. These include research into the biology of ageing (also called geroscience), innovations in assistive, monitoring, and communications technologies, and data-driven innovation in early detection and diagnosis of age-related conditions. It also touches on the drivers of research in these areas, and how these different approaches present challenges for the systems that exist to govern and regulate research and innovation. In order to examine the ethical questions that arise in relation to ageing research, the importance of also taking into account the conditions of the broader research ecosystem in which that research takes place is increasingly recognised.

Geroscience and geroscience-guided clinical trials

14. Geroscience research seeks to improve understanding of the common processes that underlie biological ageing. The ultimate aim of this research is to intervene in those processes to delay, mitigate or even prevent common age-related medical conditions, including heart disease, stroke and dementia by intervening directly in one or more of the mechanisms identified as affecting cellular ageing to prevent or reverse their effects. If successful, such an approach could potentially be more effective than treating individual age-related conditions separately as they arise, which often leads to harmful interactions between different medicines. To date, a number of animal studies have shown positive results by targeting the underlying mechanisms of ageing. Following these findings, several drug classes have been taken forward into small human clinical trials, with the aim either of influencing specific aspects of biological ageing or of directly targeting age-related diseases. Considering the evidence and information the working group reached the following conclusions.

- **Geroscience is not a magic bullet:** rather it offers scope for finding more holistic ways of preventing, delaying, and treating the common conditions of older age in the future, with the primary aim of reducing the amount of time spent in ill health at the end of life (often described as ‘compression of morbidity’).
- **Geroscience should not be seen (primarily) as being about living longer:** strong views were expressed among contributors to this inquiry about how the reputation of the field is tarnished by those who wish to promote extreme life extension, distracting from the valuable focus on improving healthspan for the many, not the few.
- **Geroscience should be seen as complementary to other areas of research and healthcare,** for example providing knowledge that underpins and supports individual and societal means of promoting good health through improvements in factors such as child poverty, housing, employment, local environments, diet, exercise, and social interaction.

Assistive, monitoring, and communications technologies

15. There is a vast range of assistive, monitoring, and communications technologies that have the potential to play a role in influencing how our bodies age, or how we live in later life. Such innovations may help to build physical reserve and delay a person’s loss of function; promote reablement after injury or treatment; compensate for lost function; or support care provision. However, technologies that compensate for a lost function, or provide care when reablement is still possible, can also have a negative effect on people’s life and health. For practical reasons, we have focused primarily on technologies that are targeted specifically at older adults or are likely to be used by older adults. Examples highlighted in Chapter 3 include:

- Devices that **support people to live independently despite a degree of loss of intrinsic capacity;**
- Technological approaches to **disease prevention and rehabilitation;**
- Devices that enable **remote contact and support** and provide **reassurance to carers** and family members;
- **Telehealth and telecare systems;**
- **Companion or emotional support technologies; and**
- **Practical support for care staff or informal carers.**

Data-driven innovation in earlier diagnosis and treatment

16. Increasing attention is being devoted to the aim of detecting the common diseases of older age much earlier, specifically using data-driven innovations and artificial intelligence. There are many potential benefits of earlier diagnosis, for example facilitating earlier, more effective treatment where this is available and enabling people to plan ahead for what a particular condition might mean for their everyday lives. However, we discuss how early diagnosis may not be welcomed universally, particularly where effective treatment or appropriate support is not available after diagnosis.

Chapter 4 – Ethical challenges

17. In Chapter 4, we present an overview of the ethical issues raised with the working group by those who contributed evidence, examples, and experiences to our inquiry, using their own words where possible. This evidence took many forms, with contributions from older adults and intergenerational groups through a series of public engagement activities; from many researchers, practitioners, and people working in health and science policy who shared their expertise with us; and from participants in our public dialogue who shared their own views on ageing and the role of science and technology, and then reviewed our early findings and tentative conclusions. The working group was particularly struck by the extent to which clear common themes emerged from these multiple forms of input and engagement, despite the variety and breadth of research and innovation under consideration, and the diversity of experience of the contributors. These include the following.
 18. **Whose voices are heard?** A core ethical concern that emerged across all the various sources of evidence was over the extent to which older adults' values and perspectives are included in the way that research is prioritised, planned, and carried out, and the implications of this for older adults themselves. This raises a series of important questions, including: 'Who benefits, and how, from ageing research?', 'Who sets the agenda and determines the need?' and 'Who takes part in research?'
 19. **Equitable access:** from many of our discussions with public contributors and experts, we heard that questions of affordability, availability, and appropriateness of design affect older adults' abilities to benefit from effective novel interventions. Concerns were also raised about the reliability of increasingly digitised services, older adults' confidence in using them, and the risk that increasingly automated forms of support may add to existing inequalities through digital exclusion.
 20. **Choice and control:** technological innovations, and new approaches to treatment, may increase the options open to all of us as we get older, and enable us to live independently for longer. However, the way some technologies are used may also act to limit the control that older adults have over their own lives: for example where a person's physical safety is prioritised (by others) over their own important needs and interests. Contributors to the working group's inquiry questioned whether people would still be able to choose to have hands-on care, and whether they might feel 'pushed' into taking long-term preventative medications or being screened for conditions that are not currently affecting them, regardless of their own preferences. The question of *who* has the power to make the decisions, and on what basis, emerged as an issue of primary importance in considering these choices.

21. **Impact on relationships:** concerns were expressed that data-driven healthcare, and more technological approaches to care and support, might have a negative impact on relationships with health and care professionals, and on losing valued human contact more generally. However, the opposite possibility was also highlighted: in particular, the scope for rehabilitative and adaptive technologies to enable older adults to live with relative independence and maintain the relationships and activities that they value.
22. **Trust and trustworthiness:** underpinning many of the ethical considerations summarised above and described in Chapter 4 is a central question about whether people can have confidence in the innovative technologies and interventions under consideration. Questions of trust arose in diverse ways, including scepticism about the motivations driving research, concern over the use of data, and uncertainty as to whether the implied promises associated with research could, in fact, be delivered.
23. **Sustainability:** it was strongly argued that more collaborative and cross-disciplinary working will be required across the research, health, and care systems, if research benefits are to be translated into practice in ways that are sustainable (in time, finances, or physical resources) over the long term. As a result, serious consideration needs to be given to the prioritisation of taking a public health and preventative approach to supporting people to live well in older age as the more pragmatic response.

Chapter 5 – Developing an ethical framework

24. Chapter 5 explores in more depth some of the ideas and concepts that underpin the ethical considerations identified in Chapter 4. Drawing on evidence and insights from experience presented to the working group, it proposes an ‘ethical framework’ that identifies the values, principles, and factors that are most important in the context of biomedical research and innovation concerned with ageing.
25. In this chapter, we put forward the following considerations that should underpin the use of biomedical developments and technological innovation in response to the needs of older people.
 - Ethical reasoning needs to take into account that **ageing is a fundamental feature of human life**. It is not a kind of aberration from an idealised ageless norm. The equal human worth of all older adults, and the capacity to flourish at whatever age, must be the starting point of any research and policy in this field.
 - The **diversity of older adults** needs to be explicitly recognised in all ageing-related research and associated policy/implementation. This includes the diversity of their background and experiences (both lifelong and in older age); of their evolving needs for care and support; and of their contributions to the care and support of others.
 - Developments in any of the areas of biomedicine and technology covered within this inquiry should be **evaluated by reference to their ability to enhance genuine opportunities for a person to flourish** (promoting our capabilities to be and do what we value). An approach to research and innovation **founded on coproduction involving people of all ages and representing a broad range of backgrounds and experiences** will be essential in order to achieve this, particularly given the diversity of situations and goals that will influence any individual’s ability to flourish.
 - **Research and innovation cannot take place in a vacuum:** the scope for particular interventions, goods, or services to provide genuine opportunities to flourish will be strongly determined by structural factors including lifelong discrimination, economic

situation, local environment, and social support. These factors need to be taken into account throughout the research process, with the **aim of prioritising initiatives that will reduce, not increase, inequalities in older age**. They will also need to be at the forefront of policy considerations when rolling out innovations that have demonstrated a potential to bring benefits.

- Of central concern is the risk that unequal power relationships, whether between older adults and institutions, or older adults and other individuals, might increase the likelihood of oppression, discrimination, forms of domination, social exclusion, or stigmatisation. A key question to ask with respect to any proposed novel intervention or technology should be: **how will it enhance the control that older adults have over their lives, and support them in more equal relationships with those around them?**
 - As populations age, the need for care and support increases. The report advocates a ‘care ethics’ approach that highlights how this need for care and support from others generate responsibilities, with an emphasis on the role of sympathy and attending directly to concrete features of situations; caring attitudes; and responsiveness to the care or support needs of others. Recognising that dependent relationships are fundamentally part of the human condition, care ethics seeks to analyse what responsibilities might be associated with providing that care, to ensure that inherent imbalances of power are managed in ways that are positive both for those receiving and for those giving care, through continuing to promote the ideal of ‘equal voice’ regardless of dependency. The contribution that technological developments may make to providing care should thus be understood with reference to **how technology can support, not replace, important human relationships**. A key element of this is sensitivity to circumstances where technological approaches may in fact be preferred. In some cases, for example, where questions of personal privacy are at stake, technology may offer valued alternatives to human assistance. In giving priority to older adults’ capability to form and maintain relationships, and to the role that relationships can play in enabling us to flourish in later life, it is crucial to pay attention to the way that **power** can be exercised in both personal and professional relationships.
 - Research processes, the new interventions that are developed as a result of that research, and the way that these interventions are made available to the wider public all need to be demonstrably **trustworthy**. The starting point for demonstrating trustworthiness (on the part of the many and various stakeholders in this field) is that of the motivations that underlie the research and innovation agenda itself, alongside the manner in which research is conducted and its outcomes are then made available to wider publics. They also need to be **sustainable** in the resources they consume, including in terms of energy, time, and finance.
26. As indicated in the diagram below, these considerations can be presented in the form of an ethical framework and tool to help all those concerned with the development, conduct, and implementation of research relating to living well in older age think through the ethical implications of their work.



Diagram by Lou Dunn

Chapter 6 – Recommendations

27. Chapter 6 lays out 15 recommendations, aimed at different stakeholders, which will need to be addressed if our proposals for the ethical conduct of research that seeks to influence our experience of ageing are to be realised in practice. We also reiterate that biomedical research and technological innovation can only ever be one part of a wider approach to supporting people to live well in older age, especially with respect to addressing structural inequalities, and that current pressures on public services will have an inevitable impact on researchers and practitioners' ability to innovate.

Recommendations

Recommendation 1: We recommend that everyone with influence over research and innovation concerned with ageing, from individual research teams and practitioners to governments and funders, takes account of the ethical framework and toolkit presented in this report to guide their thinking. In particular, we recommend that the toolkit is used as a guide in processes for scrutinising funding applications, for the ethical review of research in this area, and when making decisions about the translation of research into practice.

We restate here our conclusion in Chapter 1 that reducing inequalities in the ability to live well in older age should be a core, indeed primary, aim of research and innovation in this field.

Recommendation 2: We recommend that a cross-governmental strategy to support the delivery of the 2017 Ageing Society Grand Challenge aims, as recommended by the House of Lords Science and Technology Committee, should be supported by an intergenerational public advisory forum including both older adults and contributors from across younger generations.

The remit of the forum, made up of a diverse membership of both individuals and representative organisations concerned with ageing, would be to put the experience of older adults at the heart of policymaking, challenge ageist assumptions, and encourage a broader life-course approach to ageing policy.

Recommendation 3: We recommend that research funders, regulators, research ethics committees, and journals should all require meaningful collaboration with older adults as part of their work with public contributors in any research seeking to influence our experience of ageing. In particular, they should expect to see evidence that the public contributors to any research project reflect the diversity of those likely to be affected by it, including those who are most disadvantaged. Funders should ensure that both timescales and budgets make proper allowance for a partnership approach.

Recommendation 4: We recommend that public research funders with a remit to support research in ageing should collaborate to establish and fund the infrastructure (systems, staff, expertise) necessary to support partnerships between research teams and public contributors able to contribute diverse understandings and experiences of older age.

Recommendation 5: We recommend that funders of research in ageing should require (and fund) researchers to collect a minimum demographic dataset about research participants. Further work may be required to specify such a data set, but it should include as a minimum age, sex/gender, ethnicity, socioeconomic status, and nature of access to informal social support. They should then make use of this data in future grant

rounds, to fund research that specifically aims to fill identified gaps in the coverage of the diversity of experiences of older adults. Research ethics committees should expect robust justification if researchers are not planning to collect, or analyse, such demographic data.

Recommendation 6: We recommend that the Medicines and Healthcare products Regulatory Agency (MHRA) continue actively to engage with funders and researchers in addressing the challenges that may hinder older people with multiple long-term conditions being included in research relevant to them. If necessary, we encourage the MHRA to consider whether a mandatory approach should be explored, mandating the inclusion of data obtained through the participation of older research participants, and/or participants living with multiple long-term conditions, as part of licensing authorisations, where new products will be relevant to the older population.

Recommendation 7: We recommend that the Health Research Authority (HRA), working with funders such as the National Institute for Health and Care Research (NIHR), takes the lead in identifying and disseminating examples of good practice in the inclusion of older adults, particularly older adults with impaired mental capacity, in research. These should be shared with ethics committees to support them when scrutinising relevant research proposals.

Recommendation 8: We recommend that research funders provide dedicated funding to support research teams and engagement practitioners in developing relationships with older adults in their communities and with the care sector, in order to build up the connections and expertise necessary to enable older adults with care and mobility needs to participate in research.

Recommendation 9: We recommend that the researchers and research funders responsible for large-scale volunteer databases and cohort studies proactively review how these studies might need to be adapted to ensure that they capture both the breadth of diversity in the ageing process, and the scope to intervene positively in the ageing process.

Recommendation 10: If the initial two-year funding allocation for the UK Ageing Networks demonstrates proof of concept, we recommend that all the relevant funding councils within UK Research and Innovation (UKRI) should commit to long-term joint funding of the UK Ageing Networks to ensure a truly interdisciplinary approach.

Recommendation 11: We recommend that public and charitable funding for research in ageing within the UK (including that directed via partnership approaches with the commercial sector) should be based explicitly on a public health, life-course approach. Such an approach would:

- recognise the importance of interventions and support across the life course and into later life to enable people to live as healthily as possible, with a particular focus on preventative approaches;
- prioritise the needs of those who are currently most disadvantaged, with a particular focus on addressing structural and institutional barriers to ageing well; and
- see scientific and technological innovation as an important complement to, but not substitute for, wider social policies that are fundamental to supporting people in ageing well.

Recommendation 12: We recommend that the British Standards Institution (BSI), the Medicines and Healthcare products Regulatory Agency (MHRA), Innovate UK, and other stakeholders should collaborate to develop accredited standards that promote ethical and inclusive research practices with respect to technologies designed to support people

to live well in older age. We commend our ethical framework and tool as a starting point for such standards.

Recommendation 13: We recommend that research funders should take active steps to promote closer working between the researchers they fund and those directly involved in providing the services that the research aims to influence. Possible approaches include creating grant opportunities directly aimed at partnerships between researchers and practitioners.

Recommendation 14: We recommend that, following existing good practice in screening policy, any new screening or testing programmes associated with age-related conditions should only be rolled-out if accompanied by robust, properly funded, services that offer meaningful support to people who receive such diagnoses and their families and those who provide care and support.

Recommendation 15: We recommend that providers of undergraduate education for health professionals and biomedical scientists ensure that their students gain a rounded, interdisciplinary, understanding of ageing, including the ethical considerations set out in our ethical framework and toolkit.

Introduction

Ageing affects all of us. We all aspire to live well as we get older, and we are all affected by demographic shifts in the population. Yet the prevalent rhetoric of ‘demographic time bombs’ or ‘silver tsunamis’ is contributing to a culture where older adults are seen as a separate, and problematic, part of our society. In this framing, biomedical and technological innovations are often presented as solutions to a ‘problem’ of too many people needing too much care. The Nuffield Council on Bioethics established this inquiry to explore the ethical implications of this policy direction in the UK.

The resulting report takes a very different approach. Drawing on contributions from older adults, intergenerational dialogues, practitioners, and experts from many different disciplines, it challenges the ‘othering’ of older adults within policy, within practice, and even within some approaches to ethics. It emphasises instead the rich diversity of people considered to be ‘old’, recognising how many in their 70s, 80s, and 90s continue to engage actively within their communities, while others, much younger, are prevented from living the lives they want to lead as a result of vast inequalities in healthy life expectancy. It also highlights how there are many different ways of contributing and caring – and that many older adults, regardless of their own health, continue to contribute in multiple valued ways to their communities, friends, and family.

This report places the perspectives, preferences, and agency of older adults at the heart of ethical deliberation, challenging ‘compassionate ageism’ that sees only dependency and vulnerability in older age. It also critiques the notion of ‘healthy’ or ‘successful’ ageing, recognising that not everyone can remain in good health all their life (and few will not experience dependency at the very end of their life), but that all can live well in later life if given the opportunities to do so. The aims of biomedical research and technological innovation need to be reframed around this concept of supporting and enabling flourishing – of providing opportunities for us all to live lives that we value – despite the precarity that older age ultimately brings. Crucially, addressing the inequalities and discrimination throughout the life course that currently lead to such disparities in experience in later life needs to take centre stage in this endeavour.

This report is the result of a two-year inquiry led by an expert working group, involving a series of creative engagement events with older adults and intergenerational discussion groups; contributions from practitioners and academics from many different disciplines through responses to an open call for evidence and participation in roundtable meetings; and critique of emerging findings through a public dialogue and through external expert review. It sets out an ethical framework and toolkit for all those involved in the endeavour of research and innovation – from research funders, policymakers, ethics committees, and regulators, to those directly involved in conducting research and translating the outcomes of research into innovative practices. Recognising the influence of the wider research ecosystem on the scope for those on the ground to practise ethically, it includes wide-ranging recommendations to government, research funders, regulators, and others with influence on the conduct and publication of research. We hope our analysis, our ethical toolkit, and our recommendations will help embed an approach to research that puts the diversity, agency, and value of older adults firmly at the heart of all research concerned with ageing.

Chapter 1

The age shift in the UK
population

Chapter 1 – The age shift in the UK population

Overview of Chapter 1

Living longer – but not for all

- More people are living for longer than ever before in the UK. This has significant implications both for the wellbeing of individuals in later life – our capacity to live lives that are fulfilling as well as long – and for wider society.
- However, a longstanding trend in rising life expectancy is beginning to level off and even fall. It also masks significant variations across the country. People in wealthier areas live up to 10 years longer on average than those in more deprived areas.
- Increases in overall life expectancy are also not being accompanied by equivalent increases in healthy life expectancy. More people will experience longer periods of poor health and disability in the later part of their lives. Inequalities in healthy life expectancy are particularly concerning. People in wealthier areas live up to 20 years longer in good health than those in more deprived areas.
- People with experience of racial inequalities, disabled people, and those who are less well off are more likely than others to be affected earlier in their lives with age-related medical conditions.

The age shift in the population

- The overall population structure within the UK is changing, with the result that a growing proportion of the population is over 65. In particular, there are significant increases in the numbers and proportion of the population who are over 85. This age shift in the population is driven by decreasing birth rates and changes in patterns of immigration, as well as increasing life expectancy.

The role of research and innovation

- There has been considerable policy attention paid to the role that biomedical research and technological innovation might play in responding to the age shift in the population. This includes developments in:
 - understanding the biology of ageing ('geroscience') – with the aim of intervening in the underlying causes of biological ageing;
 - assistive, monitoring, and communications technologies;
 - innovations in earlier diagnosis and treatment of age-related conditions.
- The age shift is often presented negatively, as a challenge to society in terms of ever-increasing needs for support for older adults, combined with decreasing capacity to provide that support. These assumptions risk leading to a focus on technology primarily as a substitute for human care and support. They also build in negative assumptions about older adults' capacity to manage their own lives and contribute to society.
- In contrast to this negative approach, **we argue for an emphasis on the opportunities that longer, healthier life offers for all generations. Biomedical research and technological innovation can potentially play an important role in supporting people to thrive and flourish in later life. However, this must be considered alongside the many non-technological ways in which society needs to change in order to better meet the needs of older adults.**
- In particular, research and innovation should be concerned with addressing inequalities in health and wellbeing in older age, experienced as a result of disadvantage and discrimination throughout the life course.

Introduction: biomedical research, technology, and ageing

- 1.1 Across the world, the people alive today are expected to live longer than any generation before.¹ In countries such as the UK, a longstanding trend of rising average life expectancy (albeit impacted very recently by the COVID-19 pandemic),² accompanied by falling birth rates and changing patterns of immigration, is leading to a significant age shift within society, where older adults constitute an increasing proportion of the population. The potential implications, both for older adults themselves and for wider society, are the focus of growing attention on the part of politicians and policymakers, and are widely discussed in the media.
- 1.2 Much of this debate is founded on assumptions that associate greater age solely or primarily with higher needs for care and support. However, this somewhat passive stereotype of older age is increasingly being challenged through recognition of the crucial economic and social contribution that older adults continue to make in many ways, including through active engagement (paid and unpaid) in local communities, and in the provision of care for others. The importance of continuing contribution – being able to help others and contribute to wider society, and to be valued and recognised for this – emerged as a powerful theme in the many discussions the working group held with older adults throughout this inquiry (see paragraphs 2.23–2.30).
- 1.3 A key factor affecting people’s experiences in later life is their state of physical and mental health, and the period of time in which they live with poor health towards the end of their life. However, increases in life expectancy seen in recent decades are not being accompanied by parallel increases in *healthy* life expectancy – that is, the number of years a person can expect to live in good general health (see paragraphs 1.11–1.13). Instead, increases in life expectancy in the UK are leading to longer periods of disability and poor health for many in older age. This is not, however, inevitable.
- 1.4 The promotion of good physical and mental health across the life course is already understood as a significant driver of active and independent later life, although much remains to be done in translating the evidence base in this area into practice (see paragraphs 2.9–2.10).³ The crucial role of the wider social and physical environment in supporting healthy ageing and wellbeing throughout life has also been given greater prominence through the World Health Organization’s (WHO) championing of ‘age-friendly environments’, and the more recent concept of ‘longevity cities’ (see paragraphs 1.19–1.24 and Box 1.7). Alongside these environmental and structural approaches to ageing policy, there is also strong interest, both in the UK and beyond, in the role that biomedical research and technological innovation might play: both in helping people live well in later life, and in helping society respond appropriately to the age shift in the population (see Box 1.1 for an overview of UK initiatives and statements). Such research and innovation is very wide-ranging and includes developments in:

¹ United Nations (2022) *World population prospects 2022: summary of results*, available at: https://www.un.org/development/desa/pd/sites/www.un.org.development.desa.pd/files/wpp2022_summary_of_results.pdf.

² See, for example, The King’s Fund (2022) *What is happening to life expectancy in England?*, available at: https://www.kingsfund.org.uk/publications/whats-happening-life-expectancy-england#footnotea_dmrurlf; and Office for National Statistics (2021) *Dataset: single-year life tables, UK: 1980 to 2020*, available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/datasets/singleyearlifetablesuk1980to2018>.

³ International Longevity Centre UK (2022) *A window of opportunity: delivering prevention in an ageing world*, available at: <https://ilcuk.org.uk/delivering-prevention-in-an-ageing-world/>.

- **research into the biology of ageing (geroscience):** increasing understanding of the underlying causes of biological ageing, with the aim of actively intervening in the biological ageing process in order to extend the period of life lived in good health, and potentially the overall length of life itself;
- **assistive, monitoring, and communications technologies:** the use of both specialist and general consumer technologies to help people stay connected and self-reliant for longer; and/or to provide information, reassurance, and support for families and other carers; and
- **innovative predictive and diagnostic technologies:** developments in the use of data and digital tools, including the use of artificial intelligence (AI) and machine learning, to support earlier identification, diagnosis, and treatment of diseases that commonly occur in older age.

Box 1.1: UK policy emphasis on innovation and ageing

A number of recent UK Government initiatives and strategies have emphasised the role of research and innovation in responding to the age shift in society.

- The Ageing Society Grand Challenge, launched in the 2017 *Industrial Strategy*, set ambitious targets to “ensure that people can enjoy at least 5 extra healthy, independent years of life by 2035, while narrowing the gap between the experience of the richest and poorest”.⁴ The strategy placed a strong emphasis on the role of innovation in achieving this target, within both the healthcare and social care systems, and through broader technological developments to support independent living. These targets have since been restated in the 2022 white paper *Levelling up the United Kingdom*⁵ and in the 2022 *Women’s Health Strategy for England*.⁶ Progress on these targets was reviewed by the House of Lords Science and Technology Select Committee in 2021, with concern expressed that much more coordinated cross-governmental action would be required to achieve them.⁷
- The 2021 *Life Sciences Vision* identified “addressing the underlying biology of ageing” as one of the “missions [that] will also help the National Health Service (NHS) to solve some of the biggest healthcare problems of our generation”.⁸ The vision included a number of preconditions that would be essential to its success, including that “investment in science and research in life sciences must be maintained and grown over the next decade”.⁹
- The 2021 *UK Innovation Strategy* argues that “innovation is central to the largest challenges the world faces, from climate change and the ageing society to global pandemics,” and promises a “suite of Innovation Missions focused on some of this

⁴ See: Department for Business, Energy and Industrial Strategy (26 January 2021) *The grand challenge missions*, available at: <https://www.gov.uk/government/publications/industrial-strategy-the-grand-challenges/missions>; and Department for Business, Energy and Industrial Strategy (12 March 2018) *Government announces £300 million for landmark ageing society grand challenge*, available at: <https://www.gov.uk/government/news/government-announces-300-million-for-landmark-ageing-society-grand-challenge>. We note that since March 2023, the *Industrial Strategy* has transitioned into the *Plan for Growth* and its related strategies.

⁵ Department for Levelling Up, Housing and Communities (2022) *Levelling up the United Kingdom*, available at: <https://www.gov.uk/government/publications/levelling-up-the-united-kingdom>, at page 7 and 12.

⁶ Department of Health and Social Care (2022) *Women’s health strategy for England*, available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1100706/Womens-Health-Strategy-England-print.pdf, at chapter 17.

⁷ House of Lords Science and Technology Select Committee (2021) *Ageing: science, technology and healthy living*, available at: <https://publications.parliament.uk/pa/ld5801/ldselect/ldsctech/183/183.pdf>.

⁸ Department for Business, Energy and Industrial Strategy and Office for Life Sciences (2021) *Life sciences vision*, available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1013597/life-sciences-vision-2021.pdf, at page 9.

⁹ *ibid*, at page 10.

government's foremost policy priorities".¹⁰ This will include the development of a "Quantum Healthy Longevity Innovation Mission".¹¹

- The 2021 adult social care white paper *People at the Heart of Care* sets out the aspiration of the English Department of Health and Social Care (DHSC) to "be at the forefront of global care technology innovation, drawing on the existing strengths of the UK's life sciences and research sector to develop, deploy and scale care technologies that improve people's lives and their care outcomes".¹²
- The 2022 policy paper from the DHSC, *Data saves lives*, highlights the importance of data-driven technologies in providing effective health and care services, with concrete commitments including "investing in secure data environments to power life-saving research and treatments".¹³ The accompanying *Plan for digital health and social care* set out the DHSC's "vision for a digital future".¹⁴

- 1.5 As we explore in later chapters of this report, developments in these three broad fields of research and innovation offer scope for important future benefits, both for individuals and for wider society. However, they also raise significant ethical questions, not least about how ageing is perceived and older adults valued in our society, issues that we explore in more depth in the next chapter with a particular focus on structural ageism.¹⁵ Given the strong emphasis in UK Government policy on these kinds of science- and technology-driven approaches, the Nuffield Council on Bioethics has taken the view that ethical engagement with these issues should be undertaken as a matter of priority, to minimise the risk that unexamined assumptions and approaches to ageing might be 'baked in' from very early in the process of research and development. These concerns, and their contemporary policy importance in the UK and beyond, influenced the terms of reference of this inquiry, which centre on the role of biomedical science (covering the spectrum of laboratory science to interventional clinical trials) and technological innovations relevant to ageing. However, as we discuss further below (see paragraphs 1.19–1.24), we have remained alert throughout to the fact that this area of inquiry constitutes only one of the many factors influencing the scope to live well in later life.
- 1.6 For the same reasons of policy relevance, the focus of this inquiry has primarily been on the situation in the UK. However, where appropriate we have also brought in wider perspectives, both because of scope to learn from international experiences, and in light

¹⁰ Department for Business, Energy and Industrial Strategy (2021) *UK innovation strategy: leading the future by creating it*, available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1009577/uk-innovation-strategy.pdf, at pages 4 and 80.

¹¹ Woods T, Palmarini N, Corner L *et al.* (2022) Quantum healthy longevity for healthy people, planet, and growth *The Lancet Healthy Longevity* and Collider Health blog (2022) *Healthy longevity for all: a blueprint to maximise equitable health and wealth*, available at: <https://www.colliderhealth.com/blog>.

¹² Department for Health and Social Care (2021) *People at the heart of care: adult social care reform white paper*, available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf, at page 43.

¹³ Department for Health and Social Care (2022) *Data saves lives: reshaping health and social care with data*, available at: <https://www.gov.uk/government/publications/data-saves-lives-reshaping-health-and-social-care-with-data/data-saves-lives-reshaping-health-and-social-care-with-data>.

¹⁴ Department for Health and Social Care (2022) *A plan for digital health and social care*, available at: <https://www.gov.uk/government/publications/a-plan-for-digital-health-and-social-care/a-plan-for-digital-health-and-social-care>.

¹⁵ For a more detailed account on how science and technology have shaped understandings of 'ageing' in the first place, see: Moreira T (2016) *Science, technology and the ageing society*, 1 Edition (London: Routledge).

of the expressed desire of the UK Government that the UK should act as a global leader in this field.¹⁶

Population trends and inequalities

Life expectancy and lifespan

- 1.7 Average life expectancy at birth has been increasing steadily across the world for decades, although over the last decade the rate of increase has begun to slow down and even level off in some countries, including the UK and the US.¹⁷ In higher income countries, attention has shifted to consider life expectancy from 65 or even 85, which has also shown a general upward trend. Thus people in the UK who were aged 65 years in 2020 can expect to live, on average, a further 19.7 years for males and 22 years for females; and this is projected to rise to 21.9 years for males and 24.1 years for females who are aged 65 years in 2045.¹⁸
- 1.8 Statistics for life expectancy are by their nature both a prediction and an average, and can be calculated in different ways: 'period' life expectancy at birth represents the average number of years that a newborn would live if the pattern of mortality in the given year for a particular location were to stay the same throughout their life, while 'cohort' life expectancy, by contrast, accounts for improvements in mortality during life, and hence tends to be higher.¹⁹ Using cohort projections, baby boys born in the UK in 2020 can expect to live on average to age 87.3 years and girls to age 90.2 years, taking into account projected changes in mortality patterns over their lifetime.²⁰ These life expectancies are projected to increase for babies born in 2045, by 2.8 years to reach 90.1 years for boys, and by 2.4 years to 92.6 years for girls.²¹ Indeed, an estimated 13.6 per cent of boys and 19 per cent of girls born in the UK in 2020 are expected to live to at least 100 years of age, with this rising to 20.9 per cent of boys and 27 per cent of girls born in 2045.²²
- 1.9 However, as indicated in Box 1.2, expectations of longer life are distributed very unevenly, even within a high-income country such as the UK, with differences in period life expectancy varying by as much as ten years between richer and poorer parts of the country.²³ Indeed, some of the levelling-off in life expectancy seen particularly in recent years in the UK, the European Union, and the US has been attributed to these growing inequalities.

¹⁶ See, for example, Department of Health and Social Care (2022) *The future of clinical research delivery: 2022 to 2025 implementation plan*, available at: <https://www.gov.uk/government/publications/the-future-of-uk-clinical-research-delivery-2022-to-2025-implementation-plan/the-future-of-clinical-research-delivery-2022-to-2025-implementation-plan>. See also: Department for Digital, Culture, Media and Sport (2022) *UK digital strategy*, available at: <https://www.gov.uk/government/publications/uks-digital-strategy/uk-digital-strategy>, at section 6.

¹⁷ Our World in Data (2019) *Life expectancy*, available at: <https://ourworldindata.org/life-expectancy>. See also: Noppert GA, Duchowny KA, and Clarke PJ (2022) Declining US life expectancy since covid-19—structural inequities foreshadow future fallout *British Medical Journal* **378**: o2249.

¹⁸ Office for National Statistics (2022) *Past and projected period and cohort life tables: 2020-based, UK, 1981 to 2070*, available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/bulletins/pastandprojecteddatabfromtheperiodandcohortlifetables/2020baseduk1981to2070>.

¹⁹ OECD (2022) *Life expectancy at birth (indicator)*, available at: <https://data.oecd.org/healthstat/life-expectancy-at-birth.htm>.

²⁰ Office for National Statistics (2022) *Past and projected period and cohort life tables: 2020-based, UK, 1981 to 2070*, available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/bulletins/pastandprojecteddatabfromtheperiodandcohortlifetables/2020baseduk1981to2070>.

²¹ *ibid.*

²² *ibid.*

²³ Centre for Ageing Better (2022) *The state of ageing 2022*, available at: <https://ageing-better.org.uk/sites/default/files/2022-03/The-State-Ageing-2022-report.pdf>, at page 4.

- 1.10 Lifespan, on the other hand, is a measure of the actual length of an individual's life: the most common age at death in the UK in 2018 and 2020, for example, was 86.7 years for males and 89.3 years for females.²⁴ There is some indication from very long-lived populations that the median age at death is also being driven upwards, with an increase not only in the number of centenarians, but also in the number of 'super-centenarians': those who live to ages over 110.²⁵ There is a vibrant and still contested debate over the maximum lifespan of human beings, and whether this can be significantly extended.²⁶

Box 1.2: Trends in period life expectancy in the UK: unequal life chances

- Period life expectancy at birth across the UK has been rising for 40 years, and has reached 79 for males and nearly 83 for females.²⁷ (As noted in paragraph 1.8, these estimates are higher if calculated as 'cohort' life expectancies that account for improvements in mortality over this time period – these period estimates assume the same levels of mortality every year).
- However, the *rate* of increase in life expectancy has been slowing. In 2021, virtually no increase was predicted for females born between 2018 and 2020 and, for the first time, a small decline was predicted in life expectancy at birth for males, largely due to the impact of COVID-19.²⁸ The pattern was similar for predicted life expectancy at age 65: this levelled off for women over 65 and fell slightly for men over 65.²⁹
- It is currently unclear whether the past trend of ever-increasing life expectancy will return when the country emerges from the COVID-19 pandemic.³⁰ However, it is important to note that the reversal in this trend had started in the UK *before* the pandemic, as headline national data masks substantial differences in life expectancy in different parts of the country. Between 2015 to 2017 and 2018 to 2020, life expectancy at birth in England among males and females living in the most deprived areas had already fallen, well before the effects of the COVID-19 pandemic were experienced.³¹
- The most recent estimates suggest that there is a nearly 10-year gap in male life expectancy between those born in the most and least deprived areas of England, while the gap for females is 8 years. In the period 2018 to 2020, male life expectancy at birth in the most deprived areas of England was 73.5 years, compared with 83.2

²⁴ Office for National Statistics (2021) *National life tables – life expectancy in the UK: 2018 to 2020*, available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/bulletins/nationallifetablesunitedkingdom/2018to2020>.

²⁵ Robine J-M, and Herrmann FR (2020) Maximal human lifespan, in *Encyclopedia of Biomedical Gerontology*, Rattan SIS (Editor) (Oxford: Academic Press).

²⁶ Harper S (2015) Addressing longevity, life expectancy and health life expectancy *Journal of Population Ageing* **8(4)**: 223-6; and Eisenstein M (2022) Does the human lifespan have a limit? *Nature* **601(7893)**: S2-s4.

²⁷ Office for National Statistics (23 September 2021) *National life tables - life expectancy in the UK: 2018 to 2020*, available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/bulletins/nationallifetablesunitedkingdom/2018to2020#main-points>.

²⁸ *ibid.*

²⁹ *ibid.*

³⁰ See: Hiam L, and Dorling D (2022) The end of great expectations? *British Medical Journal* **377**: e071329; and Islam N, Jdanov DA, Shkolnikov VM et al. (2021) Effects of covid-19 pandemic on life expectancy and premature mortality in 2020: time series analysis in 37 countries *British Medical Journal* **375**: e066768. See also: Aburto JM, Kashyap R, Schöley J et al. (2021) Estimating the burden of the COVID-19 pandemic on mortality, life expectancy and lifespan inequality in England and Wales: a population-level analysis *Journal of Epidemiology and Community Health* **75(8)**: 735-40.

³¹ Office for National Statistics (2022) *Health state life expectancies by national deprivation deciles, England: 2018 to 2020*, available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthinequalities/bulletins/healthstatelifeexpectanciesbyindexofmultipledeprivationimd/2018to2020#life-expectancy-at-birth-by-the-english-index-of-multiple-deprivation>; and The Health Foundation (2018) *The gap in healthy life expectancy between the most and least deprived areas in England*, available at: <https://www.health.org.uk/the-gap-in-healthy-life-expectancy-between-the-most-and-least-deprived-areas-in-england>.

years in the least deprived areas. For females, the equivalent estimates were 78.3 years and 86.3 years, respectively.³²

- 'Experimental' statistics from the Office for National Statistics found that both males and females in the white and mixed ethnic groups had lower life expectancy at birth than all other ethnic groups in England and Wales during 2011 to 2014.³³ In more recent years, between 2017 and 2019, despite overall mortality declining sharply in all ethnic groups, ethnic differences remained similar, with the white group having a higher mortality than any other ethnic group. However, during the COVID-19 pandemic mortality was higher in Bangladeshi and Pakistani males and females and in Black Caribbean males than in the white British group.³⁴

Healthy life expectancy

- 1.11 The overall increase in life expectancy seen across the globe over recent decades has not been accompanied by an equivalent increase in healthy life expectancy – the period of life lived in good health.³⁵ This suggests that, on current trends, more and more people will be living for a longer period with disability and poor health at the end of their lives. This trend is also found in the UK, as set out in Box 1.3.
- 1.12 Moreover, as we described above with respect to total life expectancy, there is significant inequality with respect to healthy life expectancy, depending on where people live and their relative wealth: for women in England, this is nearly 20 years; and for men, 18 years. There is also some evidence to suggest that the *degree* of poor health and disability experienced is also linked to affluence.³⁶

Box 1.3: Healthy life expectancy in the UK

Healthy life expectancy has not kept pace with the increase in life expectancy in the UK, meaning that people are spending more years in poor health. For example, a boy born in England in 2018 to 2020 can expect to live to 79.4 years; however, his healthy life expectancy is only 63.1 years, meaning he is predicted to spend 16.3 years in poor health. Similarly, a girl born in England at the same time can expect to live to 83.1 years, with 19.3 of these years spent in poor health.³⁷

³² Office for National Statistics (2022) *Health state life expectancies by national deprivation deciles, England: 2018 to 2020*, available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthinequalities/bulletins/healthstatelifeexpectanciesbyindexofmultipledeprivationimd/2018to2020#life-expectancy-at-birth-by-the-english-index-of-multiple-deprivation>.

³³ Office for National Statistics (2021) *Ethnic differences in life expectancy and mortality from selected causes in England and Wales: 2011 to 2014*, available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/articles/ethnicdifferencesinlifeexpectancyandmortalityfromselectedcausesinenglandandwales/2011to2014>; and The BMJ Opinion blog (20 August 2021) *Ethnic differences in life expectancy in England and Wales: the unexpected?*, available at: <https://blogs.bmj.com/bmj/2021/08/20/ethnic-differences-in-life-expectancy-in-england-and-wales-the-unexpected/> (2021) *Ethnic differences in life expectancy in England and Wales: the unexpected?*, available at: <https://blogs.bmj.com/bmj/2021/08/20/ethnic-differences-in-life-expectancy-in-england-and-wales-the-unexpected/>.

³⁴ The King's Fund (2021) *The health of people from ethnic minority groups in England*, available at: <https://www.kingsfund.org.uk/publications/health-people-ethnic-minority-groups-england>.

³⁵ WHO (2020) *Global health estimates: life expectancy and healthy life expectancy*, available at: <https://www.who.int/data/gho/data/themes/mortality-and-global-health-estimates/ghe-life-expectancy-and-healthy-life-expectancy>.

³⁶ Bennett HQ, Kingston A, Spiers G *et al.* (2021) Healthy ageing for all? comparisons of socioeconomic inequalities in health expectancies over two decades in the cognitive function and ageing studies I and II *International Journal of Epidemiology* **50(3)**: 841-51.

³⁷ The King's Fund (2022) *What is happening to life expectancy in England?*, available at: https://www.kingsfund.org.uk/publications/whats-happening-life-expectancy-england#footnotea_dmrurf.

The most recent data shows that healthy life expectancy at birth in the UK showed no significant change overall between 2015 to 2017 and 2018 to 2020.³⁸ However, the picture is not even across the UK. In Scotland over this period, there was a statistically significant decrease of more than a year in male healthy life expectancy at birth, whereas no significant change was observed in the other constituent countries of the UK, or for females.³⁹

As is the case with total life expectancy, predictions of healthy life expectancy vary significantly depending on relative wealth in different areas within the UK.

- The latest predictions for healthy life expectancy at birth in England, published in April 2022, identified a nearly 18-year gap in healthy life expectancy between males in the most and least deprived areas, and nearly 20 years for females.⁴⁰
- For both males and females, coming from the most deprived areas in England is associated with increased years spent in less good general health, with recent data predicting 21.2 years living in poorer health for males in the most deprived areas compared with 12.7 years for males in the least deprived areas. Similarly, females from the most deprived areas were predicted to spend 26.4 years in poorer health compared with 15.6 years for females from the least deprived areas.⁴¹
- In Scotland, recent data shows that overall healthy life expectancy increased between 1995 and early 2010, and then declined by approximately 2 years between 2011 and 2019. Despite this decline being observed for both the most and least deprived groups, a greater decline of around 3.5 years was observed for those living in the 20 per cent most deprived areas.⁴²

1.13 These vast inequalities in both life expectancy and healthy life expectancy across the UK illustrate very powerfully the extent to which our rate of biological ageing is far from fixed by reference to our chronological age.⁴³ This poses a clear challenge to common and fatalistic assumptions that health problems in later life are inevitably ‘down to your age’ (see paragraphs 2.9–2.13). We explore below the importance of taking into account the many different, and interlinked, factors that influence such inequalities in healthy life expectancy, and the implications for how these might most effectively be tackled (see paragraphs 1.19–1.24).

Population structures and assumptions about the age shift

“We’ve become accustomed to our ageing population being presented as a bad thing. The impact of ageing is frequently portrayed as being

³⁸ Office for National Statistics (2022) *Health state life expectancies, UK: 2018 to 2020*, available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/bulletins/healthstatelifeexpectanciesuk/2018to2020>.

³⁹ *ibid.*

⁴⁰ Office for National Statistics (2022) *Health state life expectancies by national deprivation deciles, England: 2018 to 2020*, available at:

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthinequalities/bulletins/healthstatelifeexpectanciesbyindexofmultipledeprivationimd/2018to2020#life-expectancy-at-birth-by-the-english-index-of-multiple-deprivation>.

⁴¹ *ibid.*

⁴² Walsh D, Wyper GMA, and McCartney G (2022) Trends in healthy life expectancy in the age of austerity *Journal of Epidemiology Community Health* **76(8)**: 743-5.

⁴³ This is powerfully expressed in recent research by The Health Foundation: “our analysis shows, on average, a 60-year-old woman in the poorest area of England has diagnosed illness equivalent to that of a 76-year-old woman in the wealthiest area”, see: The Health Foundation (2022) *Quantifying health inequalities in England*, available at: <https://www.health.org.uk/news-and-comment/charts-and-infographics/quantifying-health-inequalities>.

*overwhelmingly negative for our economy and society. Worse, that impact is seen as completely predetermined, rather than something we can act to mitigate. In reaction to this a 'positive ageing' movement has sought to present old age as an entirely positive time to be celebrated. In doing so, we risk undermining the real individual, societal, and policy changes facing us as more of us are living longer."*⁴⁴

*"Some older people are fit and healthy and still working and their needs may be very different to someone with complex health and care needs (who may or may not be aged over 65). Older people are not a homogenous group (even without thinking of what age constitutes an older person)."*⁴⁵

- 1.14 The overall population structure within the UK is changing, with the result that a growing proportion of the population is over 65. In particular, there are significant increases in the number and proportion of the population who are over 85 (see Box 1.4). This 'age shift' or 'age structural change' in the population is driven by a combination of factors: decreasing birth rates and changes in patterns of migration, as well as increasing life expectancy.⁴⁶

Box 1.4: Age structure in the UK population

Since the 1980s, the UK population has steadily increased, with an estimated population of 67 million in mid-2020.⁴⁷ As the UK population has grown, there has been a shift in the age structure towards older ages, with the number of people aged 85 years and over reaching 1.7 million in 2020 (2.5% of the UK population).⁴⁸ It is projected that by mid-2045, the number of older adults aged 85 years and over will double to 3.1 million (making up 4.3% of the total UK population).⁴⁹ In 2021, the number of people aged 65 years and over in England and Wales was larger than those under 15 years old.⁵⁰

The shift towards an increase in older adults in the UK population has been attributed primarily to a combination of declining fertility rates and people living longer lives (declining mortality rates).

- Despite an increase in the number of live births in England and Wales in 2021, the number of live births is lower than live births pre-COVID-19 in 2019, and still aligns with the long-term trend of decreasing birth rates.
- In 2021, fertility rates in England and Wales increased for the first time since 2012, to 1.61 children per woman. When broken down by age group, the small increase in

⁴⁴ International Longevity Centre UK, responding to our call for evidence.

⁴⁵ Vicki Goodwin, responding to our call for evidence.

⁴⁶ See: Office for National Statistics (2021) *Overview of the UK population: January 2021*, available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/overviewoftheukpopulation/january2021>; and Harper S (2016) The important role of migration for an ageing nation *Journal of Population Ageing* **9(3)**: 183-9.

⁴⁷ 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>.

⁴⁸ *ibid.*

⁴⁹ *ibid.*

⁵⁰ Office for National Statistics (2022) *Population and household estimates, England and Wales: census 2021*, available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/bulletins/populationandhouseholdestimatesenglandandwales/census2021#age-and-sex-of-the-population>.

fertility rates has been shown to be driven by women at older ages and is decreasing in younger age groups, particularly for those aged under 20 years.⁵¹

- Mortality rates have been decreasing since 2001, leading to an overall rise in life expectancy, despite the significant increase in mortality for both males and females observed in 2020 linked to the COVID-19 pandemic. Improvements in nutrition, hygiene, housing, healthcare, and other public health measures have contributed to reduced mortality rates.⁵² For example, the development of combination long-term antiretroviral therapy for people with HIV (with high CD4 cell counts) has resulted in an improvement in life expectancy to close to that of the general population for those who are successfully treated.⁵³

Migration is documented as being a driving force behind an increase in population size in the UK, with more than half of the increase in UK population between 2001 and 2020 attributed to the direct contribution of net migration.⁵⁴ As well as changing population sizes, migration has an impact on age structure by slowing down structural population ageing in host countries, not only because migrants tend to be younger, but also because of higher fertility levels.⁵⁵ Compared with those born in the UK, migrants in the UK are less likely to be children or of retirement age. In 2021 it was estimated that migrants are more likely to be aged 26 to 64 years, with 70 per cent of foreign-born residents falling in this age category compared with 48 per cent of the UK born residents.⁵⁶

- 1.15 A common way of analysing the implications of population structures within a particular country or region has been the 'age dependency ratio', defined as the ratio of people aged over 64 ('dependents') to those of 'working age'.⁵⁷ A rising dependency ratio (as seen in the UK over the last 10–15 years) is seen as a source of concern, leading to widespread debate about how public sector finances, in particular, can respond to this so-called 'demographic time bomb'.⁵⁸ However, this approach to analysing the social and personal implications of age structural change has been strongly challenged, because of its overly simplistic categorisation of all adults over 64 as dependent and passively in need of support from younger people.⁵⁹ A particular focus of criticism of this metric is its starting assumption that life necessarily follows a sequential pattern of study, work, retirement, without any reference to the scope (and increasing reality) of different and more flexible modes of living and contributing – including contributions made throughout the life course outside the paid economy.

⁵¹ Office for National Statistics (2022) *Births in England and Wales: 2021*, available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/bulletins/birthsummarytablesenglandandwales/2021>.

⁵² Office for National Statistics (2022) *Deaths registered in England and Wales: 2021*, available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2021#age-standardised-mortality-rates-by-sex>.

⁵³ See, for example, Trickey A, Zhang L, Sabin CA et al. (2022) Life expectancy of people with HIV on long-term antiretroviral therapy in Europe and North America: a cohort study *The Lancet Healthy Longevity* **3** (Supplement 1): S2.

⁵⁴ The Migration Observatory (2023) *The impact of migration on UK population growth*, available at: <https://migrationobservatory.ox.ac.uk/resources/briefings/the-impact-of-migration-on-uk-population-growth/>.

⁵⁵ Harper S (2016) The important role of migration for an ageing nation *Journal of Population Ageing* **9**(3): 183-9.

⁵⁶ The Migration Observatory (2022) *Migrants in the UK: an overview*, available at: <https://migrationobservatory.ox.ac.uk/resources/briefings/migrants-in-the-uk-an-overview/>.

⁵⁷ The World Bank (2019) *Age dependency ratio, old (% of working-age population)*, available at: <https://data.worldbank.org/indicator/SP.POP.DPND.OL>.

⁵⁸ See, for example, media coverage such as The Telegraph (13 July 2022) *Europe faces ageing population nightmare in 'absolute collapse'*, available at: <https://www.telegraph.co.uk/business/2022/07/13/europe-faces-ageing-population-nightmare-absolute-collapse/>.

⁵⁹ See, in particular, Dixon A (2020) *The age of ageing better?* (London: Bloomsbury).

- 1.16 As we have already seen in our discussion of the inequalities within the UK with respect to both overall and healthy life expectancy, people's health and support needs during later life are extraordinarily variable, and their ability and desire to remain socially and economically active is similarly diverse. It is certainly important not to downplay the likely support needs of older adults with high health needs – but equally important not to lose sight of the ways in which many people remain highly active and engaged in their 60s, 70s, 80s, and beyond. This introduces a theme throughout the report – that the way we think about ageing as a society, and our often unconscious ageism, influences the path that research and innovation takes, and needs repeatedly to be challenged.
- 1.17 This critique of how we need to think about the consequences of demographic change also highlights a crucial question about the nature of the challenges that biomedical science and technological innovation are being expected to address. In other words, how is the 'problem' being defined, to which science and technology might be a solution? In particular, it is important to question the common assumption that increasing numbers of older people should be characterised primarily as representing a burden on society that will become increasingly hard for that society to afford. **The starting point for this working group in embarking on its inquiry is that the focus of social policy in this area should be on the opportunities offered by longer, healthier life, including the opportunity to continue to play an active role within one's community. The specific role of this inquiry is then to consider the role that research and innovation can play, within this wider picture, in supporting people to flourish in older age, for both current and future generations of older adults across the whole of society. This includes being aware of the many non-technological ways in which society needs to change to better meet the needs of older people.**
- 1.18 The tendency, both in public policy concerned with ageing and in the media, to think in terms of 'burden' also highlights the need for a more nuanced account of dependency, an issue to which we return in Chapter 5 (see in particular paragraphs 5.3–5.10).

The wider context: ageing, public health, and inequalities

"The current gaps in health outcomes between most and least deprived individuals reveal striking improvements to health inequalities can likely be made by addressing social determinants of health, without relying entirely on such advances in biomedical and technological approaches."⁶⁰

"We have been saying for some time that we must address all the social determinants of health – education, jobs, homes, jobs, opportunities and the communities we live in – to achieve long lives spent in good health and to narrow health inequalities."⁶¹

"Research should focus more on 'what works' and then on communicating these messages. For example, we know physical activity works but we aren't managing to convince people to do it."⁶²

- 1.19 The specific focus within this inquiry on biomedical research and technological innovation is influenced both by the Nuffield Council's own terms of reference, and by its current

⁶⁰ The Academy of Medical Sciences, responding to our call for evidence.

⁶¹ Centre for Ageing Better blog (23 July 2021) *Why are people living longer?*, available at: <https://ageing-better.org.uk/blogs/why-are-people-living-longer>.

⁶² International Longevity Centre UK, responding to our call for evidence.

policy relevance. However, as we emphasised in our introduction, we are highly alert to the need to avoid looking at the contribution of such research and innovation in a vacuum. In exploring the question as to the role that biomedical research and technological innovation can play, we are also bound to look at the question of what can be better achieved in other ways, or indeed through a combination of technological and non-technological approaches, drawing on many other forms of research endeavour including the social and behavioural sciences.⁶³ Our remit within this inquiry is thus not only to explore what biomedical science and technology can offer, but also what they cannot or should not offer, or where they should play a subsidiary or hybrid role.

- 1.20 In particular, it is essential to emphasise the central role of the wider **social determinants of health** in influencing both how our bodies age, and our associated capacity to live well in later life. To this extent, policy concerned with ‘healthy ageing’ or ‘healthy longevity’ overlaps to a very strong degree with another major area of public policy: that of public health.⁶⁴ Numerous reports over recent decades (including the *Black Report*,⁶⁵ the *Marmot Review*,⁶⁶ and the *Marmot Review 10 years on*⁶⁷) have documented how poverty, inequality, discrimination, and disadvantage of many kinds strongly influence health, both by their direct impact on mental and physical health, and by the way in which they affect access to, and use of, healthcare services.⁶⁸ As Marmot put it succinctly: “Health inequalities arise from a complex interaction of many factors – housing, income, education, social isolation, disability – all of which are strongly affected by one’s economic and social status.”⁶⁹
- 1.21 These well-evidenced and interconnecting factors that affect health and life chances from childhood onwards have cumulative effects that then strongly influence how people experience getting older and living in older age.⁷⁰ Indeed, the WHO’s *World Report on Ageing and Health* highlights how 75 per cent of the diversity in people’s physical and mental capacities in older age is “largely the result of the cumulative impact of behaviours and exposures during a person’s life course”.⁷¹ This is where an intersectional perspective is particularly important: depending on people’s life experiences and circumstances, the effects of a number of different forms of disadvantage will not only accumulate over time but also compound, leading to multiple jeopardy in later life. The

⁶³ See, for example, Collider Health blog (2022) *Healthy longevity for all: a blueprint to maximise equitable health and wealth*, available at: <https://www.colliderhealth.com/blog>.

⁶⁴ See: Public Health England (2019) *All our health: about the framework*, available at: <https://www.gov.uk/government/publications/all-our-health-about-the-framework/all-our-health-about-the-framework>.

⁶⁵ Socialist Health Association (1980) *The black report 1980*, available at: <https://www.sochealth.co.uk/national-health-service/public-health-and-wellbeing/poverty-and-inequality/the-black-report-1980/>.

⁶⁶ Institute of Health Equity (2010) *Fair society, healthy lives (the Marmot review)*, available at: <https://www.instituteoftheequity.org/resources-reports/fair-society-healthy-lives-the-marmot-review>.

⁶⁷ The Institute of Health Equity (2020) *Health equity in England: the Marmot review 10 years on*, available at: <https://www.health.org.uk/publications/reports/the-marmot-review-10-years-on>.

⁶⁸ See: The King’s Fund (2022) *Equity and endurance: how can we tackle health inequalities this time?*, available at: <https://www.kingsfund.org.uk/publications/how-can-we-tackle-health-inequalities>; and The Health Foundation (2018) *What makes us healthy? An introduction to the social determinants of health*, available at: <https://www.health.org.uk/publications/what-makes-us-healthy>.

⁶⁹ Institute of Health Equity (2010) *Fair society, healthy lives (the Marmot review)*, available at: <https://www.instituteoftheequity.org/resources-reports/fair-society-healthy-lives-the-marmot-review>.

⁷⁰ See, for example, The Health Foundation (2022) *Quantifying health inequalities in England*, available at: <https://www.health.org.uk/news-and-comment/charts-and-infographics/quantifying-health-inequalities>; and Bennett HQ, Kingston A, Spiers G *et al.* (2021) Healthy ageing for all? comparisons of socioeconomic inequalities in health expectancies over two decades in the cognitive function and ageing studies I and II *International Journal of Epidemiology* **50**(3): 841-51. For a policy overview on the impact of the social determinants of health on healthy life expectancy, see: Centre for Ageing Better blog (2022) *Why are only some of us living longer?*, available at: <https://ageing-better.org.uk/blogs/why-are-only-some-us-living-longer>.

⁷¹ WHO (2015) *World report on ageing and health*, available at: <https://apps.who.int/iris/handle/10665/186463>, at page 66.

following influential and intersecting factors need to be taken into account in exploring how both today's and future older generations can better be supported to flourish.

- **Lifelong experiences of discrimination and exclusion**, in particular through structural and interpersonal racism, and the impact of this both on people's socioeconomic situations and directly on their physical and mental health.⁷²
- **Poverty**:⁷³ including the associated impacts of poor housing and homelessness,⁷⁴ insecure work,⁷⁵ and difficulties in maintaining a healthy diet.⁷⁶ While remaining in work for longer can be an important factor in financial security in later life, raising the state pension age in the UK has been shown to lead to increased poverty among 65 year olds.⁷⁷
- **Sex/gender**: women spend a significantly greater proportion of their lives in poor health and disability when compared with men (see Box 1.3) and, as recognised in the 2022 *Women's Health Strategy for England*, have long experienced inadequate care and support with respect to age-related medical conditions because of a 'male by default' approach to clinical research and care.⁷⁸ This has led to a treatment gap both with respect to particular vulnerabilities related to biological sex (such as the risks of osteoporosis after the menopause), and gender-specific presentation of conditions that affect everyone (such as cardiovascular disease) resulting in delayed diagnosis. Older transgender adults are at particularly high risk of poor physical and mental health.⁷⁹
- **Disability**: people living with disability experience barriers in many aspects of their lives, which in turn impact on their ability to be financially secure and socially connected in later life.⁸⁰ People living in poverty are more likely to develop long-term health conditions or impairments earlier in life, the experience of which predicts further health inequalities later. At whatever point in life people start to live with disability, important issues arise around accessible environments, including accessible

⁷² See, for example, Lewisham Council and Birmingham City Council (2022) *Birmingham and Lewisham African Caribbean health inequalities review (BLACHIR)* available at: https://www.birmingham.gov.uk/downloads/file/23111/blachir_report; Dreyer NA (2022) Strengthening evidence-based medicine with real-world evidence *The Lancet Healthy Longevity* **3(10)**: e641-e2; and The Hastings Center (2022) *Racism and health equity*, available at: <https://www.thehastingscenter.org/briefingbook/racism-and-health-equity/>. See also: ScienMag (9 August 2022) *BU researcher receives \$4M NIH grant to study the impact of cumulative racism on brain health*, available at: <https://scienmag.com/bu-researcher-receives-4m-nih-grant-to-study-the-impact-of-cumulative-racism-on-brain-health/>.

⁷³ Independent Age (2022) *Longer-term pensioner poverty and poverty transitions: a quantitative analysis of the understanding society survey (USoc)*, available at: <https://www.independentage.org/longer-term-pensioner-poverty-and-poverty-transitions-a-quantitative-analysis-of-understanding>. For public attitudes to, and concerns about, the state pension, see: Phoenix Insights (2022) *'Reaching a certain age': public attitudes to the state pension*, available at: https://www.thephoenixgroup.com/sites/phoenix-group/files/EC1162679_Phoenix_Insights_StatePensionReport.pdf. For a robust discussion of how secure income and high social status affect longevity, see: The Lancet Healthy Longevity (2022) *HM Queen Elizabeth II: an exemplar of healthy longevity* *The Lancet Healthy Longevity* **3(10)**: e636.

⁷⁴ See, for example, Brown RT, Evans JL, Valle K *et al.* (2022) Factors associated with mortality among homeless older adults in California: The HOPE HOME Study *JAMA Internal Medicine* **182(10)**: 1052-60.

⁷⁵ Frech A, Damaske S, and Ohler A (2022) The life course of unemployment and midlife health *Journal of Aging and Health* **34(6-8)**: 1081-91.

⁷⁶ See, for example, analysis by the Food Foundation that it would take 74% of disposable income for those in the bottom 10% of income to follow healthy eating guidelines: The Food Foundation (2021) *The broken plate*, available at: <https://foodfoundation.org.uk/sites/default/files/2021-10/The-Broken-Plate.pdf>, at page 18.

⁷⁷ Institute of Fiscal Studies (2022) *How did increasing the state pension age from 65 to 66 affect household incomes?*, available at: <https://ifs.org.uk/publications/how-did-increasing-state-pension-age-65-66-affect-household-incomes>. For public attitudes to, and concerns about, the state pension, see: Phoenix Insights (2022) *'Reaching a certain age': public attitudes to the state pension*, available at: https://www.thephoenixgroup.com/sites/phoenix-group/files/EC1162679_Phoenix_Insights_StatePensionReport.pdf.

⁷⁸ Department of Health and Social Care (2022) *Women's health strategy for England*, available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1100706/Womens-Health-Strategy-England-print.pdf, chapter 17.

⁷⁹ Fredriksen-Goldsen KI, Cook-Daniels L, Kim H-J *et al.* (2013) Physical and mental health of transgender older adults: an at-risk and underserved population *The Gerontologist* **54(3)**: 488-500.

⁸⁰ See, for example, VODG (2022) *Commission on covid-19, disability and systemic racism*, available at: <https://www.vodg.org.uk/resources/projects/commission/commission-covid-19-disability-systemic-racism.html>.

housing,⁸¹ the availability of necessary home adaptations,⁸² and the provision of adequate housing with care support.⁸³

- **Educational disadvantage:** lower levels of education are strongly associated with poorer baseline health in older age, although further research is needed to understand the mechanisms of health inequalities across education and wealth in different societies.⁸⁴
- **Regional disparities:** in addition to the inequalities of health linked with location and deprivation, set out in Box 1.3, other aspects of place, such as rurality, can play a significant part in access to health services.⁸⁵

1.22 In 2016, the Foresight programme within the Government Office for Science published a major review, *Future of an Ageing Population*, to consider what action should be taken in response to the demographic shift taking place within the UK (see paragraphs 1.14–1.18).⁸⁶ While specifically focusing on what action might need to be taken to help ensure that people in later life are “empowered, skilled, healthy and able to contribute fully to society”, the review’s conclusions and recommendations, set out in Box 1.5, covered remarkably similar ground to earlier inquiries concerned more broadly with health inequalities, such as the Marmot Review.

Box 1.5: Foresight report: *Future of an Ageing Population* (2016)

The factors identified include the following.

- **The role of work:** supporting the ageing population to lead fuller and longer working lives, including through adaptations to the workplace, and enabling people to reskill during their working lives.
- **Lifelong learning:** addressing falling participation in lifelong education and training, barriers to later life learning, with a particular focus on technological and financial skills through life.
- **Housing and neighbourhood:** ensuring there is appropriate housing, thinking ‘beyond the building’ to include the neighbourhood and community; and preparing for the impact of variable home ownership rates, including the financial burden of large mortgages or renting in retirement.
- **The role of families:** including being alert to increasingly diverse family types, and their variable ability to provide social support and care; and considering the impact of policies on the whole life course, including understanding dependencies within generations.

⁸¹ See, for example, Irwin Mitchell (2022) *Unlocking potential for seniors housing development: meeting the need of an ageing population*, available at: <https://www.irwinmitchell.com/news-and-insights/in-focus/seniors-housing-report>.

⁸² Chandola T, and Rouxel P (2022) Home modifications and disability outcomes: a longitudinal study of older adults living in England *The Lancet Regional Health - Europe* **18**: 100397; and British Society of Gerontology blog (26 May 2022) Home adaptations and disability outcomes among older adults living in England, available at: <https://ageingissues.wordpress.com/2022/05/26/home-adaptations-and-disability-outcomes-among-older-adults-living-in-england/>.

⁸³ A review, led by Professor Les Mayhew and the International Longevity Centre UK, has begun to identify the level of unmet need for housing-with-care for older people in the UK, see: The Associated Retirement Community Operators (7 March 2022) *Calls for right to suitable housing for older people as review launches to assess shortfall*, available at: <https://www.arcouk.org/press-release/calls-for-right-to-suitable-housing-for-older-people-as-review-launches-to-assess>.

⁸⁴ See, for example, Wu YT, Daskalopoulou C, Muniz Terrera G *et al.* (2020) Education and wealth inequalities in healthy ageing in eight harmonised cohorts in the athlos consortium: a population-based study *Lancet Public Health* **5(7)**: e386-e94.

⁸⁵ The Covid-19 pandemic has impacted dementia diagnosis rates and regional variations of support and performance in England, see: Future Health (2022) *Levelling up dementia diagnosis: tackling variations in diagnosis rates in England*, available at: https://www.futurehealth-research.com/site/wp-content/uploads/2022/05/220505_Levelling-Up-Dementia-Diagnosis-Web-.pdf.

⁸⁶ 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/816458/future-of-an-ageing-population.pdf.

- **The role of health and care systems:** adapting systems to respond to changing demand; supporting family and other unpaid carers; and capitalising on opportunities of new technologies.
- **Social, physical, and technological connectivity:** responding to the transport needs of different age groups; designing the built environment to maximise the physical mobility of older adults; and addressing barriers to technology use.

1.23 Recent research with people living in some of the areas of England with particularly low healthy life expectancy also demonstrated strong awareness among members of the public of how these wider social factors affect their ability to maintain healthy lifestyles earlier in life (see Box 1.6).⁸⁷

Box 1.6: What people living in areas with low healthy life expectancy want: the *Healthy Places* report

The *Healthy Places* report presented perspectives on how people imagine a healthy place to live. It drew on six focus groups in three areas with some of the lowest healthy life expectancies in the country (Wakefield, West Bromwich, and Blackpool), alongside a national online poll. “Participants spoke passionately about what they imagined a healthy place to be: a place where they can safely enjoy a walk in local parks, where they feel connected with other members of their community, and where they have ample access to green space. These views are shared by the wider public who want to see funding for GPs and hospitals, but also green spaces, affordable housing, low pollution and low crime.” The following are some of the quotes from participants presented in the report.

- “For me, it’s open green spaces. So access to parks and green spaces where you can get fresh air and exercise.” *Participant, Wakefield*
- “[Work] is good for your mental health as well. It provides routines and stability.” *Participant, West Bromley*
- “Free exercise for the younger generation as well. Some clubs and outdoor sort of clubs for those because in a few years’ time, they’re going to become our age. So I think that has a knock on effect.” *Participant, Wakefield*
- “If there’s a lack of jobs, or apathy, then you know, they just end up in this unhealthy lifestyle of eating unhealthy, drinking, a lot smoking.” *Participant, Blackpool*
- “Quality housing, get rid of absent landlords.” *Participant, Blackpool*

1.24 We set out below in Box 1.7 some (necessarily indicative) examples of initiatives that have been seeking in recent years to address these wider social and environmental influences on how people age within the UK. The Welsh Government has also launched a dedicated **Ageing Strategy**,⁸⁸ supported by a Ministerial Advisory Forum on Ageing that enables older adults and organisations representing older people to comment on and shape policy within the Welsh Government,⁸⁹ and both Wales and Northern Ireland have Older People’s Commissioners to champion older adults’ interests.⁹⁰ There is

⁸⁷ Public First (2022) *Healthy places: the case for action on healthy life expectancy*, available at: <https://www.publicfirst.co.uk/wp-content/uploads/2022/07/Healthy-Places-Public-First-for-the-Health-Foundation.pdf>, at page 11.

⁸⁸ Welsh Government (2021) *Age friendly Wales: our strategy for an ageing society*, available at: <https://gov.wales/sites/default/files/pdf-versions/2021/10/4/1633593161/age-friendly-wales-our-strategy-ageing-society.pdf>.

⁸⁹ Welsh Government (2020) *Ministerial advisory forum on ageing*, available at: <https://gov.wales/ministerial-advisory-forum-ageing-mafa>.

⁹⁰ Older People’s Commissioner for Wales (2022) *An independent voice and champion for older people*, available at: <https://olderpeople.wales/>; and Commissioner for Older People for Northern Ireland (2022) *About us*, available at: <https://www.copni.org/about-us>.

strong pressure for similar approaches elsewhere in the UK.⁹¹ These positive developments, however, are taking place in the context of the major challenges of social isolation and reduced physical activity experienced by so many older adults during COVID-19 (see Box 2.9), the impacts of the current cost-of-living crisis, and significant funding and staffing pressures on public services.⁹²

Box 1.7: Policy initiatives supporting wider social and environmental influences on ageing

- Building on the World Health Organization-led approach of ‘age-friendly environments’,⁹³ the UK Network of **Age-friendly Communities** is a growing movement with over 50 members across England, Scotland, Wales, and Northern Ireland.⁹⁴ This initiative involves local groups, councils, businesses, and residents all working together to identify and make changes in physical and social environments, such as transport, outdoor spaces, volunteering and employment, leisure, and community services. The newer concept of **longevity cities** aims to focus on the “urban physical environment” by bringing together innovation, services, data, and experiences to maximise the potential of high streets, businesses, and neighbourhoods so that everyone can live healthier, longer lives.⁹⁵
- Organisations such as the Centre for Ageing Better and the International Longevity Centre UK are spearheading initiatives to support **flexible work environments** that enable people to work for longer and have an adequate income in retirement.⁹⁶
- The Housing Learning and Improvement Network (LIN) aims to “[bring] together housing, health and social care professionals in England, Wales, and Scotland to exemplify **innovative housing solutions** for an ageing population”.⁹⁷ Funded by the Dunhill Medical Trust in 2021, the LIN launched the Technology for our Ageing Population: Panel for Innovation (TAPPI) project, which aims to identify technology and digital infrastructure that supports future care needs and that can be built into new housing. The initiative finished phase one in 2021, which included hearing from people with lived experience on technological opportunities and barriers, especially

⁹¹ See, for example, Anchor (2022) *A minister for older people*, available at: <https://www.anchor.org.uk/media/campaigns-and-research/minister-for-older-people>; Express (3 September 2022) *Give them a voice: brits support express campaign for minister for older people*, available at: <https://www.express.co.uk/news/uk/1663908/minister-for-older-people-give-them-a-voice-campaign>; and Centre for Ageing Better (20 October 2022) *Calls for an older people’s commissioner in England made in House of Lords*, available at: <https://ageing-better.org.uk/news/calls-older-peoples-commissioner-england-made-house-lords>.

⁹² See, for example, Local Government & Social Care Ombudsman (12 October 2022) *Complaints about English social care increasingly due to funding constraints*, available at: <https://www.lgo.org.uk/information-centre/news/2022/oct/complaints-about-english-social-care-increasingly-due-to-funding-constraints-ombudsman>.

⁹³ WHO (2022) *Age-friendly environments*, available at: <https://www.who.int/teams/social-determinants-of-health/demographic-change-and-healthy-ageing/age-friendly-environments>.

⁹⁴ See: Centre for Ageing Better (2022) *UK network of age-friendly communities*, available at: <https://ageing-better.org.uk/uk-network-age-friendly-communities>. See also: Age Cymru (2022) *Age friendly Wales*, available at: <https://www.ageuk.org.uk/cymru/our-work/age-friendly-wales/#>; and WHO (2018) *The global network for age-friendly cities and communities*, available at: https://www.who.int/ageing/projects/age_friendly_cities_network/en/.

⁹⁵ See: Wang C, Sierra Huertas D, Rowe JW *et al.* (2021) Rethinking the urban physical environment for century-long lives: from age-friendly to longevity-ready cities *Nature Aging* **1(12)**: 1088-95; and National Innovation Centre Ageing blog (4 September 2021) *Health is the new wealth – Newcastle: city of longevity*, available at: <https://uknica.co.uk/blog/2021/09/04/health-is-the-new-wealth-newcastle-city-of-longevity/>.

⁹⁶ See, for example, Centre for Ageing Better (23 June 2022) *New training increases support for older jobseekers in Greater Manchester*, available at: <https://ageing-better.org.uk/news/new-training-increases-support-older-jobseekers-greater-manchester>; Centre for Ageing Better (2022) *Employment*, available at: <https://ageing-better.org.uk/employment>; and International Longevity Centre UK (2022) *Work for tomorrow: can innovation support work in an ageing world?*, available at: <https://ilcuk.org.uk/wp-content/uploads/2022/09/ILC-Work-for-Tomorrow-Key-Learnings.pdf>. Also see: Business for Health (2021) *Business framework for health*, available at: <https://www.businessforhealth.org/business-index>.

⁹⁷ Housing LIN (2022) *Who we are*, available at: <https://www.housinglin.org.uk/AboutHousingLIN/>.

during COVID, and setting out ten practical principles for using technology in houses for older people.⁹⁸ The second phase of TAPPI was launched in March 2022.⁹⁹

- Following on from the launch of the Office of Health Improvement and Disparities, organisations such as Age UK¹⁰⁰ and the Centre for Ageing Better¹⁰¹ are bringing attention to the impact that **racism and discrimination** has on health in later life.

Acting on the evidence

- 1.25 The size of the gap – up to 20 years – between the healthy life expectancy of people living in different parts of the UK, and the strength of the evidence base underpinning public health interventions, reinforces the scope for drawing on *existing* knowledge to narrow that gap (see also paragraphs 2.9–2.13). While science and innovation are likely to have much to offer – and indeed innovation may play a transformative role in helping implement what is already known¹⁰² – the willingness of policymakers to respond to the findings of researchers will be crucial if those findings are to make a recognisable difference to people’s lives.¹⁰³ These decisions are often both politically and financially challenging: in April 2022, for example, the then Chancellor of the Exchequer made explicit reference to the “hard conversations” that would be needed with respect to the funding that would be required to enable people to live with dignity in retirement.¹⁰⁴ While this inquiry has been primarily concerned with the research endeavour, we have also sought where possible to address the importance of translation – how research and innovation actually impact on people, the associated ethical questions that arise, and the need for those with the power to act on the evidence to do so.
- 1.26 In particular, in thinking about translation, a primary concern for the working group has been to consider how innovations in biomedical research and technological innovation may have scope to help reduce the inequalities we have highlighted – or, on the contrary, whether there are risks that such innovations may actually *exacerbate* existing inequities.
- 1.27 **We conclude that reducing inequalities in the ability to live well in older age should be a core aim of research and innovation in this field. The UK Government’s expressed aim of offering global leadership in this field reinforces the importance of ensuring that this concern to reduce inequalities is solidly embedded in the UK approach.**

⁹⁸ Housing LIN (2021) *The TAPPI inquiry report*, available at: https://www.housinglin.org.uk/_assets/Resources/Housing/Support_materials/Reports/HLIN-TAPPI-Report.pdf.

⁹⁹ Housing LIN (29 March 2022) *The Dunhill Medical Trust officially launch TAPPI: phase 2 from principles to implementation, in partnership with the Housing LIN and TSA*, available at: <https://www.housinglin.org.uk/News/The-Dunhill-Medical-Trust-officially-launch-TAPPI-Phase-2-From-Principles-to-Implementation-in-partnership-with-the-Housing-LIN-and-TSA/>.

¹⁰⁰ Age UK (22 October 2021) *Breaking down the barriers of ethnic inequalities in health*, available at: <https://www.ageuk.org.uk/discover/2021/october/breaking-down-the-barriers-of-ethnic-inequalities-in-health/>

¹⁰¹ Centre for Ageing Better (2021) *Ethnic health inequalities in later life*, available at: <https://ageing-better.org.uk/sites/default/files/2021-11/health-inequalities-in-later-life.pdf>.

¹⁰² See, for example, the government funding a free NHS 12-week weight loss plan app to help individuals maintain a healthier weight: Department of Health and Social Care (4 March 2021) *New specialised support to help those living with obesity to lose weight*, available at: <https://www.gov.uk/government/news/new-specialised-support-to-help-those-living-with-obesity-to-lose-weight>. A UKRI project exploring housing design innovations to address the impact of people’s homes on their experience of cognitive changes, see: UKRI (2022) *Designing homes for healthy cognitive ageing: cognitive ageing: co-production for impact and scale (DesHCA)*, available at: <https://gtr.ukri.org/projects?ref=ES%2FV016059%2F1>.

¹⁰³ See, for example, the International Longevity Centre UK response to the Government’s Levelling Up White Paper: International Longevity Centre UK (3 February 2022) *ILC responds to government’s levelling up white paper*, available at: <https://ilcuk.org.uk/ilc-responds-to-governments-levelling-up-white-paper/>.

¹⁰⁴ For Chancellor Rishi Sunak’s Mais lecture 2022, see: WiredGov (25 February 2022) *Chancellor Rishi Sunak’s mais lecture 2022*, available at: <https://www.wired.gov.net/wg/news.nsf/articles/Chancellor+Rishi+Sunaks+Mais+Lecture+2022+25022022134300?open>.

Chapter 2

Attitudes to ageing

Chapter 2 – Attitudes to ageing

Overview of Chapter 2

Why attitudes to ageing matter in research

- Research and development connected with ageing does not take place in a vacuum. It is influenced and steered by prevailing attitudes to ageing, and by often negative assumptions and stereotypes about the attributes and roles of older adults.

Ageing in years, biological ageing, and ageism

- The term 'ageing' is used in two quite different ways. Chronological ageing refers to our age in years and, depending on many factors, can be experienced positively. Biological ageing refers to the biological changes that take place throughout our lives in our bodies. These lead, over time, to declining function, and ultimately to death.
- The relationship between these two aspects of ageing is not straightforward. We cannot change how we age chronologically. However biological age is malleable – many factors (both inside and outside our control) affect how, and how fast, our bodies age.
- While it is an inevitable part of being human that our bodies will age, and ultimately decline, this does not affect our equal moral worth as human beings. In practice, however, negative attitudes to people because of their age (ageism) can have a powerful influence on older adults' life experience and opportunities including by negatively affecting both their health and their sense of themselves. Ageist attitudes can get built into research and innovation – for example by assuming that older adults will not value or want particular things.

A life-course approach to ageing

- Ageing (both biological and chronological) takes place throughout life – we do not 'become old' at a particular age. Specific markers associated with old age, such as retirement from work, or the age at which a state pension is paid, reflect particular societies' choices, expectations, and economic models.
- Our experiences throughout our lives affect how and at what speed our bodies age, highlighting the scope for intervening early to support better health and physical function in older age. Much is already known about the effectiveness of taking a preventative approach to good health, through supporting healthy lifestyles, and tackling the 'social determinants of health' such as poverty and discrimination.
- However, everyone's life course is different – what is normal healthwise for one person in their 80s may be normal for another in their 50s. People living with lifelong health conditions or disabilities may have a different trajectory from those without. Research, and the implementation of new treatments and services resulting from research, will need to take this diversity into account.

What does it mean to 'age well'?

- People value many things other than their health in older age – indeed health is often valued as a means to do other things (achieve personal goals, stay connected with family and friends, support others, get out and about) rather than simply for itself. Being able to do valued activities in turn promotes health and wellbeing.
- This report uses the language of 'ageing well' (rather than 'healthy' or 'successful' ageing) to capture this wider sense of what is valued in later life. It also recognises that not everyone can age healthily – but everyone can age well.

Introduction: why attitudes to ageing matter in research

“One of the great mysteries of the modern era is why having invested so heavily in health & living longer, we don’t adapt the world so we can live well as we age. I think it’s because we’re focussed on living longer by evading ageing, not on becoming older.”¹⁰⁵

“[importance of] changing the social perceptions of ageing – to reduce the fatalism sometimes associated with the ageing process”.¹⁰⁶

“The range of research topics may be circumscribed by attitudes to ageing. Much population research focuses on negative aspects of ageing, including the development of health problems, decline in cognitive function, poverty, loneliness, disability and so on. These are important issues, but at the same time there is growing evidence that sustained social and intellectual engagement and sense of purpose are important to the maintenance of health and wellbeing.”¹⁰⁷

- 2.1 Research and development connected with ageing does not take place in a vacuum. The focus of research agendas and funding, the priority given to particular research projects, and the way that individual research projects are conducted are all influenced and shaped by attitudes to ageing prevailing in contemporary society – and by associated assumptions about the attributes, roles, needs, and preferences of older adults. Buried within some of the existing approaches to age-related biomedical research and innovation are deeply embedded assumptions about ageing and older age.
- 2.2 The relevance of the attitudes and assumptions underlying research in this field for the ethical conduct of such research was highlighted by one of the contributors to the Future of Ageing Open Forum, held by the working group in partnership with Sonder Radio, to elicit experiences and perspectives on ageing from diverse older adults in Manchester.¹⁰⁸ They identified how the very offer of “biomedical solutions to ageing” itself raised ethical questions: “which says ageing in itself is a bad thing, it doesn’t think of ageing as part of the life course or think of older adults as people in our communities”.¹⁰⁹ In other words: how is the ‘problem’ being presented or understood, for which research and innovation is seeking to offer a solution? This challenge to how research in ageing should be framed, and what it is seeking to achieve, mirrors similar contemporary challenges to the question of how the care ‘sector’ is understood and what it should fundamentally be aiming to do: as seen, for example, in the vision of social care presented by the user-led organisation

¹⁰⁵ Twitter (2021) *Tweet: Neil Crowther*, available at: <https://mobile.twitter.com/neilmcrowther/status/1476167374827147269>.

¹⁰⁶ Dr Philippa Brice, PHG Foundation, responding to our call for evidence, citing: PHG Foundation (2018) *My healthy future: healthy ageing workshop*, available at: <https://www.phgfoundation.org/media/269/download/mhf-older-people-workshop-outcome.pdf?v=1&inline=1>.

¹⁰⁷ Professor Andrew Steptoe, responding to our call for evidence.

¹⁰⁸ Nuffield Council on Bioethics (2022) *Open forum with members of the Greater Manchester Older People’s Network, in collaboration with Sonder Radio*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/open-forum-with-members-of-the-greater-manchester-older-peoples-network-gmopn-and-other-residents-in-manchester-organised-in-collaboration-with-sonder-radio>.

¹⁰⁹ *ibid.*

Social Care Future,¹¹⁰ and in Age Platform Europe's position paper on care and support for older adults understood as empowerment throughout life.¹¹¹

- 2.3 In order to develop an ethical framework to help support research and innovation related to ageing, we need first to identify and critique the assumptions about ageing and older age that permeate both research and wider social policy. It is also important to recognise how the term 'ageing' itself is understood in different and sometimes conflicting ways. This chapter will begin by unpacking some of the different ways in which the term 'ageing' is used, and explore how these ambiguities can connect with ageism and the 'othering' of older adults, in ways that profoundly affect the direction of research and innovation. It will then touch briefly on what is known about people's preferences and needs as they get older – what 'living well' in older age might look like. Only then can we start to consider what biomedical science and technological innovation can offer in this field, and what ethical considerations should shape research agendas, practice, and implementation.

What do we mean by 'ageing'?

Chronological and biological ageing

"Ageing is not a pathological process and is globally accepted as a normal human attribute, with longevity being a privilege that we all hope to enjoy."¹¹²

"[F]rom a biological perspective, ageing is a largely deteriorative process, leading to degeneration, illness and death. Biologists call this senescence, a term which avoids the confusion that the word ageing can cause ... From my perspective as a scientist, talking of promoting positive attitudes to ageing in the context of research makes about as much sense as promoting positive attitudes to cancer."¹¹³

- 2.4 'Ageing' takes place throughout our lives. As the two quotations above illustrate, however, the term is used in (at least) two quite distinct ways:
- in terms of *getting older in years* ('chronological ageing'). In this sense, ageing can be experienced as positive, depending on many factors; and
 - in terms of *biological ageing*, leading to declining function. This is not positive in itself: indeed, ageing in this sense has been described as "a progressive degenerative state accompanied by tissue stem cell depletion, tissue inflammation, matrix alterations, cellular senescence, and metabolic dysfunction".¹¹⁴ However, crucially, the rate of

¹¹⁰ #socialcarefuture argues that the role of social care is to support people to live a good life: "we all want to live in the place we call home, with the people and things we love, in communities where we look out for one another, doing what matters to us.", see: #socialcarefuture (2023) *A vision for the future of social care*, available at: <https://socialcarefuture.org.uk/a-vision-for-the-future-of-social-care/>.

¹¹¹ Age Platform Europe (2021) *Care must empower us throughout our lives: our views on change in care and support for older people*, available at: <https://www.age-platform.eu/publications/care-must-empower-us-throughout-our-lives-age-position-paper>.

¹¹² Rabheru K, Byles JE, and Kalache A (2022) How "old age" was withdrawn as a diagnosis from ICD-11 *The Lancet Healthy Longevity* **3(7)**: e457-e9.

¹¹³ David Gems, responding to our call for evidence.

¹¹⁴ Chakravarti D, LaBella KA, and DePinho RA (2021) Telomeres: history, health, and hallmarks of aging *Cell* **184(2)**: 306-22.

progressive degeneration that our bodies inevitably undergo is highly malleable and, moreover, continues to be malleable throughout our lives.¹¹⁵

- 2.5 Failing to separate out these meanings of ageing can lead to the risk of people ‘talking past each other’ when discussing the challenges and opportunities of longer life and the age shift in the population. It can also be a major factor in ageism, automatically equating the (negative) physical changes in older age with the lives and experiences of older adults.¹¹⁶ It is certainly true that our bodies will eventually decline: that is part of being human. But physical decline does not affect our equal moral worth, or our ongoing human rights such as the rights to liberty and to a private and family life. The way that we live our lives and the contribution that we can make to others are not determined, even if they are influenced, by our ageing bodies.¹¹⁷
- 2.6 The fact that biological ageing is highly malleable – that our physical ageing trajectories are far from fixed – is a central underlying tenet of the biomedical research that we go on to review in the next chapter (see paragraphs 3.5–3.12). It also underlies the whole discipline of preventative approaches to good health (see paragraphs 2.9–2.13). It remains the case, however, that both healthcare practice and wider service provision commonly overlook this – with avoidable or reversible physical decline often simply being put down to ‘your age’.

An inclusive life-course approach to ageing

“Effective policy to promote healthy ageing should incorporate early social interventions in younger populations to yield improved health outcomes in later life.”¹¹⁸

“We have found in studies like ELSA [English Longitudinal Study of Ageing] that there are tremendous advantages in studying trajectories of change from middle-age into older age rather than separating the two. Experiences and actions taken in middle age (in lifestyle, economic choices, social participation, personal relationships, etc) have a profound impact on later life wellbeing, health and prosperity.”¹¹⁹

- 2.7 We are all ageing, both chronologically and biologically, throughout our lives. There is no set point when people enter ‘old age’ in any meaningful sense. Assumptions of old age as starting at a particular point, such as retirement, the state pension age, or on first becoming a grandparent, need to be recognised as social constructs, linked with social policies, structures, and expectations in particular societies.¹²⁰ Yet older adults are often

¹¹⁵ A further important aspect of ageing is ‘psychological ageing’ – our own sense of how old we are and what this means for us, which can then have a direct influence on the ways that our bodies age. See, for example, Kalir DM, Shrira A, Palgi Y *et al.* (2023) Feeling younger, rehabilitating better: reciprocal and mediating effects between subjective age and functional independence in osteoporotic fracture and stroke patients *Gerontology* **69**(1): 109-17; Sohn E (2022) How the COVID-19 pandemic might age us *Nature* **601**(7893): S5-s7; and *ibid.*

¹¹⁶ See, for example, Harper S (2020) The COVID-19 pandemic and older adults: institutionalised ageism or pragmatic policy? *Journal of Population Ageing* **13**(4): 419-25.

¹¹⁷ For discussion of how ageism and ‘ableism’ intersect, see: Berridge CW, and Martinson M (2018) Valuing old age without leveraging ableism *Generations* **41**(4): 83-91; and Reynolds JM, and Landre A (2022) Ableism and ageism: insights from disability studies for aging studies, in *Critical humanities and ageing: forging interdisciplinary dialogues*, de Medeiros K, Goldman M, and Cole T (Editors) (London: Routledge).

¹¹⁸ The Academy of Medical Sciences, responding to our call for evidence.

¹¹⁹ Professor Andrew Steptoe, responding to our call for evidence.

¹²⁰ Harper S (2006) *Ageing societies: myths, challenges and opportunities*, 1st Edition (London: Routledge); and Harper S (2023) *Ageing societies: risk and resilience*, (London: Routledge) (forthcoming 2023). In the Nuffield Council on Bioethics ‘future of

‘othered’, as if they form a separate, and distinct, social group or population (see paragraphs 2.15–2.22).

- 2.8 We discuss later the ethical ramifications of thinking about older age, and older adults, as being in some way distinct from the rest of the population, and the importance of rethinking our reference points for what is normal or mainstream (see paragraphs 5.3–5.10). Here, we make the more practical claim that there is no simple cohort that can be labelled ‘older adults’ or ‘the elderly population’: we will all become part of such a cohort at some point unless we are unfortunate enough to die early; and there is no defined joining point. Thinking about the challenges and opportunities associated with ageing is about everyone, whether now or in the future. This critique of thinking about ‘the elderly population’, as if older adults constituted a distinct and constant cohort of a country’s population, also highlights the importance of the language used when talking about ageing and older adults (see paragraph 2.17 and Box 2.5).
- 2.9 All these factors highlight the importance of taking a **life-course approach** in how we understand and approach ageing. In the context of this inquiry, this requires us to look at influences on biological ageing throughout life and how they can be mediated, whether through intervening directly in a person’s health, by providing tailored forms of adaptation or support to individuals, or by wider environmental changes.¹²¹ Such an approach is essential for a number of reasons. From an ethical perspective it continually prompts us to think about ageing and older age as part of a continuum that affects us all, and not as something negative that is about other people – hence challenging both the othering and fear associated with older age (see paragraphs 2.15–2.22). From a highly practical perspective, it highlights the central importance of **preventative approaches to good health throughout life**, reinforcing how much could be done with existing knowledge to enable people to live for longer in better health (see Box 2.1). This in turn provides a constructive challenge to those working within research and innovation in ageing regarding how they build on what is already known when identifying research priorities – and in particular of not overlooking the importance of preventative and rehabilitative approaches (e.g., see paragraph 5.51).
- 2.10 The need to focus on the scope for preventative approaches to improve people’s health throughout their lives – both at individual level (promoting healthy lifestyles) and wider public health approaches combatting the social determinants of health – was emphasised to the working group by members of the public, and by those working in the field who responded to our call for evidence. One participant in the Future of Ageing Open Forum held in partnership with Sonder Radio, for example, commented robustly how “We have the technology/wherewithal already, but a lot of the challenges of old age harks back to our earlier lives: whether we have the right diets, education opportunities, the right kind of housing ... [we are] storing up problems for the future for older people by the way that we are treating older people now (don’t even mention global warming...). Lots of simple solutions to enable people to live longer, fuller, healthier lives already there!”¹²² The Academy of Medical Sciences similarly highlighted how “the importance of

ageing’ public dialogue older participants emphasised how ‘old age’ is redefined as you get older because you still “don’t feel old”, while younger participants were more likely to identify retirement age as a fixed point for the start of ‘old age’, see: Nuffield Council on Bioethics (2023) *Public dialogue report on the future of ageing*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/public-dialogue-on-the-future-of-ageing>, at page 12.

¹²¹ See, for example, with reference to accessibility considerations, whether to meet physical or mental access needs: Dementia Services Development Centre (2022) *Environments for Ageing and Dementia Design Assessment Tool (EADDAT)*, available at: <https://www.dementia.stir.ac.uk/our-services/ea-ddat>.

¹²² Nuffield Council on Bioethics (2022) *Open forum with members of the Greater Manchester Older People’s Network, in collaboration with Sonder Radio*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence->

a preventative health strategy to extend healthy lifespan in an equitable manner” had been a strong theme at the ageing conference held by the Academy in partnership with the Royal Society in 2020.¹²³

Box 2.1: Preventative approaches to healthy ageing: healthy behaviours and low-tech interventions

Population studies have demonstrated how improvements in just four health-related behaviours (exercise, smoking, alcohol intake, and fruit and vegetable consumption) can predict a 14-year increase in lifespan.¹²⁴ Similarly, dementia is increasingly understood as the product of accumulated risk factors over life, many of which are modifiable.¹²⁵

Respondents to the working group’s call for evidence highlighted how preventative approaches in each of these domains might look different at different stages of life – and, crucially, how they remain important and effective in later life (it is never ‘too late’ to take preventative approaches). This was powerfully illustrated during the early stages of the COVID-19 pandemic: the detrimental impact of lockdowns on older adults’ physical conditioning, and the associated increased risk of falls, illustrated the significance of even very gentle exercise associated with leaving the house and walking round the block in helping maintain mobility and independence in later life.¹²⁶

Examples of tailored interventions at various life stages, cited in the literature and highlighted to the working group by respondents, include:

- fostering healthy attitudes and behaviours towards alcohol, smoking, diet, and exercise from a young age to reduce age-related health risks;¹²⁷
- intervening to prevent or mitigate mental disorders in adolescence;¹²⁸
- encouraging new mothers to do regular pelvic floor exercises, to prevent urinary incontinence in older age;¹²⁹
- taking action to promote good bone health, including through diet and exercise, particularly after the menopause;¹³⁰

gathering/open-forum-with-members-of-the-greater-manchester-older-peoples-network-gmopn-and-other-residents-in-manchester-organised-in-collaboration-with-sonder-radio.

¹²³ The Academy of Medical Sciences, responding to our call for evidence, citing: Royal Society and Academy of Medical Sciences (2020) *Healthy ageing*, available at: <https://royalsociety.org/-/media/events/2020/02/tof-healthy-ageing/Healthy-Ageing-Conference-Report-2020.pdf>. See also: The Academy of Medical Sciences (30 July 2020) *A ripe old age should be for everyone*, available at: <https://acmedsci.ac.uk/more/news/a-ripe-old-age-should-be-for-everyone>.

¹²⁴ Khaw KT, Wareham N, Bingham S et al. (2008) Combined impact of health behaviours and mortality in men and women: the EPIC-Norfolk prospective population study *PLoS Medicine* **5(1)**: e12. See also: Steel N, Ford JA, Newton JN et al. (2018) Changes in health in the countries of the UK and 150 English local authority areas 1990-2016: a systematic analysis for the global burden of disease study 2016 *Lancet* **392(10158)**: 1647-61.

¹²⁵ See, for example, LaPlume AA, McKetton L, Levine B et al. (2022) The adverse effect of modifiable dementia risk factors on cognition amplifies across the adult lifespan *Alzheimer’s & Dementia: Diagnosis, Assessment & Disease Monitoring* **14(1)**: e12337; and Livingston G, Huntley J, Sommerlad A et al. (2020) Dementia prevention, intervention, and care: 2020 report of the Lancet Commission *The Lancet* **396(10248)**: 413-46.

¹²⁶ Public Health England (2021) *Wider impacts of COVID-19 on physical activity, deconditioning and falls in older adults*, available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1010501/HEMT_Wider_Impacts_Falls.pdf. See also: the ‘Sit up, get dressed and keep moving!’ campaign, trying to reduce risks of deconditioning in hospital: British Geriatrics Society (29 July 2020) ‘Sit up, get dressed and keep moving!’, available at: <https://www.bgs.org.uk/policy-and-media/sit-up-get-dressed-and-keep-moving>.

¹²⁷ Royal Society and Academy of Medical Sciences (2020) *Healthy ageing*, available at: <https://royalsociety.org/-/media/events/2020/02/tof-healthy-ageing/Healthy-Ageing-Conference-Report-2020.pdf>.

¹²⁸ Moffitt TE, and Caspi A (2019) Psychiatry’s opportunity to prevent the rising burden of age-related disease *JAMA Psychiatry* **76(5)**: 461-2.

¹²⁹ The Academy of Medical Sciences, responding to our call for evidence. See also: Okeahialam NA, Oldfield M, Stewart E et al. (2022) Pelvic floor muscle training: a practical guide *British Medical Journal* **378**: e070186.

¹³⁰ Department of Health and Social Care (2022) *Women’s health strategy for England*, available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1100706/Womens-Health-Strategy-England-print.pdf, at page 108.

- good dental hygiene, and access to dental care, throughout life;¹³¹
- giving up smoking at any age;¹³²
- access to podiatry, particularly when foot self-care becomes difficult, to minimise foot pain, reduce the impact of diabetes, and maximise mobility;¹³³ and
- tailored exercise in older age,¹³⁴ and practical steps to prevent falls.¹³⁵

2.11 As Box 2.1 illustrates, there are many ways in which individuals can be enabled to adopt healthy behaviours at different stages in their lives, or minimise risks such as falls. These modifiable factors that affect how our bodies age are known to be strongly influenced by our lived environment including, crucially, socioeconomic factors.¹³⁶ One very powerful example is the link between affordability and healthy dietary choices.¹³⁷ Other factors that are potentially modifiable lie, in practice, outside the control of (most) individuals to change: for example the health impact of living in polluted areas with few green spaces and little opportunity for physical exercise.¹³⁸ The retention of basic physical capacities that can have a major impact on people’s ability to live well in later life – such as being able to eat and walk without pain – is affected both by economic disadvantage and by lack of access to preventative health services such as dentistry and podiatry.¹³⁹

2.12 As we discussed in Chapter 1 (see paragraphs 1.21–1.24), the social determinants of health exercise a powerful influence on health inequalities throughout life – emphasising again the importance of taking a life-course approach to ageing, and of recognising how those who have been disadvantaged earlier in life are likely to be particularly disadvantaged as older adults.¹⁴⁰ To be effective and equitable, approaches to prevention thus need to respond to social as well as behavioural causes of unhealthy lifestyles¹⁴¹ – and to be particularly alert to the risk that technology-driven approaches

¹³¹ See, for example, Aida J, Takeuchi K, Furuta M *et al.* (2022) Burden of oral diseases and access to oral care in an ageing society *International Dental Journal* **72(4)**: S5-S11. For the link between poor periodontal health and cognition, see: Asher S, Stephen R, Mäntylä P *et al.* (2022) Periodontal health, cognitive decline, and dementia: a systematic review and meta-analysis of longitudinal studies *Journal of the American Geriatrics Society* **70(9)**: 2695-709; and Wu H, Qiu W, Zhu X *et al.* (2022) The periodontal pathogen fusobacterium nucleatum exacerbates alzheimer’s pathogenesis via specific pathways *Front Aging Neuroscience* **14**: 912709.

¹³² See, for example, National Institute on Aging (2019) *Quitting smoking for older adults*, available at: <https://www.nia.nih.gov/health/quitting-smoking-older-adults>.

¹³³ Menz HB (2016) Chronic foot pain in older people *Maturitas* **91**: 110-4.

¹³⁴ Bull FC, Al-Ansari SS, Biddle S *et al.* (2020) World Health Organization 2020 guidelines on physical activity and sedentary behaviour *British Journal of Sports Medicine* **54(24)**: 1451-62.

¹³⁵ Age UK (2022) *Avoiding a fall*, available at: <https://www.ageuk.org.uk/information-advice/health-wellbeing/exercise/falls-prevention/>.

¹³⁶ Marteau TM, Rutter H, and Marmot M (2021) Changing behaviour: an essential component of tackling health inequalities *British Medical Journal* **372**: n332; and Loder E (2022) Improving our chances of a healthier future *British Medical Journal* **378**: o2274.

¹³⁷ Harrington J, Lutomski J, Molcho M *et al.* (2009) Food poverty and dietary quality: is there a relationship? *Journal of Epidemiology and Community Health* **63 (Supplement 2)**: 16.

¹³⁸ See, for example, European Environment Agency (2019) *Healthy environment, healthy lives: how the environment influences health and well-being in Europe*, available at: <https://www.eea.europa.eu/publications/healthy-environment-healthy-lives>; and Röhr S, Pabst A, Baber R *et al.* (2022) Social determinants and lifestyle factors for brain health: implications for risk reduction of cognitive decline and dementia *Scientific Reports* **12(1)**: 12965. Research has identified modifiable risk factors for dementia, from air pollution and lower levels of education, to obesity, depression, smoking and high alcohol consumption, see: Livingston G, Huntley J, Sommerlad A *et al.* (2020) Dementia prevention, intervention, and care: 2020 report of the Lancet Commission *The Lancet* **396(10248)**: 413-46.

¹³⁹ See, for example, inequalities in access to dental care among older adults and the impacts on physical health: Janto M, Iurcov R, Daina CM *et al.* (2022) Oral health among elderly, impact on life quality, access of elderly patients to oral health services and methods to improve oral health: a narrative review *Journal of personalized medicine* **12(3)**: 372. For the challenges of foot self-care among older adults, including support and financial barriers, see: Miikkola M, Lantta T, Suhonen R *et al.* (2019) Challenges of foot self-care in older people: a qualitative focus-group study *Journal of Foot and Ankle Research* **12(1)**: 5.

¹⁴⁰ See: Kroger T (2022) Social inequalities and care poverty, in *Care poverty: when older people’s needs remain unmet*, Kroger T (Editor) (Basingstoke: Palgrave Macmillan). See also: Walsh S, Merrick R, and Brayne C (2022) The relevance of social and commercial determinants for neurological health *The Lancet Neurology* **21(12)**: 1151-60.

¹⁴¹ See, for example, Marteau TM, Rutter H, and Marmot M (2021) Changing behaviour: an essential component of tackling health inequalities *British Medical Journal* **372**: n332; and Loder E (2022) Improving our chances of a healthier future *British Medical Journal* **378**: o2274.

such as lifestyle apps may actually add to inequality.¹⁴² Current examples of initiatives seeking to promote cultures of prevention both in wider social policy and in business culture (reflecting growing awareness of ‘commercial’ as well as ‘social’ determinants of health) are set out in Box 2.2.

Box 2.2: Policy and business approaches to prevention

The **International Longevity Centre UK** has conducted extensive work on ‘Delivering prevention in an ageing world’ and is now developing a Healthy Ageing and Prevention Index, which aims to capture economic and environmental aspects, as well as health aspects, of population health.¹⁴³ In a new programme of work from 2022–2025, they are aiming to use the index as a tool to encourage countries around the world to:

- invest in systems and structures designed for prevention;
- democratise access to prevention – to reduce health inequalities;
- inspire and engage policymakers, health professionals, and individuals – to invest, promote, and take action on prevention; and
- effectively utilise technology – to improve access to healthcare, improve uptake rates, reduce barriers, and empower patients.

There is also increasing awareness of what have been described as the ‘commercial determinants of health’ – the impact that business practices can have on our health.¹⁴⁴ In response, **Business for Health (B4H)** is working with the Confederation of British Industry (CBI) to incentivise and measure business contribution to increases in healthy life expectancy and reductions in inequalities with respect to health and wellbeing. With funding from the Health Foundation, B4H is developing the Business for Health Index, intended to measure the positive and negative health impacts of employers, businesses, and investors in three key areas:

- direct impact on employee health;
- secondary impacts on health via products and services; and
- contribution to community and societal resilience.

Building on the climate change agenda and net zero targets, B4H is aiming to bring health into the ‘environmental, social, and governance’ (ESG) agenda, thereby driving ‘ESHG’ investment: that is, investment that takes full account of environmental, social, health, and governance concerns. An ESHG framework focused on equitable health outcomes could help the business and investor community drive positive change, through long-term strategic projects that reduce the risk factors that can damage health, such as unhealthy food, poor work, pollution, and poor housing, and are incentivised and measured by their impact on positive health and wellbeing outcomes.¹⁴⁵

¹⁴² See, for example, Department of Health and Social Care, Office for Health Improvement and Disparities, Maggie Throup MP, and The Rt Hon Sajid Javid MP (22 October 2021) *New pilot to help people eat better and exercise more*, available at: <https://www.gov.uk/government/news/new-pilot-to-help-people-eat-better-and-exercise-more>; Western MJ, Armstrong MEG, Islam I et al. (2021) The effectiveness of digital interventions for increasing physical activity in individuals of low socioeconomic status: a systematic review and meta-analysis *International Journal of Behavioral Nutrition and Physical Activity* **18(1)**: 148; and Régnier F, and Chauvel L (2018) Digital inequalities in the use of self-tracking diet and fitness apps: interview study on the influence of social, economic, and cultural factors *JMIR mHealth and uHealth* **6(4)**: e101-e.

¹⁴³ International Centre Longevity UK (2022) *Delivering prevention in an ageing world programme*, available at: <https://ilcuk.org.uk/delivering-prevention-in-an-ageing-world/>.

¹⁴⁴ See, for example, SPECTRUM (2021) *The Commercial Determinants of Health (CDOH)*, adverse policy influence and conflicts of interest, available at: https://www.ed.ac.uk/files/atoms/files/spectrum_cdoh_and_policy_influence_131221.pdf.

¹⁴⁵ Business for Health blog (24 May 2021) *Levelling up health: why five more years of healthy life is a win-win for business and society*, available at: <https://www.businessforhealth.org/blogs/levelling-up-health-why-five-more-years-of-healthy-life-is-a-win-win-for-business-and-society>; and Business for Health blog (17 February 2022) *The positive disruptive power of business to enhance health*, available at: <https://www.businessforhealth.org/blogs/the-positive-disruptive-power-of-business-to-enhance-health>.

- 2.13 Despite the well-established evidence base on the modifiable nature of many of the risk factors for diseases associated with older age, relatively low priority is given either within or beyond the healthcare system to preventative approaches.¹⁴⁶ The working group's attention was drawn, for example, to the way that preventative and rehabilitative services are underfunded, and hence often underprovided: for example, while it would be unacceptable to prescribe an inadequate dose of chemotherapy, it is routine for physiotherapists only to be able to offer limited amounts of home-based rehabilitation, regardless of the lost opportunities for older people to maximise their recovery and prevent further deterioration.¹⁴⁷ Research into preventative approaches is similarly poorly funded, accounting for only 5.4 per cent of total public spending on health research.¹⁴⁸ Moreover, the importance of tackling hidden and stigmatised conditions such as incontinence are often overlooked in favour of initiatives and research tackling areas perceived as new, exciting, or groundbreaking (see also paragraph 4.17).¹⁴⁹
- 2.14 This recognition of the central role that preventative and public health approaches need to play in supporting a life-course approach to ageing well is particularly important in the context of growing awareness of the threats of climate change, and of the urgency of building sustainability into all aspects of health and healthcare. Indeed, population ageing has been described as a “crucible where health, sustainability, and equity interact and where alignment of agendas is crucial”.¹⁵⁰ There is an increasing call for a greater alignment of these agendas at both global and national level (see Box 2.3).

Box 2.3: Connecting climate change, sustainability, and ageing

It is well documented that population ageing will have an impact on our planet: from both increasing population growth and ever-increasing pressure on natural resources. It is also well evidenced that climate change will affect people's health. Older adults are likely to be disproportionately affected by changes to the climate, both directly (e.g., through the impact of extreme weather events, such as heatwaves, severe storms, and flooding) and indirectly (associated with factors such as the inability to produce enough nutritious food due to soil degradation or an increase in vector-borne disease transmission).¹⁵¹

Although it is widely recognised that there are explicit links between health, ageing, and climate change, in practice these policy agendas are often disconnected.¹⁵² In the 2015 World Health Organization's *World Report on Ageing and Health*, for example, it was noted that the lack of progress in global healthy ageing was at least in part due to lack of consideration of the health and wellbeing of older adults in the context of other global public health agendas, and, in particular, in the Sustainable Development Goals. The report went on to argue that: “without considering the health and well-being of older adults, many of these agendas do not make sense or will simply be unachievable”.¹⁵³

¹⁴⁶ For a robust critique of this ‘sickcare’, see: Collider Health blog (2022) *Healthy longevity for all: a blueprint to maximise equitable health and wealth*, available at: <https://www.colliderhealth.com/blog>.

¹⁴⁷ See, for example, Howard-Wilsher S, Irvine L, Fan H et al. (2016) Systematic overview of economic evaluations of health-related rehabilitation *Disability and Health Journal* **9(1)**: 11-25; and comments submitted by external reviewers.

¹⁴⁸ The Academy of Medical Sciences (2016) *Improving the health of the public by 2040*, available at: <https://acmedsci.ac.uk/snip/uploads/5807581429f81.pdf>.

¹⁴⁹ The Academy of Medical Sciences, responding to our call for evidence.

¹⁵⁰ Mavrodaris A, Lafortune L, and Brayne CE (2022) The future longevity: designing a synergistic approach for healthy ageing, sustainability, and equity *Lancet Healthy Longevity* **3(9)**: e584-e6.

¹⁵¹ Mavrodaris A, Mattocks C, and Brayne CE (2021) Healthy ageing for a healthy planet: do sustainable solutions exist? *The Lancet Healthy Longevity* **2(1)**: e10-e1.

¹⁵² Mavrodaris A, Lafortune L, and Brayne CE (2022) The future longevity: designing a synergistic approach for healthy ageing, sustainability, and equity *Lancet Healthy Longevity* **3(9)**: e584-e6.

¹⁵³ WHO (2015) *World report on ageing and health*, available at: <https://apps.who.int/iris/handle/10665/186463>, at page 4.

The International Centre for Longevity UK recently highlighted four key areas where alignments between these agendas can be made.¹⁵⁴

- **Healthy and sustainable places:** considering the links between sustainable transport, housing, and built environments and demographic change; for example, many adaptations needed for sustainability could also make infrastructure more age friendly. This alignment is highlighted in the UN Sustainable Development Goal 11 on sustainable cities and communities, where it discusses the need for cities to be inclusive to older adults and more environmentally sustainable.¹⁵⁵
- **Sustainable food can facilitate healthy ageing:** developing food systems that could both improve population health and support environmental sustainability, and also considering how healthier diets using sustainable food can optimise healthy ageing.¹⁵⁶
- **Sustainability and public health:** considering how, in some cases, improving environmental sustainability could also produce direct health benefits; for example, implementing sustainable public transport and active travel, which also increases exercise such as walking and cycling.¹⁵⁷
- **The longevity economy:** recognising that increased life expectancy could be a major driver of sustainable growth; for example, older consumers are the fastest growing consumer base that could play a role in green growth initiatives.¹⁵⁸

Recognising the role played by ageism

“Old age is not a disease, but ageism is.”¹⁵⁹

“Attitudes to ageing shape research and innovation in the form of compassionate ageing, which, however well-meaning, overlooks older adults as key actors. More importantly, compassionate ageing makes assumptions about the needs of older people, portraying them as needy and deserving of special policies or services to help them.”¹⁶⁰

“Worry about ageism – we internalise it too – we see ourselves as portrayed in the media – it’s unrelenting. We really need to tackle ageism”¹⁶¹

¹⁵⁴ YouTube (22 September 2022) *Longevity – the missing link in the climate change debate*, available at: <https://www.youtube.com/watch?v=3ARNcd-gOZk>; and International Longevity Centre UK blog (22 February 2023) *Connecting climate change, longevity and ageing by David Sinclair*, available at: <https://ilcuk.org.uk/connecting-climate-change-longevity-and-ageing/>.

¹⁵⁵ SDG: United Nations Sustainable Development (2022) *11: make cities and human settlements inclusive, safe, resilient and sustainable*, available at: <https://sdgs.un.org/goals/goal11>.

¹⁵⁶ Willett W, Rockström J, Loken B *et al.* (2019) Food in the anthropocene: the EAT–Lancet commission on healthy diets from sustainable food systems *The Lancet* **393**(10170): 447–92.

¹⁵⁷ The King’s Fund (2012) *Sustainable health and social care: connecting environmental and financial performance*, available at: https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/sustainable-health-social-care-appleby-naylor-mar2012.pdf.

¹⁵⁸ International Longevity Centre UK (2019) *Maximising the longevity dividend*, available at: <https://ilcuk.org.uk/wp-content/uploads/2019/12/Maximising-the-longevity-dividend.pdf>.

¹⁵⁹ Rabheru K, Byles JE, and Kalache A (2022) How “old age” was withdrawn as a diagnosis from ICD-11 *The Lancet Healthy Longevity* **3**(7): e457–e9.

¹⁶⁰ Dr Hannah R Marston, Dr Deborah J. Morgan, Dr Gemma Wilson-Menzfeld, Ms Jessica R. Gates, and Mr Robbie Turner, responding to our call for evidence.

¹⁶¹ Nuffield Council on Bioethics (2022) *Open forum with members of the Greater Manchester Older People’s Network, in collaboration with Sonder Radio*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence->

- 2.15 Being old(er) is routinely ‘othered’ in day-to-day discourse. Older adults are typically described in the media as someone else’s parent or grandparent; they are assumed to be less capable of protecting their own interests or of making their own decisions, and hence in need of protection or support by others; and they can be the subject of mockery and distaste.¹⁶² Despite the fact that different generations of adults inevitably connect through family structures, the needs and interests of older and younger populations are often pitted against each other in policy and media debates as if they were completely separate groups.¹⁶³
- 2.16 As contributors to the Future of Ageing Open Forum illustrate in Box 2.4, ageism is present, insidiously, in much public discourse and public policy about ageing.¹⁶⁴ This varies from casual discrimination in day-to-day life, as highlighted in campaigns against ‘everyday ageism’,¹⁶⁵ to active mistreatment and infantilisation in care settings.¹⁶⁶ The low status of those working in the social care sector may also be seen as a reflection of the low status accorded to those needing care and support.¹⁶⁷

Box 2.4: Future of Ageing Open Forum: comments on ageism

Throughout the Future of Ageing Open Forum, participants shared their experiences and views on ageism.

- Describing being “furious” that people make assumptions by looking at older adults “face[s], hair, and wrinkles” that they are “the old bat in the corner”.
- Often being asked in discussions “do you have anyone in your family who is able to go online for you?”
- Expressing that “it’s not just young generations that give us a bad name but it’s some older people too ... the subject of death always comes around.”
- Being stereotyped due to physical appearances: “Don’t count us/yourself out because you’ve got a few grey hairs.”

gathering/open-forum-with-members-of-the-greater-manchester-older-peoples-network-gmopn-and-other-residents-in-manchester-organised-in-collaboration-with-sonder-radio.

¹⁶² See, for example, the discussion of ‘othering’: Centre for Ageing Better (2020) *Doddery but dear? Examining age-related stereotypes*, available at: <https://ageing-better.org.uk/sites/default/files/2021-08/Doddery-but-dear-examining-stereotypes.pdf>; and Simone de Beauvoir’s analysis of how one’s own fear of one day getting old is expressed in terms of distaste and othering of older adults: aeon (14 June 2022) *Old not other*, available at: <https://aeon.co/essays/simone-de-beauvoir-on-facing-old-age-and-avoiding-bad-faith>.

¹⁶³ See, for example, the headline in (although it is striking how the text of the article itself is more nuanced than the headline, making links between poorer younger people and poorer pensioners): inews (2 July 2022) *The government has chosen to widen social divisions by helping pensioners at the expense of younger people*, available at: <https://inews.co.uk/opinion/the-government-has-chosen-to-widen-social-divisions-by-helping-pensioners-at-the-expense-of-younger-people-1716969>.

¹⁶⁴ Nuffield Council on Bioethics (2022) *Open forum with members of the Greater Manchester Older People’s Network, in collaboration with Sonder Radio*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/open-forum-with-members-of-the-greater-manchester-older-peoples-network-gmopn-and-other-residents-in-manchester-organised-in-collaboration-with-sonder-radio>.

¹⁶⁵ Centre for Ageing Better (10 June 2022) *Ageing Better to deliver new campaign against age-based discrimination*, available at: <https://ageing-better.org.uk/news/ageing-better-deliver-new-campaign-against-age-discrimination>. See also: Centre for Ageing Better blog (30 May 2022) *How do we challenge the ageist narrative that exists in society?*, available at: <https://ageing-better.org.uk/blogs/how-do-we-challenge-ageist-narrative-that-exists-in-society>; and Euronews (22 February 2022) *‘I’m old, not stupid’: campaigning pensioner forces Spanish banks to tackle exclusion of elderly*, available at: <https://www.euronews.com/next/2022/02/22/i-m-old-not-stupid-campaigning-pensioner-forces-spanish-banks-to-tackle-exclusion-of-elder>.

¹⁶⁶ See, for example, the discussion of ‘elderspeak’ leading to ‘refusals of care’: Shaw CA, Ward C, Gordon J et al. (2022) Elderspeak communication and pain severity as modifiable factors to rejection of care in hospital dementia care *Journal of the American Geriatrics Society* **70(8)**: 2258-68. For the routine use of incontinence pads for older adults with dementia regardless of their continence and independence, see: University of West London (2022) *Understanding how to facilitate continence for people with dementia in acute hospital settings: raising awareness and improving care – an ethnographic study*, available at: <https://www.uwl.ac.uk/research/research-centres-and-groups/geller-institute-ageing-and-memory/continence-care-people>.

¹⁶⁷ #socialcarefuture (2021) *Working in social care is boring, thankless & unenviable - sign up today!*, available at: <https://socialcarefuture.org.uk/working-in-social-care-is-boring-thankless-unenviable-sign-up-today/>.

- Negative views on ageing are often talked about frequently when there are also many positive experiences of ageing that should be highlighted, such as retirement: “It’s an opportunity to learn new skills such as volunteering.”
- Emphasising that older adults are “continuing contributors in society” and even in older age “you can still contribute and rock it”.

2.17 Choice of language and terminology plays an important role in how older adults are regarded (see Box 2.5). Phrases such as ‘the elderly’ or even ‘the older population’ can be problematic, with the use of ‘the’ risking depersonalising and objectifying people and serving to marginalise a large part of the population. This terminology also implies a homogeneity and commonality of experience that simply does not exist.¹⁶⁸ As we noted in Chapter 1, any individual’s experience of ageing and older age will depend on multiple factors which combine and intersect in each of us in a unique way (see paragraph 1.21). Moreover, those often classed together as ‘the older population’ belong to an extraordinarily broad age range of five or more decades; by contrast, it is hard to imagine any discussion of social policy that would group together 0–50 year olds in a single cohort. Our preferred terminology of referring to ‘older adults’ reflects how, as we age, we do not leave adulthood.

Box 2.5: The importance of language

Throughout its inquiry, the working group was alerted to the importance of the language used, both when referring to older adults (whether individually or collectively), and in the way that care and support is described. Participants at one roundtable discussion, for example, highlighted a number of commonly used terms that can contribute to undermining the agency and individuality of older adults. Such embedded assumptions and attitudes then risk being ‘carried over’ into how research and innovation in ageing is framed.¹⁶⁹ Examples cited included the following.

- Concern about ageing being presented as a ‘problem’ to which ‘solutions’ are necessary – as for example when ageing is described as a ‘silent pandemic’.¹⁷⁰
- Preference for talking about ‘providing’ rather than ‘delivering’ services – it was argued that the commonly used term ‘service delivery’ implies no agency or involvement on the part of the person using the service.
- Avoiding the terminology of ‘implementing’ policies or services – this again sounds like something that is being ‘done to’ other people, rather than with and for them.
- Preference for shifting to talking about ‘consumers’ rather than ‘service users’, creating a very different power dynamic.

Advocacy groups such as Social Care Future have also highlighted the importance of language in referring to those who ‘draw on social care’ to live their lives. People are not defined by their use of care and support – rather, they need that care and support to “live their lives in the way that we want to, with meaning, purpose and connection, whatever our age or stage of life”.¹⁷¹

¹⁶⁸ Independent Age (2020) *In focus: experiences of older age in England*, available at: https://www.independentage.org/sites/default/files/2020-03/Report_vF_0.pdf.

¹⁶⁹ Technologies roundtable, 21 July 2021 (see Appendix 1). See also: Rewriting social care blog (9 August 2019) *Why language matters*, available at: <https://rewritingsocialcare.blog/2019/08/09/why-language-matters/>.

¹⁷⁰ Department for Business, Energy and Industrial Strategy (2021) *Life sciences vision*, available at: <https://www.gov.uk/government/publications/life-sciences-vision>, at page 7.

¹⁷¹ #socialcarefuture (2023) *A vision for the future of social care*, available at: <https://socialcarefuture.org.uk/a-vision-for-the-future-of-social-care/>.

Similar issues arise around the routine use of the term ‘carers’: while this terminology may be appropriate in many ways, reference to ‘carers’ can in some circumstances be used to overlook or diminish the agency of the person being ‘cared for’. This contrasts with the use of the term of ‘personal assistants’ employed by some younger adults with disabilities, which suggests a very different power relationship.

As we explore in the following chapter, language of ‘curing’ or ‘treating’ ageing, in the context of research relating to the underlying causes driving the biology of ageing, is similarly problematic in associating ageing with a disease state (see paragraph 3.18).

- 2.18 Substantial work has been undertaken at many levels to call out and challenge ageism by, among others, the World Health Organization (WHO),¹⁷² the European Commission,¹⁷³ and the Centre for Ageing Better.¹⁷⁴ The WHO’s *Global report on ageism*, for example, identifies three effective strategies for reducing ageism: policy and law to address discrimination; educational interventions to counter stereotypes and provide accurate information; and interventions to encourage intergenerational contact.¹⁷⁵ Similar themes emerged in the intergenerational engagement that contributed to this project, with participants at the Exeter intergenerational roundtables and in our public dialogue both strongly reiterating the value of facilitating intergenerational interaction, with benefits seen as accruing for both older and younger people.¹⁷⁶ Research into dementia-friendly communities has similarly highlighted how greater awareness and social connection between generations can challenge stereotypes and reduce fear of the unknown.¹⁷⁷
- 2.19 Focusing more narrowly on questions of research and technology, the WHO has also explored the extent to which ageism may have an impact on the way that artificial intelligence (AI) is increasingly being deployed in the provision of health services.¹⁷⁸ While highlighting the potential that AI holds for improving older adults’ health and wellbeing, the WHO’s policy brief highlights the risks that ageism may lead to the encoding of stereotypes, prejudice, or discrimination in AI technologies in ways that could limit benefits for older adults, or directly undermine the quality of healthcare available to them. Practical recommendations include a strong emphasis on participatory design with older adults, age-inclusive data collection, and a strong emphasis on the rights of older adults to exercise choice, all themes which emerged strongly in our own engagement and evidence-gathering (see Chapters 4 and 5).
- 2.20 In challenging ageist assumptions, including ‘compassionate’ forms of ageism that treat all older adults as equally and inherently vulnerable,¹⁷⁹ it is of course critical not to lose sight of the fact that some older adults *will* be vulnerable, or find themselves in situations

¹⁷² WHO (2021) *Global report on ageism*, available at: <https://www.who.int/publications/i/item/9789240016866>.

¹⁷³ EuroAgeism (2022) *EuroAgeism*, available at: <https://euroageism.eu/>.

¹⁷⁴ Centre for Ageing Better (2021) *Reframing ageing: public perceptions of ageing, older age and demographic change*, available at: <https://ageing-better.org.uk/sites/default/files/2021-07/Reframing-ageing-public-perceptions.pdf>.

¹⁷⁵ WHO (2021) *Global report on ageism*, available at: <https://www.who.int/publications/i/item/9789240016866>. See also: Mikton C, de la Fuente-Núñez V, Officer A *et al.* (2021) Ageism: a social determinant of health that has come of age *The Lancet* **397(10282)**: 1333-4.

¹⁷⁶ Nuffield Council on Bioethics (2022) *Intergenerational roundtable event in Exeter*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing>; and Nuffield Council on Bioethics (2023) *Public dialogue report on the future of ageing*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/public-dialogue-on-the-future-of-ageing>.

¹⁷⁷ Pech M, Meillon C, Marquet M *et al.* (2022) The “alzheimer village”: assessment of alzheimer’s disease representations in the general population: a cross sectional phone survey *Alzheimer’s & Dementia: Translational Research & Clinical Interventions* **8(1)**: e12328.

¹⁷⁸ WHO (2022) *Ageism in artificial intelligence for health*, available at: <https://www.who.int/publications/i/item/9789240040793>.

¹⁷⁹ See, for example, the ‘Valuable, not Vulnerable’ campaign: Centre for Ageing Better blog (1 October 2020) *Valuable not vulnerable – how Greater Manchester is changing the narrative on ageing*, available at: <https://ageing-better.org.uk/blogs/valuable-not-vulnerabgoole-how-greater-manchester-changing-narrative-ageing>.

that render them vulnerable, for a variety of reasons. In their response to our call for evidence, the International Longevity Centre UK, for example, strongly emphasised the need to see both positives and negatives in ageing, arguing that: “[the potential longevity dividend] will only be realised if we seize the opportunities of ageing whilst recognising the need to highlight the problems of old age and invest in prevention.”¹⁸⁰

- 2.21 Some commentators, concerned with the risks of over-idealising older age, have instead proposed the concept of **precarity** as a defining feature of older age, suggesting, for example, that: “defining aging as precarious is an explicit critique of the idealistic sentiments of ‘successful ageing,’ but it also more adequately accounts for older adults’ situational and political vulnerabilities.”¹⁸¹ Such an approach recognises how age-related biological change inevitably has an impact on us and our life plans, and requires both adaptation and a re-evaluation of priorities, but without making unwarranted assumptions as to whether these experiences are necessarily positive or negative. The important role of recognising and adapting to change, not least in order to continue to contribute within society, was reiterated by one participant in the Manchester Open Forum who commented: “We’ve got to adapt ... older people I think have to adapt to changes in their health and changes in their situations.”¹⁸²
- 2.22 More broadly, in being alert to the dangers both of ageism and of over-idealising older age, it is essential to challenge a dominant public rhetoric that often pits older and younger members of society against each other, in ways that actively contribute to ageism.¹⁸³ Yet this rhetoric fails to recognise how different generations, far from being alienated, connect within their families; how disparities in wealth are primarily socioeconomic, rather than age-based; how older adults contribute within both their families and social circle, and in wider society; and most of all the rich diversity among, as well as between, generations.

What does it mean to ‘age well’?

“The overriding ambition must be to ensure those in receipt of support or care are enabled to enjoy their rights to live purposeful lives as active members of families and communities.”¹⁸⁴

“We all want to live in the place we call home with the people and things that we love, in communities where we look out for one another, doing the things that matter to us.”¹⁸⁵

“Many research studies are ‘deficit’ orientated: addressing health problems or functional limitations associated with the ageing process. It would be good to see a stronger focus (from research funders and

¹⁸⁰ International Longevity Centre UK, responding to our call for evidence.

¹⁸¹ Dunn M (2018) Realizing and maintaining capabilities: late life as a social project *Hastings Center Report* 48 (Supplement 3): S25-S30.

¹⁸² Nuffield Council on Bioethics (2022) *Open forum with members of the Greater Manchester Older People’s Network, in collaboration with Sonder Radio*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/open-forum-with-members-of-the-greater-manchester-older-peoples-network-gmopn-and-other-residents-in-manchester-organised-in-collaboration-with-sonder-radio>.

¹⁸³ See, for example, inews (2 July 2022) *The government has chosen to widen social divisions by helping pensioners at the expense of younger people*, available at: <https://inews.co.uk/opinion/the-government-has-chosen-to-widen-social-divisions-by-helping-pensioners-at-the-expense-of-younger-people-1716969>.

¹⁸⁴ Anonymous response to our call for evidence.

¹⁸⁵ #socialcarefuture (2023) *What is #socialcarefuture*, available at: <https://socialcarefuture.org.uk/>.

individual researchers) on what it mean to age well, what the good life in late life consists in, etc.”¹⁸⁶

“Participants [in the PHG Foundation’s workshop on healthy ageing] noted a ‘tyranny of low expectations’ whereby older people may be thought of as being multi-morbid and with physical impairments limiting their abilities. On the other hand, focusing too much on capabilities and what older people can do could be harmful for those who lack sufficient capabilities, who might also be blamed for their failure to help themselves.”¹⁸⁷

2.23 Although the primary focus of this inquiry has been on health-related research and innovation (not least because of the terms of reference of the Nuffield Council on Bioethics itself),¹⁸⁸ it is very important to recognise that physical and mental health are far from the only factors that affect a person’s capacity to live well in their later life. Indeed, a number of studies have highlighted that older adults are often less concerned than younger generations with the physical impacts of ageing, and that health is often valued primarily instrumentally, for what it enables people to do, be, and achieve, rather than solely as an end in itself.¹⁸⁹

2.24 Consistent themes that emerge from social science research and from public engagement with older adults by organisations concerned with ageing highlight the central importance for many older adults of factors such as maintaining meaningful engagement with the world (recognising that this will take many different forms), being valued, being able to maintain personal interests, and being able to contribute, as well as being able to maintain good health.¹⁹⁰ Drawing on a wide range of research methods, including focus groups with older adults, Age UK, for example, has developed an index of wellbeing in later life that identifies the following five key areas of wellbeing.

- **Personal**, for example, thinking skills, level of education, and marriage.
- **Social**, for example, creative and cultural participation, having friends, and openness (as a personal characteristic).
- **Health**, for example, physical activities, mental health, and diagnosis with a health condition(s).
- **Resources**, such as owning a house, working, and level of pension income.
- **Local**, for example, satisfaction with local leisure or medical services.¹⁹¹

2.25 As illustrated by the breadth of Age UK’s categories (and in particular the focus on resources and access to local services), it is important to keep in view the wider socioeconomic factors that strongly affect ageing throughout the life course, alongside the evidence of what people personally value in their later life (see in particular

¹⁸⁶ Michael Dunn, responding to our call for evidence.

¹⁸⁷ Dr Philippa Brice, PHG Foundation, responding to our call for evidence.

¹⁸⁸ Nuffield Council on Bioethics (2023) *Aims and values*, available at: <https://www.nuffieldbioethics.org/about-us/aims-and-values>.

¹⁸⁹ See, for example, Centre for Ageing Better (2021) *Reframing ageing: public perceptions of ageing, older age and demographic change*, available at: <https://ageing-better.org.uk/sites/default/files/2021-07/Reframing-ageing-public-perceptions.pdf>; and Stephens C, Breheny M, and Mansvelt J (2015) Healthy ageing from the perspective of older people: A capability approach to resilience *Psychology & Health* **30(6)**: 715-31. See also: University of Birmingham (2014) *Healthy ageing in the 21st century: the best is yet to come*, available at: <https://www.birmingham.ac.uk/Documents/research/policycommission/healthy-ageing/Healthy-Ageing-Policy-Commission-Report.pdf>. See also: Nuffield Council on Bioethics (2023) *The future of ageing: evidence reviews*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering-2>.

¹⁹⁰ Nuffield Council on Bioethics (2023) *The future of ageing: evidence reviews*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering-2>.

¹⁹¹ Age UK (2017) *A summary of Age UK’s index of wellbeing in later life*, available at: <https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/health--wellbeing/ageuk-wellbeing-index-summary-web.pdf>.

paragraphs 1.20–1.24). These wider factors have been drawn out by the user-led organisation Social Care Future, for example, in its exploration of what disabled people of all ages would like to see from social care. Social Care Future has identified five common themes that resonate with many of Age UK's categories, with a vision of:

- communities where everyone belongs;
- living in the place we call home;
- leading the lives we want to lead;
- more resources, better used; and
- sharing power as equals.¹⁹²

2.26 These themes of inclusion, security and personal choice also emerged very strongly in a number of engagement events that the working group held with older adults in Manchester and West Bromwich. In a discussion of the role technology and geroscience might play in ageing well, for example, members of the West Bromwich African Caribbean Resource Centre (WBACRC) strongly emphasised the importance of fundamental needs such as adequate housing that play a life-long role in health and wellbeing, along with a specific focus on independence, community, and social connection in later life (see Box 2.6).¹⁹³

Box 2.6: Focus group discussion with members of West Bromwich African Caribbean Resource Centre, March 2022

All of the people who took part in the focus group were aged 75 years and older, lived in the local West Bromwich area, and were of African Caribbean origin. Using photographs as prompts, participants discussed a number of health and wellbeing technologies that are intended to help older adults in later life. Throughout the participants' discussion, there was less value placed on having new technology in the home to contribute to healthy ageing, or living longer, but rather a greater emphasis on community and fundamental needs being met.

In particular, members emphasised the importance of:

- good quality housing that can be kept warm;
- access to transport;
- exercise;
- independence; and
- strong social relationships and connections.

2.27 Participants in a workshop hosted with members of Greater Manchester Growing Older with Learning Disabilities (GM GOLD) explored what mattered most to them in later life through creating 'dream machines' that would help them with valued activities. While the machines created varied widely, common themes included a strong emphasis on

¹⁹² #socialcarefuture (2021) *Whose social care is it anyway?*, available at: <https://socialcarefuture.org.uk/wp-content/uploads/2021/07/whose-social-care-is-it-anyway-report.pdf>.

¹⁹³ Nuffield Council on Bioethics blog (12 July 2022) *The future of ageing – learning from the West Bromwich African Caribbean Resource Centre*, available at: <https://www.nuffieldbioethics.org/blog/the-future-of-ageing-learning-from-the-west-bromwich-african-caribbean-resource-centre>.

independence (and a desire for technology to reduce the need to rely on others, especially where privacy was at stake) and social connection (see Box 2.7).¹⁹⁴

Box 2.7: GM GOLD workshop: creating your ‘dream machine’, June 2022

Greater Manchester Growing Older with Learning Disabilities (GM GOLD) members used a variety of craft materials to present what they would like technology to do for them as they get older. While this engagement activity was focused around the possibilities offered by technology, it was striking how it elicited questions of what is most valued, whether or not this could be achieved by technological means. Members produced representations of the following ‘dream machines’.

- **Invisible robot** – a discreet machine to help with communication.
- **Marvellous medication machine** – which would dispense tablets automatically, be easy to handle, and able to provide basic healthcare advice, such as what to do if you forget a dose.
- **Automatic word reader** – able to read out letters without the invasion of privacy involved in family or care staff being involved.
- **Arthur the cleaning robot** – a brightly coloured (hence easily visible) robot to clean hard-to-reach places in the home.
- **The dream bus** – a self-driving vehicle to reduce the amount of time spent on public transport and enhance social opportunities.
- **Eye-leen** – a machine involving multiple cameras to provide alerts to someone able to help if they fell.
- **A robot to help with reading and writing** – thus reducing reliance on family members who currently help in this way.
- **More opportunities to spend time with friends and family** – instead of having more technology.

2.28 Members of Greater Manchester Older People’s Network (GMOPN) who took part in an ‘Open Forum’ broadcast by Sonder Radio highlighted a wide variety of factors they felt constituted ageing well, with a strong focus on ‘not just existing’ but also continuing to have mental stimulation; enjoying yourself; being connected with others; and, crucially being able to contribute (see Box 2.8).¹⁹⁵

Box 2.8: Ageing well – Open Forum with Greater Manchester Older People’s Network and Sonder Radio, August 2021

Throughout the Open Forum broadcast, members of the Greater Manchester Older People’s Network (GMOPN) and Sonder Radio discussed what living well in older age meant to them.

- “Independence – I need to be able to cook for myself or as simple as having a wash ... not having to rely on other people all the time.”
- “Not just surviving ... increasing mental stimulation whether that’s learning new skills and supporting each other in your community.”
- “Having enough to pay your bills, having the one home, and food.”

¹⁹⁴ Nuffield Council on Bioethics blog (29 October 2022) *If you could design your ‘dream machine’ to help you in older age, what would it be?*, available at: <https://www.nuffieldbioethics.org/blog/if-you-could-design-your-dream-machine-to-help-you-in-older-age-what-would-it-be>.

¹⁹⁵ Nuffield Council on Bioethics (2022) *Open forum with members of the Greater Manchester Older People’s Network, in collaboration with Sonder Radio*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/open-forum-with-members-of-the-greater-manchester-older-peoples-network-gmopn-and-other-residents-in-manchester-organised-in-collaboration-with-sonder-radio>.

- “Keeping mentally active.”
- “Not just existing but contributing – more than getting on with the daily monotony. We need to flourish and we need to contribute to society ... In the last four to six years, I have done more in that respect than any other time in my life. I am doing things nowadays that I would never have believed I could actually do.”
- “Wellbeing is good health, while living well is enjoying things.”
- “Social isolation is a real issue – and particularly for the LGBT community.”

2.29 The implications of these contributions for our inquiry were well summed up for the working group by participants in the working group’s public dialogue, who concluded 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.”¹⁹⁶ In Chapter 5, in our own analysis of an ethical basis for the conduct of research and innovation in ageing, we draw strongly on these insights relating to the aims and aspirations towards which such research and innovation should be directed.

2.30 Drawing together the themes of this chapter, we highlight the importance of conceptualising aspirations for later life not in terms of ‘healthy’ or ‘successful’ ageing, but much more broadly, using the language of ‘**ageing well**’ or ‘**flourishing**’ in later life.¹⁹⁷ Such an approach explicitly includes within its scope and focus of concern older adults with life-limiting disabilities and conditions, those living in precarious or marginalised situations, and indeed those experiencing a period of significant decline and incapacity before death: a period that will be experienced by the majority of people who do not die prematurely, and which with palliative and supportive care can be experienced as positive.¹⁹⁸ We return to these themes, and their central relevance for the direction and conduct of research and innovation, in more detail in Chapter 5.

Learning from COVID-19

2.31 This inquiry has taken place in the context of the COVID-19 pandemic, which for more than two years has dominated social and economic policy across the world, and has dramatically affected everyone’s lives. Many of the themes that have been explored in the first two chapters of this report, and which form the backdrop to our consideration of the role of biomedical research and technological innovation in ageing, emerged in stark relief in the experiences of older adults during the pandemic. These are briefly illustrated in Box 2.9.

Box 2.9: COVID-19 case study

¹⁹⁶ Nuffield Council on Bioethics (2023) *Public dialogue report on the future of ageing*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/public-dialogue-on-the-future-of-ageing>, at page 8.

¹⁹⁷ The Hastings Center Special Report features several collected essays on what makes a good life in late life, see: The Hastings Center (2022) *What makes a good life in late life? citizenship and justice in aging societies*, available at: <https://www.thehastingscenter.org/publications-resources/special-reports-2/what-makes-a-good-life-in-late-life-citizenship-and-justice-in-aging-societies/>; and The Hastings Center (2016) *Ageing*, available at: <https://www.thehastingscenter.org/briefingbook/aging/>.

¹⁹⁸ See, for example, Marie Curie (2022) *What is palliative care?*, available at: <https://www.mariecurie.org.uk/help/support/diagnosed/recent-diagnosis/palliative-care-end-of-life-care>.

COVID-19 presented, and continues to present, genuine challenges to older adults' health. Many of the public health policies implemented at the beginning of the pandemic, at a time of very limited knowledge of how the virus would spread and the impact it would have, were taken with the **expressed aim of protecting older adults** who appeared as a group to be at much greater risk of serious illness and death than other parts of the population, and who were prioritised for vaccination once available. Indeed, one of the strong criticisms of the approach to successive lockdowns during 2020 and 2021 was that the interests of older and disabled people were being prioritised over the needs of, for example, schoolchildren and students.¹⁹⁹

Nevertheless, the level of **excess mortality among older adults**, particularly those living in care homes, was very high, and many of these deaths have been held to be preventable.²⁰⁰ The Health Foundation has identified five factors that contributed to these excess deaths: slow policy action with respect to social care; prioritisation of the NHS over social care; a narrow focus on care homes, as opposed to other kinds of social care need; unmet need, especially for those drawing on home care; and a backdrop of political neglect.²⁰¹

Other COVID-related policies proposed and/or implemented in the UK and in many other countries across the world illustrated some of the challenges explored in this chapter, including **lack of recognition of the vast diversity of people considered as old**; the exercise of **'compassionate ageism'** in which a focus on older adults' physical safety did not include recognising their agency; and in the **'othering' of older adults** as being in some way a distinct group, separate from mainstream society. The following are some examples.

- National directions to discharge many older adults already in hospital at the start of the pandemic to care homes, even though effective systems were not yet in place to test for SARS-CoV2 infection.²⁰² In thus 'freeing up' hospital beds for other patients, older adults living in care homes were put at increased risk of exposure.
- Consideration of applying lockdown or social-distancing requirements to all over 70s, even when relaxed for other age groups, regardless of personal choice or level of risk.²⁰³
- Strict lockdown requirements and limitations on visitors for those living in care homes, which were maintained over a very long period of time, including when the rest of the population was actively being encouraged to 'eat out to help out'.²⁰⁴ The aim of the policy was to help prevent infection entering care homes; however, care home residents did not have any voice in this decision, despite the by-then well-documented mental and physical health impacts of social isolation.²⁰⁵

¹⁹⁹ See, for example, Practical Ethics blog (27 January 2021) *Current lockdown is ageist (against the young)*, available at: <http://blog.practicaethics.ox.ac.uk/2021/01/current-lockdown-is-ageist-against-the-young/>.

²⁰⁰ Schultze A, Nightingale E, Evans D et al. (2022) Mortality among care home residents in England during the first and second waves of the COVID-19 pandemic: an observational study of 4.3 million adults over the age of 65 *The Lancet Regional Health Europe* **14**: 100295; and Emmer De Albuquerque Green C (2022) The human rights of people living in care homes: never again an afterthought *Nature Aging* **2(9)**: 767-9.

²⁰¹ The Health Foundation (2020) *Briefing: adult social care and COVID-19*, available at: <https://www.health.org.uk/sites/default/files/upload/publications/2020/20200730-Adult-social-care-and-COVID-19-policy-response-so-far.pdf>.

²⁰² Dyer C (2022) Covid-19: policy to discharge vulnerable patients to care homes was irrational, say judges *British Medical Journal* **377**: o1098; and McKee M (2022) No minister, a "protective ring" was not thrown around care homes *British Medical Journal* **377**: o1116.

²⁰³ Cloisters Insights blog (1 May 2020) *Coronavirus: locking the over 70's away?*, available at: <http://cloisters.com/insights/coronavirus-locking-the-over-70s-away>.

²⁰⁴ Nuffield Council on Bioethics blog (24 September 2020) *Recognising the human rights of people with dementia during COVID-19*, available at: <https://www.nuffieldbioethics.org/blog/recognising-the-human-rights-of-people-with-dementia>; and House of Commons Library (2020) *Eat out to help out scheme*, available at: <https://researchbriefings.files.parliament.uk/documents/CBP-8978/CBP-8978.pdf>.

²⁰⁵ Manchester Urban Ageing Research Group (2021) *COVID-19 and social exclusion: experiences of older people living in areas of multiple deprivation*, available at: <https://documents.manchester.ac.uk/display.aspx?DocID=56003>.

- Use in some care homes of blanket ‘do not attempt cardiopulmonary resuscitation notices’, without discussion with individual residents and their families.²⁰⁶
- Limited participation in some vaccine studies by older adults,²⁰⁷ which inflamed political and regulatory debates over the suitability of particular vaccines for older adults.²⁰⁸

In contrast, the early days of the pandemic in spring 2020, when the whole population in the UK was in lockdown, illustrated very vividly **how much older adults contribute**, both within their families and through wider society. The loss of grandparental support for childcare,²⁰⁹ and the challenges experienced in running key charitable services such as foodbanks without many of the older volunteers on whom they relied, had a major impact on those who relied on these types of formal voluntary and informal support.²¹⁰

Much more broadly, the pandemic has **brought to the fore the health impacts of discrimination, exclusion, and social disadvantage** – and how these factors may then compound and accumulate over a person’s lifetime to put minoritised and disadvantaged older adults particularly at risk.²¹¹ Examples include the following.

- Recognition of how the risk of serious illness or death from COVID-19 is not simply correlated with age but also with many other factors affecting lifelong health, including ethnicity, sex/gender, comorbidities, and socioeconomic status.²¹² Vulnerability to COVID-19 is further affected by occupational and social factors: an older adult who lives in a multigenerational household with family members working in essential public-facing occupations, for example, will be much less able to reduce their exposure to the virus than adults of similar ages living in other circumstances.²¹³
- Systemic discrimination in the healthcare system, including through a failure to act on longstanding evidence that pulse oximetry is less accurate in darker skinned patients, leading to delays in recognising the seriousness of some older patients’ condition.²¹⁴
- The importance of trust in health research and the wider health system – as evidenced by some of the challenges arising from lack of confidence in the vaccine programme.²¹⁵

²⁰⁶ See, for example, Joint Committee on Human Rights (2022) *Protecting human right in care settings*, available at: <https://committees.parliament.uk/publications/23214/documents/169544/default/>.

²⁰⁷ Veronese N, Petrovic M, Benetos A et al. (2021) Underrepresentation of older adults in clinical trials on COVID-19 vaccines: a systematic review *Ageing Research Reviews* **71**: 101455.

²⁰⁸ BBC News (5 February 2021) *Covid-19: fact-checking Macron’s over-65s claim about the Oxford-AstraZeneca vaccine*, available at: <https://www.bbc.co.uk/news/55919245>.

²⁰⁹ Cantillon S, Moore E, and Teasdale N (2021) COVID-19 and the pivotal role of grandparents: childcare and income support in the UK and South Africa *Feminist Economics* **27(1-2)**: 188-202.

²¹⁰ See, for example, Centre for Ageing Better (2022) *Volunteering and helping out in the COVID-19 outbreak*, available at: <https://ageing-better.org.uk/sites/default/files/2022-03/Volunteering-and-helping-out-in-the-covid-19-outbreak.pdf>; and Power M, Doherty B, Pybus K et al. (2020) How COVID-19 has exposed inequalities in the UK food system: the case of UK food and poverty *Emerald Open Research* **2**: 11.

²¹¹ COVID-19 has been described as the ‘disease of disparity’, see: NHS Confederation blog (24 June 2022) *The refresh of the NHS Long Term Plan should embrace the positive lessons from the pandemic*, available at: <https://www.nhsconfed.org/articles/refresh-nhs-long-term-plan-should-embrace-positive-lessons-pandemic>.

²¹² See, for example, Harper S (2020) The COVID-19 pandemic and older adults: institutionalised ageism or pragmatic policy? *Journal of Population Ageing* **13(4)**: 419-25; and Politis M (2022) Racial inequality: five minutes with . . . Michael Marmot *British Medical Journal* **378**: o1710.

²¹³ Ganguli-Mitra A, Qureshi K, Curry GD et al. (2022) Justice and the racial dimensions of health inequalities: a view from COVID-19 *Bioethics* **36(3)**: 252-9.

²¹⁴ NHS Race & Health Observatory (2021) *Pulse oximetry and racial bias: recommendations for national healthcare, regulatory and research bodies*, available at: <https://www.nhsrho.org/wp-content/uploads/2021/03/Pulse-oximetry-racial-bias-report.pdf>.

²¹⁵ Nuffield Council on Bioethics (2021) *Vaccine access and uptake*, available at: <https://www.nuffieldbioethics.org/assets/pdfs/Vaccine-access-and-uptake.pdf>.

Chapter 3

Research in ageing:
drivers, expectations, and
limitations

Chapter 3 – Research in ageing: drivers, expectations, and limitations

Overview of Chapter 3

Geroscience and geroscience-guided clinical trials

- Geroscience research seeks to improve understanding of the common processes that underlie biological ageing. The ultimate aim is to intervene in those processes to delay, mitigate, or even prevent common age-related medical conditions, including heart disease, stroke, and dementia. This is thought by many to be a more effective way of tackling these diseases than the current approach of treating them all separately, often leading to harmful interactions between different medicines.
- Much of the research is currently in animal models, and findings do not necessarily translate to humans. However, a small number of clinical trials in humans are now underway globally to test interventions that target ageing processes.
- In public and media debates, this area of research is often associated with the prospect of significantly extending the maximum human lifespan. However, the main aspiration within the clinical trials that are underway and in the pipeline is to extend healthy life expectancy – maximising the amount of our lives we spend in good health and compressing the period of ill health experienced before death.
- Geroscience should not be seen as a ‘magic bullet’. Interventions developed as a result of advances in geroscience may complement, not replace, what we already know about the benefits of living healthy lifestyles and tackling the social determinants of ill health.

Assistive, monitoring, and communications technologies

- Developments in assistive, monitoring, and communications technologies relevant to ageing include innovative approaches to prevention and rehabilitation; devices that enable remote contact and support; systems to support people to live independently despite a degree of loss of function; and improved support for care staff or informal carers in providing care.
- Such innovations may help **build reserve** and delay loss of function; promote **reablement** after injury or treatment; **compensate** for lost function; or help provide **care**. These are very different aims, and it is essential to match technologies appropriately to people’s needs. Providing technologies that compensate for lost function, or provide care, when reablement is still possible can have a negative effect on people’s life and health.
- The evidence base for many new apps and devices is not very strong. Many are not marketed as ‘medical’ devices but form part of general consumer markets, driven by commercial considerations. This creates regulatory challenges, particularly in a rapidly moving sector.

Data-driven innovation in earlier diagnosis and treatment

- Data-driven innovation, using artificial intelligence (AI) and data from many different sources, may offer the prospect of earlier detection of a range of conditions, as well as assisting in the development of biomarkers that indicate a person’s pace of biological ageing.

- The translation of research into practice raises a number of challenges, and it is important to distinguish between **predicting risk** of developing a condition, **early detection** of that condition, and **clinical diagnosis** accompanied by a treatment plan. In particular, indicators of population-level risk may not be applicable to an individual; and early detection of a condition needs to be accompanied by access to effective therapy or support in order to provide meaningful benefit.

Introduction: breadth of research

“In the short term, social interventions can achieve much more in terms of levelling up, and I believe that this should be the top priority. But the longer term gains of understanding the biology of ageing are potentially vast, of a similar order of magnitude as development of antibiotics and vaccines.”²¹⁶

- 3.1 There is a very wide range of research activity captured under the umbrella of ‘research in ageing’. As set out in Chapter 1, this inquiry has included within its remit developments in **understanding the biology of ageing** (sometimes described as ‘geroscience’); innovations in **assistive, monitoring, and communications technologies**; and **data-driven innovations in the early detection and diagnosis of age-related conditions** (see paragraph 1.4). This chapter provides a broad overview of the many different areas of research and technological innovation in scope, with pointers to more detailed accounts elsewhere. It also touches on the drivers of research in these areas, and on how each of these areas of research, in different ways, puts pressure on existing regulatory approaches. We note here that, in the context of this report, we are treating ‘technological innovation’ as a sub-category of research, to the extent that, where claims are being made as to the value of innovative devices and adaptations in supporting people to age well, these should be supported by robust evidence in the same way as biomedical interventions developed through clinical research pathways.
- 3.2 In its 2015 *World report on ageing*, the World Health Organization (WHO) identified the importance both of people’s ‘intrinsic capacities’ (the physical and mental capacities on which we can draw at any particular point in our lives), and of the environments in which we live. Together, these determine our functional abilities – our abilities to be and do what we value.²¹⁷ The diverse forms of research covered by this inquiry offer the prospect of contributing in different ways to people’s functional abilities in later life: the ultimate aim of increasing understanding of how our bodies age, for example, or of earlier detection of age-related conditions, is to be able to intervene directly to maintain and enhance people’s intrinsic physical or mental capacities into old age. Assistive technologies, on the other hand, aim to adapt environments to enable people to achieve particular tasks or participate in activities despite any age-related impairments in their health. While the main focus of this project has not included the last few months of life (which would deserve separate and extended consideration), it is important to note that both biomedical science and technology potentially have important roles to play in palliative care too.²¹⁸

²¹⁶ David Gems, responding to our call for evidence.

²¹⁷ WHO (2015) *World report on ageing and health*, available at: <https://apps.who.int/iris/handle/10665/186463>.

²¹⁸ See, for example, Marie Curie blog (8 July 2021) *What does the future of palliative care look like?*, available at: <https://www.mariecurie.org.uk/blog/future-of-palliative-care/313128>.

- 3.3 Different forms of research and innovation may thus be of greater or lesser relevance to people at different points in their lives: assistive and enabling technologies are most likely to be useful for those already living with the impacts of long-term conditions, while the longer-term aspiration of geroscience will be to intervene much earlier in life before irreversible biological damage has been acquired. However, just as preventative approaches to good health are valuable at all stages of life (see paragraph 2.10 and Box 2.1), it should be highlighted that some of the geroscience-guided clinical trials being conducted at the moment (see Box 3.2) are primarily targeting the health needs of older adults living with age-related disease, aiming to reverse rather than prevent age-related conditions. We also note that in any attempt to categorise forms of research and innovation, or their uses, there will inevitably be many blurred boundaries (see in particular paragraph 3.23).
- 3.4 As we explore in greater detail below and in later chapters, it is also necessary to be alert to how research in ageing takes place in the context of a broader research ecosystem and is shaped and influenced by that ecosystem. In the UK context, this includes the complex 'mixed economy' of commercial, public, and charitable research funders; the increasing recognition of the importance of research being understood as a partnership between researchers and the populations or communities whom the research is aiming to serve;²¹⁹ and the current state of transition in UK regulatory approaches in the years following the Brexit decision.²²⁰ This broader perspective illustrates, in particular, how it is impossible to 'carve out' biomedical and technological research neatly from other forms of research, such as the social and behavioural sciences, social care and healthcare research, public health research, and translational research. The importance of all these kinds of research working together within the ecosystem, rather than in silos, is increasingly being recognised, if not always achieved in practice (see Box 3.3).

Geroscience and geroscience-guided clinical trials

*"[A] new approach to therapeutics is required, focusing on underlying fundamental biological mechanisms common to multiple conditions. These mechanisms are in fact the mechanisms that underpin the ageing process."*²²¹

*"As the number of long-term conditions experienced by a patient increases, so does the prevalence of further age-related conditions such as frailty."*²²²

*"Physical activity and good nutrition have a huge part to play but are often relegated in favour of a magic pill."*²²³

²¹⁹ Medicines and Healthcare products Regulatory Agency (11 March 2022) *Health and social care leaders unite to improve public involvement in research*, available at: <https://www.gov.uk/government/news/health-and-social-care-leaders-unite-to-improve-public-involvement-in-research>. See also the emphasis on 'people-centred research' in: Department of Health and Social Care (2022) *The future of clinical research delivery: 2022 to 2025 implementation plan*, available at: <https://www.gov.uk/government/publications/the-future-of-uk-clinical-research-delivery-2022-to-2025-implementation-plan/the-future-of-clinical-research-delivery-2022-to-2025-implementation-plan>.

²²⁰ See: Medicines and Healthcare products Regulatory Agency (2021) *New guidance and information for industry from the MHRA*, available at: <https://www.gov.uk/government/collections/new-guidance-and-information-for-industry-from-the-mhra>. For the impact of Brexit on research funding see: Woolston C (2022) Lost funding, unwelcome moves: UK researchers speak out on ERC 'disaster' *Nature* **608(7924)**: 833-5.

²²¹ Professor Miles Witham and Professor Avan Sayer, responding to our call for evidence.

²²² The Academy of Medical Sciences, responding to our call for evidence, citing: Hanlon P, Nicholl BI, Jani BD *et al.* (2018) Frailty and pre-frailty in middle-aged and older adults and its association with multimorbidity and mortality: a prospective analysis of 493 737 UK Biobank participants *The Lancet Public health* **3(7)**: e323-e32.

²²³ Vicki Goodwin, responding to our call for evidence.

- 3.5 The field of 'geroscience' is concerned with understanding the connection between the complex processes that underpin biological ageing and the development of age-related medical conditions, such as cardiovascular disease, cancer, diabetes, and various dementias. Cells face continuous damage throughout their lifetime and have evolved multiple repair mechanisms in response. However, the effectiveness of these mechanisms declines over time, leading to an accumulation of damaged cells and a reduced ability either to replace them from stem cells, or for them to be removed by the immune system. This drives cellular ageing, which then in turn increases risk factors for many chronic diseases.²²⁴ Emerging evidence relating to nine of the cellular and molecular processes found to be associated with biological ageing was drawn together in 2013 and presented in the journal *Cell* as the 'hallmarks of ageing'²²⁵ (see Box 3.1 and Figure 3.1). While this categorisation has been the focus of much attention, it is important to note that other relevant mechanisms in ageing, outside these nine, continue to be identified,²²⁶ and that the relationships between these hallmarks, and their contribution in driving ageing, is still an area of active research.²²⁷

Box 3.1: Examples of cellular processes associated with biological ageing

- **Deregulated nutrient-sensing:** The ability of cells in the body to respond to nutrients becomes less effective with age, predisposing people to develop diabetes and suffer tissue loss such as muscle. Dietary restriction without malnutrition has been shown to prevent this decline and extend healthy lifespan in a range of animals. In humans, it has been shown to reduce risk factors for diabetes, cardiovascular disease, and cancer, and to slow biological ageing. Similar effects are seen when the activity of metabolic pathways that detect nutrients (such as the mTOR enzyme) are reduced by drugs or by gene mutations, as an alternative to restricting food intake.
- **Cellular senescence:** Damaged cells either die or become senescent cells, which remain in the body and give out inflammatory chemicals that contribute to ageing. Studies in mice have shown that removing senescent cells delays age-related diseases and extends lifespan. Clinical trials are underway in humans to determine the benefits of removing senescent cells or blocking their pro-ageing secretions with drugs.
- **Telomere attrition:** Telomeres, the tips of chromosomes, are vital for cell division and repair. Telomeres shorten every time a cell divides, and eventually their shortening causes growing cells to stop dividing and become senescent. Telomeres in many cells in the body become shorter with age. The enzyme telomerase lengthens telomeres and has been suggested as a target for anti-ageing interventions.
- **Stem cell exhaustion:** Stem cell function decreases with age, reducing the ability to replace tissues. Injecting stem cells into animals has been shown to enhance the repair of age-related damage in organs such as the brain, and to increase lifespan.
- **Altered intercellular communication:** Alterations in cell communication include 'inflammaging': a long-lasting low-level inflammation that develops with older age.

²²⁴ Kennedy BK, Berger SL, Brunet A *et al.* (2014) Geroscience: linking aging to chronic disease *Cell* **159**(4): 709-13.

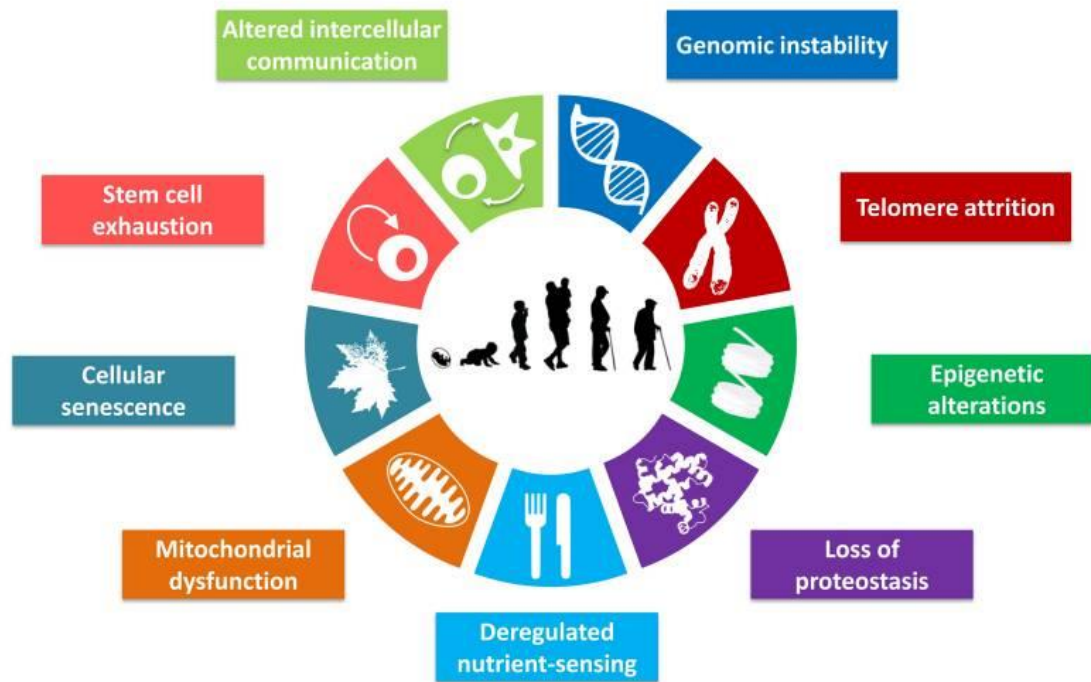
²²⁵ López-Otín C, Blasco MA, Partridge L *et al.* (2013) The hallmarks of aging *Cell* **153**(6): 1194-217.

²²⁶ Bajpai A, Li R, and Chen W (2021) The cellular mechanobiology of aging: from biology to mechanics *Annals of the New York Academy of Sciences* **1491**(1): 3-24.

²²⁷ Fraser HC, Kuan V, Johnen R *et al.* (2022) Biological mechanisms of aging predict age-related disease co-occurrence in patients *Ageing Cell* **21**(4): e13524.

Inflammaging is caused by several factors including increased obesity (fat tissue is pro-inflammatory) and a build-up of pro-inflammatory senescent cells. Inflammaging can cause damage to tissues such as blood vessels and contribute to the breakdown of tissues such as muscle and bone. Genetic, nutritional, and pharmacological interventions are being explored for restoring defective intercellular communication and reducing inflammaging.

Figure 3.1: The hallmarks of ageing, as presented in *Cell* in 2013²²⁸



3.6 A key aim of those working in the field of geroscience is to delay, mitigate, or even prevent common age-related medical conditions, by intervening directly in one or more of the mechanisms identified as affecting cellular ageing to prevent or reverse their effects. This approach builds on the concept of the malleability of ageing highlighted earlier (see paragraph 2.6): just as existing preventative health approaches can help individuals reduce their risk of long-term conditions, or delay their onset, direct intervention in mechanisms of cellular ageing, for example using pharmacological or nutritional techniques, could have a similar effect. If successful, such an approach could potentially be more effective than treating individual age-related conditions separately as they arise, especially if it had a significant preventative effect. It could also play an important role in addressing the inadequate way that current research and clinical care models treat people living with more than one chronic health condition (see paragraph 3.10). While, for some researchers, the ultimate aim of such interventions would be to extend overall human lifespan significantly, for most working in this field the primary focus is on increasing healthspan: the period of life lived in good health (see paragraphs 3.12 and 3.13).

3.7 To date, a number of animal studies have shown positive results by targeting these hallmarks of ageing with both novel and repurposed drugs, leading to improved health, delay in the onset and progression of multiple chronic conditions, and increased lifespan

²²⁸ López-Otín C, Blasco MA, Partridge L *et al.* (2013) The hallmarks of aging *Cell* **153**(6): 1194-217.

in animal models.²²⁹ As a result of these positive outcomes, several drug classes have been taken forward into small human clinical trials, with the aim either of influencing specific aspects of biological ageing or of directly targeting age-related diseases. These include **mTOR inhibitors**, **senolytics**, and **metformin** (see Box 3.2). Geroscience-guided mega-trials are on the horizon too, aiming to determine whether pharmacological interventions might be able to modulate ageing and give rise to new interventions to slow the ageing process: for example, **the Targeting Ageing with Metformin (TAME) trial**, which has been under development for some time, although not yet sufficiently funded to start recruiting participants.

Box 3.2: Overview of geroscience-guided clinical trials

In recent years, a number of clinical trials using pharmacological interventions to target ageing mechanisms in humans have begun. Despite several pharmacological interventions being investigated for their potential impact on age-related biological processes in the context of an age-related disease, the three key agents most commonly analysed in ageing studies are: mTOR inhibitors, senolytics, and metformin.

- **mTOR inhibitors**, such as rapamycin, are drugs which target and inhibit the mTOR complex. This is a protein complex that has been recognised as playing a central role in biological ageing mechanisms and has become a focus for molecular targets of ageing.²³⁰ In 2018, in a phase 2a randomised, placebo-controlled clinical trial, mTOR inhibitors were given to 264 participants aged 65 years or older to see the effect on the efficacy of an influenza vaccination, something which declines with advancing age. The study found that the amount of antibody produced after vaccination was higher and respiratory infection rates decreased for a year after taking the inhibitors. The results show the potential benefit of mTOR inhibitors for improving immune function in older adults.²³¹ However, a more recent clinical trial in 2021 found that while low doses of mTOR inhibitors were well tolerated and enhanced immune function in adults they did not reduce the incidence of respiratory tract infections.²³²
- **Senolytics** are a class of drugs that target senescent cells with the aim of eliminating them.²³³ A current ‘proof-of-concept’ study is underway in the US to evaluate whether a combination of two senolytic drugs (dasatinib and quercetin) can penetrate the brain in older adults with early Alzheimer’s disease. This study aims to lead to a larger phase 2 clinical trial to establish if senolytics may be an effective intervention for treating symptoms of Alzheimer’s disease.²³⁴ This combination of drugs was the first to report a positive effect in a clinical trial against a chronic disease, showing that the senolytics improved physical function in patients with the serious lung condition idiopathic pulmonary fibrosis.²³⁵

²²⁹ For a detailed account of the development of the field of geroscience, see: Nuffield Council on Bioethics (2023) *The future of ageing: evidence reviews*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering-2>.

²³⁰ Kapahi P, Chen D, Rogers AN *et al.* (2010) With TOR, less is more: a key role for the conserved nutrient-sensing TOR pathway in aging *Cell Metabolism* **11**(6): 453-65.

²³¹ Mannick JB, Morris M, Hockey H-UP *et al.* (2018) TORC1 inhibition enhances immune function and reduces infections in the elderly *Science Translational Medicine* **10**(449): eaaq1564.

²³² Mannick JB, Teo G, Bernardo P *et al.* (2021) Targeting the biology of ageing with mTOR inhibitors to improve immune function in older adults: phase 2b and phase 3 randomised trials *The Lancet Healthy Longevity* **2**(5): e250-e62.

²³³ Kirkland JL, and Tchkonja T (2020) Senolytic drugs: from discovery to translation *Journal of Internal Medicine* **288**: 518-36.

²³⁴ ClinicalTrials.gov (2022) *Senolytic therapy to modulate progression of alzheimer's disease (SToMP-AD)*, available at: <https://clinicaltrials.gov/ct2/show/NCT04063124>.

²³⁵ Justice JN, Nambiar AM, Tchkonja T *et al.* (2019) Senolytics in idiopathic pulmonary fibrosis: Results from a first-in-human, open-label, pilot study *EBioMedicine* **40**: 554-63.

- **Metformin** is an approved drug commonly used to treat type 2 diabetes.²³⁶ It has been shown in preclinical and clinical studies to have beneficial effects in other conditions such as cardiovascular disease, and in rodent models it appears to target a number of the hallmarks of ageing.²³⁷ A mega-trial approved by the US Food and Drug Administration (FDA) called the Targeting Ageing with Metformin (TAME) study is under development. The trial will be a double-blind placebo-controlled trial which aims to enrol 3,000 participants without diabetes between the ages of 65 and 79. It aims to measure the clinical time to the incidence of any major age-related disease such as stroke, heart failure, or death, and look at whether metformin can increase the number of years participants remain in good health. The trial is yet to begin as funding is still needed to support and launch the trial.²³⁸

3.8 While findings in animal studies are often reported in the press as exciting breakthroughs, it is important to recognise the limitations of animal models in research on ageing. The standard challenges of translating from animal to human models in research are exacerbated by the importance of psychological factors in the way in which humans age.²³⁹ To cite one researcher, “humans are not big worms or huge mice,”²⁴⁰ and humans do not behave like laboratory animals. This reiterates the importance of research in biological aspects of ageing being complemented and supported by research concerned with the social, cultural, and behavioural aspects of ageing (see paragraph 3.11). Moreover, the laboratory animals used in many studies are themselves young: for example, preclinical vaccine studies are often carried out in young animals, even though many vaccine therapies (such as cancer immunotherapies) are also targeted at older age groups, whose immune systems are not as effective as those of younger people.²⁴¹

3.9 The limitations of animal models serve to reiterate the critical importance of rigorous clinical trials in humans. There are, however, many challenges involved when setting up and running geroscience-guided clinical trials, especially when expanding these beyond the treatment of specific conditions to seek to measure more holistic factors such as extending the period of life lived with good health. Challenges include the following.

- Identifying the **most appropriate interventions** to study. This includes deciding whether to use a medication that has already been approved for other indications (where substantial data on safety will already be available²⁴²) or to develop a novel product that explicitly targets a pathway involved in biological ageing, but lacks evidence on either safety or interactions with other medications.
- Identifying the **timing of administration**, particularly when studying preventative approaches: should the intervention be given at the first sign of a negative ageing

²³⁶ Bailey CJ (2017) Metformin: historical overview *Diabetologia* **60**(9): 1566-76.

²³⁷ Martin-Montalvo A, Mercken EM, Mitchell SJ et al. (2013) Metformin improves healthspan and lifespan in mice *Nature Communications* **4**: 2192.

²³⁸ See: Thrivous blog (16 March 2021) *Tame trial may set anti-ageing drug precedent*, available at: <https://thrivous.com/blogs/views/tame-trial-may-set-anti-ageing-drug-precedent>; Barzilai N, Crandall JP, Kritchevsky SB et al. (2016) Metformin as a tool to target aging *Cell Metabolism* **23**(6): 1060-5; and American Federation for Aging Research (2021) *The TAME trial*, available at: <https://www.afar.org/tame-trial>.

²³⁹ Zhavoronkov A, Kochetov K, Diamandis P et al. (2020) PsychoAge and SubjAge: development of deep markers of psychological and subjective age using artificial intelligence *Ageing (Albany NY)* **12**(23): 23548-77.

²⁴⁰ de Magalhães JP, Stevens M, and Thornton D (2017) The business of anti-ageing science *Trends in Biotechnology* **35**(11): 1062-73.

²⁴¹ Kaeberlein M, Rabinovitch PS, Martin GM (2015) Healthy aging: the ultimate preventative medicine *Science* **350**(6265): 1191-3.

²⁴² See, for example, the database DrugAge which curates data on drugs and compounds that have promising effects in relation to ageing: Human Ageing Genomic Resources (2021) *DrugAge: the database of ageing-related drugs*, available at: <https://genomics.senescence.info/drugs/>; and Barardo D, Thornton D, Thoppil H et al. (2017) The DrugAge database of ageing-related drugs *Ageing Cell* **16**(3): 594-7. See also: Kulkarni AS, Aleksic S, Berger DM et al. (2022) Geroscience-guided repurposing of FDA-approved drugs to target aging: a proposed process and prioritization *Ageing Cell* **21**(4): e13596.

trajectory (e.g., raised blood pressure or poor blood glucose control), which involves medicating someone who is still considered healthy, or should the intervention wait until a disease is confirmed, with the aim of mitigating, rather than preventing disease?

- Determining **inclusion and exclusion criteria**: in particular in ensuring that the trial will provide meaningful evidence with respect to the people who are typically likely to use the intervention if it is shown to be effective.²⁴³ The standard approach of excluding people with multiple conditions from clinical trials is particularly problematic for research related to ageing (see paragraph 3.10).
- Choosing **'endpoints'** for the study: determining outcome measures that reliably demonstrate benefit in ways that are meaningful to the lives of older adults. Given the multiple systems involved in ageing, it is likely that novel interventions will be targeting several pathways at once, requiring both primary and secondary outcomes to be measured. Possible measures include time to clinical diagnosis of one or more age-related conditions, measures of function such as levels of mobility, and the use of questionnaires to track health-related quality of life. While biomarkers associated with the ageing process will play a valuable role in future in supporting feasible and affordable trials, it will be essential for these to correlate with aspects of ageing that are valued by older adults.²⁴⁴ We discuss biomarkers further below (see paragraphs 3.35–3.40) and return in more detail in Chapter 4 to questions of benefit and how these are determined (see paragraphs 4.2–4.10).
- Determining the **length** of the study, which will depend on the endpoints chosen. Outcome measures such as time to death, or time to the onset of a first major chronic condition, would be likely to lead to unfeasibly extended and expensive trials, especially if investigating interventions designed to be taken during middle age or even earlier. The longer the study, the greater the burden on participants (e.g., in terms of follow-up), and the more extended, and expensive, the data surveillance required. In practice, it is likely that a combination of trial evidence, including biomarkers, and observational 'real-world' evidence will be required, particularly for very long-term interventions (see also paragraph 3.11).
- Ensuring that the study design, and in particular the endpoints selected, can provide data that will be **acceptable to regulators** responsible for providing marketing authorisation for new interventions (see paragraphs 3.17–3.20).

3.10 The approach taken in geroscience of targeting multiple pathways and systems within the human body also represents a major shift in the current approach to clinical research. This has long been based on the study of one medical condition at a time, studied in patients who do not have any other conditions, in order to avoid what are seen as confounding factors. Yet many people (particularly older adults) live with multiple long-term conditions (MLTCs). This 'single condition paradigm' in research was described to the working group as "flawed" and as "requiring revision",²⁴⁵ because of its neglect of the needs of people, particularly older adults, living with MLTCs, and its failure to address wider health-related harms. Thus, for example, people with MLTCs are more likely to suffer harm from polypharmacy: the interaction of different medicines prescribed to the same person for different conditions. They are also more likely to suffer from adverse reactions to new treatments because of the inadequate evidence base as to how an older

²⁴³ See, for example, Hanlon P, Corcoran N, Rughani G *et al.* (2021) Observed and expected serious adverse event rates in randomised clinical trials for hypertension: an observational study comparing trials that do and do not focus on older people *The Lancet Healthy Longevity* **2(7)**: e398-e406.

²⁴⁴ See, for example, the related discussion of the disputed value of beta-amyloid as a surrogate endpoint for Alzheimer's disease: Alexander GC, Knopman DS, Emerson SS *et al.* (2021) Revisiting FDA approval of Aducanumab *New England Journal of Medicine* **385(9)**: 769-71.

²⁴⁵ Professor Miles Witham and Professor Avan Sayer, responding to our call for evidence.

person will react, or indeed be excluded from receiving treatments that could in fact have helped, because of concern regarding the lack of evidence.²⁴⁶ While geroscience-guided trials have a number of design challenges to resolve, as described above, the holistic approach to health that underlies them offers an important way forward in ensuring a more inclusive approach to research design, with the ultimate aim of avoiding the challenges of polypharmacy altogether (see also paragraph 4.27 and Box 4.8 on other initiatives concerning research with people with MLTCs).

- 3.11 The difficulties involved in conducting geroscience-guided clinical trials over very long time periods, noted above, illustrate the importance of considering how geroscience can complement, and be complemented by, other forms of research. In particular, respondents to the working group's call for evidence highlighted the crucial role played by high-quality longitudinal studies in improving understanding of ageing.²⁴⁷ Multidisciplinary longitudinal cohort studies, whether starting from childhood (such as the Dunedin study²⁴⁸) or from later middle age (such as the English Longitudinal Study of Ageing²⁴⁹), provide the basis for a rich understanding of the changing nature of disease across generations, and hence for improving our understanding of how most effectively to intervene to support people in ageing well. Such systematic research requires long-term, substantial, and sustained investment in cohorts in order to follow individuals across time into older age, and in particular to ensure that cohorts are sufficiently diverse.
- 3.12 In line with this recognition of the valuable complementary role played by other forms of research, contributors to the working group's inquiry emphasised how potential new therapeutics to target ageing should not be seen as providing a 'quick fix' to the ways that our bodies age, suggesting rather that they should be considered as part of a holistic approach, alongside adaptations to lifestyle and environment.²⁵⁰ The working group concluded the following.
- **Geroscience is not a magic bullet:** rather it offers scope in the future for finding more holistic and targeted ways of preventing, delaying, and treating the common conditions of older age, with the primary aim of reducing the amount of time spent in ill health at the end of life (often described as 'compression of morbidity').²⁵¹
 - **Geroscience should not be seen (primarily) as being about living longer:** strong views were expressed among contributors to this inquiry about how the reputation of the field is tarnished by those seeking extreme old age, distracting from the valuable focus on improving healthspan for the many, not the few.²⁵² It was noted, nevertheless, that it is difficult in practice to disentangle these two aims entirely: research targeting extended lifespan may in practice have value for improvements in healthspan, and vice versa.²⁵³
 - **Geroscience should be seen as complementary to other areas of research and health and social care,** including by providing knowledge that underpins and supports

²⁴⁶ Tan YY, Papez V, Chang WH *et al.* (2022) Comparing clinical trial population representativeness to real-world populations: an external validity analysis encompassing 43 895 trials and 5 685 738 individuals across 989 unique drugs and 286 conditions in England *The Lancet Healthy Longevity* **3(10)**: e674-e89; and Dreyer NA (2022) Strengthening evidence-based medicine with real-world evidence *The Lancet Healthy Longevity* **3(10)**: e641-e2.

²⁴⁷ Nuffield Council on Bioethics (2023) *The future of ageing: call for evidence summary of responses*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/public-dialogue-on-the-future-of-ageing>.

²⁴⁸ Dunedin Multidisciplinary Health & Development Research Unit (2022) *The Dunedin Study*, available at: <https://dunedinstudy.otago.ac.nz/studies/assessment-phases>.

²⁴⁹ English Longitudinal Study of Ageing (2019) *About ELSA*, available at: <https://www.elsa-project.ac.uk/about-elsa>.

²⁵⁰ Geroscience roundtable, 21 July 2021 (see Appendix 1).

²⁵¹ Fries JF (1980) Aging, natural death, and the compression of morbidity *The New England Journal of Medicine* **303(3)**: 130-5.

²⁵² See, for example, Nuffield Council on Bioethics (2023) *The future of ageing: call for evidence summary of responses*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/public-dialogue-on-the-future-of-ageing>. See also: Geroscience roundtable, 21 July 2021 (see Appendix 1).

²⁵³ Scott AJ, Ellison M, and Sinclair DA (2021) The economic value of targeting aging *Nature Aging* **1(7)**: 616-23.

individual and societal means of promoting good health, including addressing factors such as poverty, housing, employment, local environments, diet, exercise and social interaction (see paragraphs 1.20–1.21). There is, for example, a growing interest in how molecular mechanisms in humans can be targeted to improve healthspan through dietary and lifestyle factors.²⁵⁴

Drivers of geroscience

“There is a lot of hype in longevity research – No single drug or molecule yet can outdo the effects of a bad lifestyle or being in the poverty trap.”²⁵⁵

“This is not about developing the first 1,000-year-old human; it’s about ensuring old age is enjoyed and not endured. Who wants to extend lifespan if all that means is another 30 years of ill health? This is about increasing healthspan, not lifespan.”²⁵⁶

3.13 As we noted in paragraph 3.4, the current research funding situation in the UK is something of a patchwork of private, public, and charitable money. Most public and charitable funding for biomedical sciences (whether basic science or more translational research with human participants) has historically followed the ‘single disease’ model described above, which is challenging both for geroscience as a field, and for clinical research that is inclusive of people with MLTCs. This contrasts with, for example, the funding situation in the US, where the National Institute of Aging (NIA)²⁵⁷ acts as a focal point for federally funded research concerned with understanding the nature of ageing, and extending healthy years of life (a coordinated approach to public funding endorsed by some respondents to our inquiry).²⁵⁸ The role of the commercial sector similarly diverges from the situation in the US (see Box 3.4), with private or industry funding of geroscience research in the UK still at relatively low levels.²⁵⁹ Lack of venture capital, in particular, has led to some basic science discoveries made in the UK academic sector being translated into clinical trials funded and conducted in the US, rather than remaining in the UK.²⁶⁰

3.14 A number of UK Government strategies relevant to ageing research, including the *Life Sciences Vision* and *Our Future Health* (see Box 3.10), have strongly emphasised the Government’s commitment to a partnership approach across the commercial, public, and charitable sectors in these fields. The *Life Sciences Vision*, for example, spoke of the “deep collaboration between Government and industry”, which it is intended “will advance the medical science and understanding of ageing, in order to begin to advance viable products towards the clinic”.²⁶¹ However, the public funding for ageing channelled through partnerships with industry as part of the 2017 *Industrial Strategy* has all been

²⁵⁴ Malcomson FC, and Mathers JC (2018) Nutrition and ageing *Subcellular Biochemistry* 90: 373-424.

²⁵⁵ Collider Health blog (28 June 2022) *Healthy longevity for all: a blueprint to maximise equitable health and wealth*, available at: <https://www.colliderhealth.com/blog>.

²⁵⁶ The Guardian (17 February 2022) *If they could turn back time: how tech billionaires are trying to reverse the ageing process*, available at: <https://www.theguardian.com/science/2022/feb/17/if-they-could-turn-back-time-how-tech-billionaires-are-trying-to-reverse-the-ageing-process>.

²⁵⁷ National Institute on Aging (2022) *About NIA*, available at: <https://www.nia.nih.gov/about>.

²⁵⁸ Geroscience roundtable, 21 July 2021 (see Appendix 1).

²⁵⁹ See, for example, the dataset extracted by UK SPINE from the NIHR Open Data Platform, showing the breakdown of commercial and non-commercial funding of ageing research between 2008 and 2020: UK SPINE Knowledge Exchange (2022) *Funder roadmap*, available at: <https://www.kespine.org.uk/funder-roadmap>.

²⁶⁰ House of Lords Science and Technology Select Committee (2021) *Ageing: science, technology and healthy living*, available at: <https://publications.parliament.uk/pa/ld5801/ldselect/ldscitech/183/183.pdf>, at paragraph 187.

²⁶¹ Department for Business, Energy and Industrial Strategy (2021) *Life sciences vision*, available at: <https://www.gov.uk/government/publications/life-sciences-vision>, at page 57.

directed towards technological innovation (see paragraph 3.29). It did not extend to the life sciences sector, despite the latter's potentially important contributory role in the strategy's aim of extending healthy life expectancy by five years.²⁶² In its 2021 report, the House of Lords Science and Technology Select Committee highlighted the view from the research community that "the focus of the Industry Strategy Challenge fund on technological solutions and data analysis is unlikely to help deliver the target."²⁶³

3.15 Within the lifetime of this inquiry, there have been some important developments in ageing research policy in the life sciences: in particular the March 2022 announcement by the Medical Research Council (MRC) and Biotechnology and Biological Sciences Research Council (BBSRC) (with the support of the Economic and Social Research Council) of a new initiative to support 11 ageing research networks (see Box 3.3).²⁶⁴ While the funding involved is relatively modest, the explicit aim of these networks is to facilitate collaboration across the many interconnected areas of research relevant to ageing over the life course, thus promoting a more connected approach across the field, regardless of the diverse funding sources of individual projects and centres within those networks. The network UK SPINE (see Box 3.3) has also played an important, if short-lived, role in supporting collaboration between industry, charitable and public funders, and academic researchers, with the aim of creating the tools, ideas, and pathways necessary for the successful translation of increased understanding of the biology of ageing into effective interventions.

Box 3.3: UK Ageing Networks

Previous reviews have highlighted the fragmentation among systems and research on ageing, often as a result of focusing on a single aspect of ageing.²⁶⁵ In order to boost research into ageing in the UK, two cross-cutting networks have been developed.

- **UK Ageing Network:** launched in March 2022, the Biotechnology and Biological Sciences Research Council (BBSRC) and the Medical Research Council (MRC) have provided £2 million to create 11 new UK Ageing Networks to address the central aspects of the health and biology of ageing across the life course, with the aim of enabling knowledge exchange and research across many disciplines including social sciences, humanities, economics, and biomedical sciences.²⁶⁶ The networks also aim to include older adults as public contributors to enable coproduction of future ageing research studies. Examples of the networks include a project looking at the role of the skin microbiome in healthy ageing (SMiHA), research into healthy diet across the life course (Food4Years), and an ageing research translation (ART) network looking at how to translate research advancements into clinical trials.²⁶⁷
- **UK SPINE:** funded by Research England's Connecting Capabilities Fund (CCF), UK SPINE was a network of six partner research institutes aimed at improving

²⁶² House of Lords Science and Technology Select Committee (2021) *Ageing: science, technology and healthy living*, available at: <https://publications.parliament.uk/pa/ld5801/ldselect/ldscitech/183/183.pdf>, at paragraphs 198–202.

²⁶³ *ibid.*, at paragraph 202.

²⁶⁴ See: UKRI (9 March 2022) *Researchers at 28 UK universities team up to tackle healthy ageing*, available at: <https://www.ukri.org/news/researchers-at-28-uk-universities-team-up-to-tackle-healthy-ageing/>.

²⁶⁵ House of Lords Select Committee on Science and Technology (2021) *Ageing: science, technology and healthy living*, available at: <https://publications.parliament.uk/pa/ld5801/ldselect/ldscitech/183/183.pdf>; and UKRI (9 March 2022) *Researchers at 28 UK universities team up to tackle healthy ageing*, available at: <https://www.ukri.org/news/researchers-at-28-uk-universities-team-up-to-tackle-healthy-ageing/>.

²⁶⁶ UKRI (9 March 2022) *Researchers at 28 UK universities team up to tackle healthy ageing*, available at: <https://www.ukri.org/news/researchers-at-28-uk-universities-team-up-to-tackle-healthy-ageing/>; and Cox LS, and Faragher RGA (2022) Linking interdisciplinary and multiscale approaches to improve healthspan—a new UK model for collaborative research networks in ageing biology and clinical translation *The Lancet Healthy Longevity* **3(5)**: e318–e20.

²⁶⁷ UKRI (9 March 2022) *Researchers at 28 UK universities team up to tackle healthy ageing*, available at: <https://www.ukri.org/news/researchers-at-28-uk-universities-team-up-to-tackle-healthy-ageing/>.

healthspan for those with multiple age-related conditions. Its focus was on accelerating the discovery and development of potential new drugs, understanding the biological processes of ageing, and working with members of the public to understand the regulatory needs for treatments. Active from 2018 to December 2022, UK SPINE put knowledge exchange to the fore, creating a platform to bring together geroscience researchers, industry, clinicians, patients, and members of the public. The name 'UK SPINE' refers to the geographic spread of research hubs which form a spine down the UK.²⁶⁸

- 3.16 In contrast with the situation in the UK, both basic and translational geroscience research in the US is strongly driven by private capital (see Box 3.4). While the publicity associated with some prominent figures in the field can lead to attention-grabbing headlines about the possibilities of extending life by hundreds of years,²⁶⁹ in practice the focus of current clinical research is primarily on improvements in healthspan, as seen in the review of registered and ongoing phase 1 to 4 randomised clinical trials assessing pharmacological interventions for mechanisms of ageing, conducted as part of this inquiry.²⁷⁰ Nevertheless, where research is driven mainly or primarily by the commercial sector, it is important to recognise that vested interests will inevitably direct research towards profit, in ways that are not necessarily concerned with wider population health.²⁷¹ Public contributors to the working group inquiry, while realistic about the need for commercial stakeholders to make a profit, expressed strong concern about the idea that research in this area might be driven for reasons of commercial gain, not public benefit.²⁷²

Box 3.4: Private funding in the US

Despite geroscience research groups existing in almost every high-income country, the US is the world leader in geroscience research with several government-funded research programmes, such as the US National Institute on Aging, and a number of private biotechnology companies exploring potential age-related interventions. The American Federation for Aging Research (AFAR) is an example of a non-profit organisation in the US offering a model of how private funds can advance geroscience research. The AFAR has gained funding from a range of private or philanthropic sources including the Arthritis National Research Foundation and the Glenn Foundation for Medical Research.²⁷³

There is a significant difference in private funding opportunities for geroscience research between the UK and US, which has been suggested to stem from differences in “appetite for failure and risk-taking”, and this has led to a larger market for companies

²⁶⁸ UK SPINE Knowledge Exchange (2022) *About*, available at: <https://www.kespine.org.uk/about>.

²⁶⁹ See, for example, Financial Times (8 February 2017) *Aubrey de Grey: scientist who says humans can live for 1,000 years*, available at: <https://www.ft.com/content/238cc916-e935-11e6-967b-c88452263daf>.

²⁷⁰ See, for example, our evidence review on geroscience: Nuffield Council on Bioethics (2023) *The future of ageing: evidence reviews*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering-2>.

²⁷¹ See, for example, research into the treatment of neurodegenerative diseases also exploring potential applications such as cognitive enhancers or other lifestyle purposes: MIT Technology Review (25 August 2021) *The miracle molecule that could treat brain injuries and boost your fading memory*, available at: <https://www.technologyreview.com/2021/08/25/1031783/isrib-molecule-treat-brain-injuries-memory/>; and Neuralink (2022) *Engineering with the brain*, available at: <https://neuralink.com/applications/>.

²⁷² Nuffield Council on Bioethics blog (12 July 2022) *The future of ageing – learning from the West Bromwich African Caribbean Resource Centre*, available at: <https://www.nuffieldbioethics.org/blog/the-future-of-ageing-learning-from-the-west-bromwich-african-caribbean-resource-centre>; and Nuffield Council on Bioethics (2023) *Public dialogue report on the future of ageing*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/public-dialogue-on-the-future-of-ageing>.

²⁷³ Martin GM (2017) Geroscience: addressing the mismatch between its exciting research opportunities, its economic imperative and its current funding crisis *Experimental Gerontology* **94**: 46-51.

researching biological ageing in the US.²⁷⁴ Small and medium-sized enterprises (SMEs) and start-ups tend to be more disruptive in this field but often struggle to access the funding they need to progress their research programmes.²⁷⁵ Examples of US start-ups in this field that have acquired substantial financial backing, often from wealthy investors, include the Google-launched biotechnology company Calico, which aims to devise “interventions that enable people to lead longer and healthier lives”.²⁷⁶ Investors such as Amazon founder Jeff Bezos contributed to the Silicon Valley start-up Unity Biotechnology, which raised US\$116 million in 2016. This company intends to create therapies aimed at flushing out senescent cells from the body. The co-founder of Unity, Ned David, has claimed that potential drug innovations could “vaporise a third of human diseases in the developed world”.²⁷⁷ A new institute, the Cambridge Institute of Science, is being built in the UK by the US biotechnology start-up company Altos Labs which is being “backed by Silicon Valley billionaires to the tune of \$3 billion (£2.2 billion)”.²⁷⁸

Often biotechnology companies and their investors frame ageing as something to be ‘treated’ in order to ‘solve’ death. PayPal founder Peter Thiel, for example, has contributed substantial amounts of money to the Methuselah Foundation, which aims “to make 90 the new 50 by 2030” and believes it will be possible to “reverse all human ailments in the same way that we can fix the bugs of a computer program. Death will eventually be reduced from a mystery to a solvable problem”. Despite much of this research being at an early stage, this framing of ageing and discussions of ‘anti-ageing research’ often influences marketing and demand for direct-to-consumer products such as of biological age tests.²⁷⁹

Regulatory challenges

3.17 Just as the dominant paradigm in clinical research is based on treating single diseases, regulatory bodies around the world, including the US Food and Drug Administration (FDA), the European Medicines Agency, and the UK’s Medicines and Healthcare products Regulatory Agency (MHRA), grant marketing authorisations on the basis of evidence demonstrating benefit for one or more specific conditions (‘indications’). The fundamental basis of geroscience research, of intervening in the underlying mechanisms that influence how our bodies age in order to prevent, delay, or mitigate multiple medical conditions, does not fit within this regulatory approach.

3.18 In response to this regulatory impasse, there has been considerable debate as to whether ‘ageing’ itself should be classified as a disease, so that researchers working in this area could seek approval for trials with ‘reduced ageing’ as an outcome, and down the line for marketing authorisation for new interventions shown to intervene beneficially in the process of ageing, without the need to link this to any particular medical condition.²⁸⁰ This has been a controversial proposal, not least because of the way such

²⁷⁴ Crane PA, Wilkinson G, and Teare H (2022) Healthspan versus lifespan: new medicines to close the gap *Nature Aging* **2**(11): 984-8.

²⁷⁵ *ibid.*

²⁷⁶ Calico (2022) *Calico’s mission statement*, available at: <https://calicolabs.com/mission-and-values>.

²⁷⁷ The Guardian (17 February 2022) *If they could turn back time: how tech billionaires are trying to reverse the ageing process*, available at: <https://www.theguardian.com/science/2022/feb/17/if-they-could-turn-back-time-how-tech-billionaires-are-trying-to-reverse-the-ageing-process>.

²⁷⁸ *ibid.*

²⁷⁹ See, for example, Business Fast (13 June 2022) *Real age versus biological age: the startups revealing how old we really are*, available at: <https://www.businessfast.co.uk/real-age-versus-biological-age-the-startups-revealing-how-old-we-really-are/>. See also: Jain P, Binder AM, Chen B *et al.* (2022) Analysis of epigenetic age acceleration and healthy longevity among older US women *JAMA Network Open* **5**(7): e2223285-e.

²⁸⁰ See, for example, MIT Technology Review (19 October 2022) *The debate over whether aging is a disease rages on*, available at: <https://www.technologyreview.com/2022/10/19/1061070/is-old-age-a-disease/>.

a categorisation could exacerbate ageism through conflating the detrimental physical changes in older age with the lives and experiences of older adults (see paragraph 2.5). In other words, if 'ageing' were to be portrayed as a disease or indication, this could be seen as an endorsement of the idea that being old is inherently negative in itself, rather than a recognition of the scope for intervening beneficially in the rate and manner in which our bodies age. Similar concerns arise with respect to the language of 'treating' or 'curing' ageing.

- 3.19 The latest revision of the International Classification of Diseases (ICD 11) in January 2022 now uses the term "ageing associated decline in intrinsic capacity" in place of earlier proposals to use the term 'old age' (itself put forward in place of the stigmatising term 'senility' used in earlier editions).²⁸¹ The definitions used in the ICD are used for a wide variety of reporting purposes and statistics;²⁸² it remains to be seen how regulatory bodies might respond to this development, and if it will help in the development of preventative geroscience-informed trials primarily targeting ageing processes rather than age-related diseases themselves.
- 3.20 In its 2021 review of developments in research in ageing, the House of Lords Science and Technology Select Committee made the recommendation that "the Medicines and Healthcare products Regulatory Agency (MHRA) show greater willingness to approve trials which target multiple conditions",²⁸³ and the working group is aware of continuing discussions between the MHRA and other stakeholders to take this agenda forward.²⁸⁴ In particular, the House of Lords Select Committee urged the MHRA to "explore the use of novel trial endpoints, such as using biomarkers of ageing as measures of success in treatments targeting the ageing process".²⁸⁵ As we noted earlier, while biomarkers (once validated) could potentially have an important role to play in facilitating shorter trials, it will be important that they are also shown to correlate with quality-of-life factors for older adults (see paragraph 3.9). Other proposals have included a strong push for research using drugs that are already licensed, in order to provide the necessary evidence for the 'gerotherapeutic' impact of particular compounds;²⁸⁶ the use of composite endpoints as in the TAME trial (see Box 3.2); and the use of 'deficit accumulation indices' (DAIs), as a way of measuring the impact on general health of multiple coexisting conditions.²⁸⁷ Within the UK, the 'Innovative Licensing and Access Pathway' (ILAP), which includes provision for applications for the licensing of new indications, offers a possible route for exploring such novel approaches.²⁸⁸

²⁸¹ Rabheru K, Byles JE, and Kalache A (2022) How "old age" was withdrawn as a diagnosis from ICD-11 *The Lancet Healthy Longevity* **3(7)**: e457-e9.

²⁸² WHO (2022) *ICD-11 fact sheet*, available at: https://icd.who.int/en/docs/icd11factsheet_en.pdf.

²⁸³ House of Lords Science and Technology Select Committee (2021) *Ageing: science, technology and healthy living*, available at: <https://publications.parliament.uk/pa/ld5801/ldselect/ldsctech/183/183.pdf>, at paragraph 156.

²⁸⁴ Crane PA, Wilkinson G, and Teare H (2022) Healthspan versus lifespan: new medicines to close the gap *Nature Aging* **2(11)**: 984-8.

²⁸⁵ House of Lords Select Committee on Science and Technology (2021) *Ageing: science, technology and healthy living*, available at: <https://publications.parliament.uk/pa/ld5801/ldselect/ldsctech/183/183.pdf>, at paragraph 156.

²⁸⁶ Kulkarni AS, Aleksic S, Berger DM *et al.* (2022) Geroscience-guided repurposing of FDA-approved drugs to target aging: a proposed process and prioritization *Aging Cell* **21(4)**: e13596.

²⁸⁷ Ferrucci L, and Kohanski R (2022) Better care for older patients with complex multimorbidity and frailty: a call to action *The Lancet Healthy Longevity* **3(9)**: e581-e3.

²⁸⁸ NICE (2022) *Our role in the Innovative Licensing and Access Pathway (ILAP)*, available at: <https://www.nice.org.uk/about/what-we-do/life-sciences/our-role-in-the-innovative-licensing-and-access-pathway--ilap>.

Assistive, monitoring, and communications technologies

3.21 The range of assistive, monitoring, and communications technologies that have a potential role to play in influencing how our bodies age, or how we live in later life, is vast. In particular, any product or device that promotes healthy behaviours at *any* point in the life course could come within the scope of this inquiry to the extent that it could be associated with healthier life experiences in older age. For practical reasons we have focused primarily on technologies that are targeted specifically at older adults, or are likely to be used by older adults. We note here, however, the important and increasing role likely to be played in this field by consumer technologies that promote healthier lifestyles earlier in life, and we touch later on the regulatory challenges involved (see paragraphs 3.31–3.32).

3.22 Examples of technologies relevant to this inquiry are set out in Box 3.5, and include the following.²⁸⁹

- Devices that **support people to live independently despite a degree of loss of intrinsic capacity**, from kitchen adaptations, equipment to support personal mobility, and reminder systems, to more futuristic robot ‘butlers’. These may be stand-alone devices or adaptations, chosen to meet a specific need, or connected together to provide an increasingly integrated ‘smart home’.²⁹⁰ Options range from ‘low-tech’ devices that have long been on the market, such as tools to help reach or grip, to much more high-tech devices: for example voice- or phone-activated controls for heating and lighting, or ‘exoskeletons’ (wearable powered devices) to provide added strength. They may be designed to compensate for loss of physical abilities, cognitive impairment, or both.
- Technological approaches to **disease prevention and rehabilitation**, including apps designed to encourage and reinforce healthy behaviours, or identify potential risk factors such as changes in the way people walk; and virtual reality tools to support rehabilitative exercises.
- Devices that enable **remote contact and support**, and provide **reassurance to carers** and family members: from facilitating social video calls to providing active monitoring and surveillance. They can range from the use of common digital communications technologies, such as Zoom, FaceTime, WhatsApp, or Alexa, to specialised sensors that detect falls or behaviours deemed to be unusual or alarming and alert outside assistance, for example via a call centre or a direct link to a named friend or family member.
- **Telehealth and telecare systems**, ranging from reminders or check-ins delivered through a smart television, to wearables that monitor and send biometric data directly from the person to their health-monitoring system (see also paragraphs 3.35–3.40 where we explore the use of such monitoring systems in more detail).
- **Companion or emotional support technologies**, from AI-generated personalised music playlists, and digital ‘memory machines’ providing a repository of memories that can be shared with others, to robot ‘pets’ and companions that facilitate activities, encourage exercise routines, and offer basic conversation.

²⁸⁹ For a detailed account of many different types of technologies available, and the research underlying their development and use, see our evidence reviews on technologies: Nuffield Council on Bioethics (2023) *The future of ageing: evidence reviews*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering-2>.

²⁹⁰ See, for example, SHAPES (2020) *About SHAPES*, available at: <https://shapes2020.eu/about-shapes/>; and National Innovation Centre Ageing (2022) *Internet of caring things*, available at: <https://ioct.uknica.co.uk/>, although it should be noted that fully integrated smart homes or smart houses are still an emerging concept.

- **Practical support for care staff or informal carers**, such as automated systems that facilitate routine tasks such as record-keeping, or providing support for lifting.

Box 3.5: Examples of innovative technologies

Physical and cognitive assistance technologies

- ‘Hands-free’ toilets that have automatic washing and drying functions that operate while a person is seated.²⁹¹
- A knee-high robotic machine called Gita, which holds a person’s belongings and follows them throughout their day. The robotic technology is designed to assist people by carrying their groceries and shopping, and by prompting them to walk more and further distances.²⁹²
- A cashless solution for those with learning disabilities called Cash for Independent People (ChIP). Winner of the Care Innovation Challenge 2022, ChIP is a fully customisable, easy-to-use mobile banking app specifically tailored for those with learning difficulties, to make money management easier and promote independence.²⁹³

Disease prevention and rehabilitation technologies

- A wearable device called the ‘MyoSock’ that monitors muscle health and function and can evaluate the efficacy of treatments for sarcopenia (loss of muscle mass and strength). It was initially designed to help researchers measuring muscle health, but the long-term goal of this project is to develop a commercially available device for clinical and non-clinical purposes to monitor general muscle activity, similar to smart watches such as the Apple iwatch.²⁹⁴
- The ElliQ robot that encourages healthy habits for older adults. The robot’s features include personalised workouts, cognitive games, mindfulness exercises, and goal setting to motivate older adults to adopt healthier habits.²⁹⁵
- Virtual reality head-mounted display systems or headsets being investigated at the University of Bath that enable older adults to complete exercise courses to prevent falls and improve balance.²⁹⁶
- A digital service, called FitBees, involving integrated home sensors and wearable technologies or ‘smart’ garments to support physical activity among people in under-represented groups. The digital platform, funded by UK Research and Innovation (UKRI), provides motivational encouragements as well as community connections to encourage sustainable exercise in older adults.²⁹⁷

²⁹¹ See, for example, Age UK (2022) *Top tips for a more comfortable home*, available at: <https://www.ageuk.org.uk/information-advice/care/housing-options/adapting-home/making-home-comfortable/>. See also: Sync Living (2022) *Automatic toilets*, available at: <https://www.syncliving.co.uk/product/automatic-toilets/>.

²⁹² Centre for Ageing Better (2019) *Ageing and mobility: a grand challenge*, available at: <https://ageing-better.org.uk/sites/default/files/2019-09/Ageing-and-mobility-grand-challenge.pdf>; and National Innovation Centre Ageing (23 March 2021) *Pedestrianism, the future of urban mobility*, available at: <https://uknica.co.uk/pedestrianism-the-future-of-urban-mobility/>; and Piaggio Fast Forward (2022) *The following robot that moves how you move*, available at: <https://mygita.com/how-it-works>.

²⁹³ Care Innovation Hub (14 October 2022) *Team CHIP win the Care Innovation Challenge 2022*, available at: <https://careinnovationhub.org.uk/team-chip-win-the-care-innovation-challenge-2022/>.

²⁹⁴ Innovate UK KTN (2022) *Dynamic muscle function monitoring*, available at: <https://ktn-uk.org/projects/dynamic-muscle-function-monitoring/>.

²⁹⁵ ELLIQ (2022) *Introducing ElliQ: the sidekick for healthier, happier aging*, available at: <https://elliq.com/>. See also: The Washington Post (16 March 2022) *Meet ElliQ, the robot who wants to keep Grandma company*, available at: <https://www.washingtonpost.com/technology/2022/03/16/lonely-elderly-companion-ai-device/>.

²⁹⁶ University of Bath (1 December 2021) *Virtual reality could help improve balance in older people*, available at: <https://www.bath.ac.uk/announcements/virtual-reality-could-help-improve-balance-in-older-people/>.

²⁹⁷ Tendertec (1 July 2022) *FitBees*, available at: <https://tendertec.org/2022/07/01/press-release-fitbees/>; and UKRI (1 July 2022) *Winning projects will design for ageing*, available at: <https://www.ukri.org/news/winning-projects-will-design-for-ageing/>.

Telehealth and telecare systems

- A system called Minder, that aims to develop a remote monitoring, smart home system to support older adults living in their own homes, and to learn more about different health conditions, in order to treat and manage conditions better. Currently in the study phase, sensors and detection devices are placed in the homes of people living with dementia. The sensors will monitor activity and take daily measurements linked to the Minder app that will be monitored by an external team to help support the health and wellbeing of participants. People living with dementia and their families are central to developing the Minder system and exploring the ethical implications of its implementation.²⁹⁸
- GPS-fitted insoles, known as SmartSoles, designed to be worn by a person with cognitive impairment so that they can be easily located by friends, family, or carers from the GPS tracker using a smart phone app.²⁹⁹
- CareCalls, a telephone reminder and check-in service that not only reminds older adults to take their medication at a particular time but also provides calls “for those who need more in-depth interaction to check they are ok and to tackle isolation”.³⁰⁰

Emotional support technologies

- PARO, the robotic baby harp seal, designed to provide comfort for healthy older adults and those with cognitive impairments.³⁰¹
- An AI-based television-enabled application (TEA) co-designed with older adults, which aims to adapt a home television set into something that is “universally useful for enabling older people to connect with befriending services”. Initially focusing on older people in Essex and Cornwall, TEA aims to increase social connections and address loneliness by facilitating engagement opportunities.³⁰²

Technologies to provide support for care staff and informal carers

- An online support tool called Mobilise, which aims to provide a platform to support unpaid carers. This innovative online service learns “about the specific needs of an individual carer and points them to the most relevant content and peer support communities”.³⁰³
- Urinary incontinence sensors, such as the TENA SmartCare Change Indicator, to alert care staff that incontinence products need to be changed, especially designed for older adults who may not be able to communicate their needs. The technology features a reusable sensor that is attached to the absorbent product and tracks the degree of urine saturation. It alerts care staff via the TENA SmartCare Professional Care app when it’s time for the incontinence product to be changed.³⁰⁴

3.23 As these examples illustrate, technologies may be designed to be used directly by older adults themselves, whether living independently in their own homes or in some form of supported living. Alternatively, they may be primarily designed to support caregivers

²⁹⁸ UK Dementia Research Institute Care Research and Technology Centre (2021) *Pioneering new technologies aimed at supporting people to live well for longer*, available at: https://ukdri.ac.uk/uploads/UK-DRI-Care-Research-_-Technology-Booklet.pdf; and Minder Meeting Place (2023) *Minder*, available at: <https://mindermeetingplace.com/>.

²⁹⁹ SmartSole (2022) *When they wander, you'll never wonder*, available at: <https://www.gpssmartsole.com/>.

³⁰⁰ Carecalls (2021) *Reminders & check-ins to help people remain independent & happy*, available at: <https://www.carecalls.co.uk/>.

³⁰¹ McGlynn SA, Kemple S, Mitzner TL et al. (2017) Understanding the potential of PARO for healthy older adults *International Journal of Human-Computer Studies* **100**: 33-47.

³⁰² Innovate UK KTN (2022) *MediprospectusAI*, available at: <https://ktn-uk.org/projects/mediprospectusai/>.

³⁰³ Innovate UK KTN (2022) *Mobilise Care Ltd - online support for unpaid carers*, available at: <https://ktn-uk.org/projects/mobilise-care-ltd-online-support-for-unpaid-carers/>.

³⁰⁴ TENA (2022) *TENA SmartCare Change Indicator™*, available at: <https://www.tena.co.uk/professionals/innovation/smartcare/>.

(formal or informal), whether through offering time- or cost-effective alternatives to direct human assistance, by offering reassurance and information, for example to family members living elsewhere, or by providing a supportive function that enables care to be provided more easily. These distinctions, however, are far from clear: in some cases, for example, older adults may agree to make use of particular technologies to provide reassurance to others concerned about their wellbeing, rather than because of their own preferences or needs.³⁰⁵ We explore in more detail in the next chapter the question of how ‘benefit’ is understood in research concerned with ageing, and in particular the extent to which the perspectives of older adults are, or are not, the primary focus in the development and deployment of such technologies (see paragraphs 4.2–4.10).

- 3.24 Just as geroscience should not be seen as a ‘magic bullet’ for responding to the needs of older adults (see paragraph 3.12), contributors to the working group’s inquiry emphasised the complexity of ways in which the wide range of technological devices and services under consideration might affect people’s lives.³⁰⁶ In particular, they highlighted how most technologies (whether developed specifically in connection with ageing or more generally available on the consumer market) require adaptation and personalisation to meet the needs of any particular individual – and how this is not a one-off process. People’s needs change over time, and the ways that technologies are used to support them in living their lives will also need to adapt, quite apart from the way that technologies themselves tend to be subject to regular updates and developments in functionality that affect their use. Thus, the provision of a technological ‘solution’ to a particular issue or difficulty can never be seen as a one-off event.
- 3.25 Selecting the most appropriate technology, for a specific purpose at a specific time, is also crucial, particularly with respect to the use of adaptive and compensatory technologies. There is a hierarchy of loss of ability that commonly emerges in later life, leading to increasing challenges in carrying out activities of daily living. This is captured in a conceptual framework called the ‘compression of functional decline’ that identifies four distinct stages of age-related physical decline, with the aim of intervening optimally in ways that delay that progression.
- **Protection against decline:** making use of interventions that help build physical reserve and delay a person’s loss of function – for example through regular exercise and good diet.
 - **Reactivation:** recovering an ability – for example regaining the ability to walk a particular distance through rehabilitation after injury or treatment.
 - **Compensatory technology:** regaining function despite loss of a degree of physical ability – for example using a walking stick to maintain mobility.
 - **Personal support:** someone else taking over the task for the older adult – for example cooking meals or providing personal care for a person who is no longer able to perform these tasks independently, with or without technological assistance.³⁰⁷
- 3.26 These are very different aims, and it was emphasised to the working group that it is essential to match technologies appropriately to people’s actual needs. Providing technologies that compensate for lost function, or provide care, at a time when in fact it

³⁰⁵ See, for example, YouTube (2015) *Uninvited guests*, available at: <https://www.youtube.com/watch?v=Ear8W-C96bk>.

³⁰⁶ Roundtable meeting with members of Technology and Ageing Special Interest Group, British Society of Gerontology, 24 June 2021 (see Appendix 1); and Technologies roundtable, 21 July 2021 (see Appendix 1).

³⁰⁷ Gore PG, Kingston A, Johnson GR *et al.* (2018) New horizons in the compression of functional decline *Age and Ageing* **47(6)**: 764–8. See also: YouTube (2019) *Professor Peter Gore explains the LifeCurve*, available at: <https://www.youtube.com/watch?v=jem0uhgksbg>.

would still be possible for the person to regain that function (e.g., through physiotherapy or other forms of rehabilitation) can have a negative effect on people's lives and health, by prematurely speeding up the loss of valued functions. This highlights, again, the crucial importance of preventative approaches to good health – and the need for these to be given much more attention, and funding, at the level of wider social policy (see paragraph 2.13). Older adults who are fit and well tend not to feature in research data concerned with health and social care needs, precisely because they are not yet 'in the system' – and this can lead to the risk that people's capacity to maintain good health and functionality very late in life can be underestimated and disregarded.

- 3.27 While some technologies are very well established and widely available, others are still at the stage of being used only by 'early adopters' (whose experience may be very different from that of people who are less confident with innovative technologies), or indeed still at the prototype stage. These considerations illustrate the importance of technological research and innovation being accompanied and complemented by social research seeking a better understanding of people's needs and perspectives on technological approaches, and of how particular technologies are used in practice (see Box 3.6). It also highlights the importance of ensuring that expectations as to how particular technologies may change support needs and strategies in the future are well founded on evidence. Many of the projects involving robotic technologies for older adults, for example, are still at proof-of-concept stage after several decades, with few specialist robots commercially available.³⁰⁸ In contrast, robotic technologies designed for the non-specialist market, such as robot vacuum cleaners, are widely available.³⁰⁹

Box 3.6: Social research into how technology may support people to live well in older age

Examples of social research into the role and use of technologies by and for older adults, shared with the working group during the inquiry,³¹⁰ included the following.

Research into what role technology might play in different models of care and support, including supporting people with dementia in their own homes

- Looking at how to **incorporate technology into people's existing homes**, including understanding older people's perspectives as users of technology.
- Exploring **how older people used everyday (i.e., non-specialist) technologies during COVID lockdowns**, especially in supporting social networks.
- Understanding **how older people, particularly those with dementia, use technology in their everyday lives**, and what they want/need technology to do for them – with a particular focus on exploring how this could lead to more genuinely person-centred approaches to technology.
- Looking at different ways that **tech can contribute to social connectedness**, through online forums, supporting iPad use, etc.
- Exploring initiatives to **support intergenerational connection** – where older and younger people use/enjoy tech together.

Research into the role of technology in the wider environment

- Supporting older citizens' engagement in the development of 'smart cities'.
- Looking at the role of the wider environment, including in developing 'age-friendly' cities, and work on 'mobility, mood, and place'.

³⁰⁸ Bardaro G, Antonini A, and Motta E (2022) Robots for elderly care in the home: a landscape analysis and co-design toolkit *International Journal of Social Robotics* **14(3)**: 657-81.

³⁰⁹ See, for example, iRobot (2022) *Products*, available at: <https://www.irobot.co.uk/>.

³¹⁰ Roundtable meeting with members of Technology and Ageing Special Interest Group, British Society of Gerontology, 24 June 2021 (see Appendix 1).

Enabling health and care professionals to provide better care

- Looking at the **integration of data across the NHS and social care** (which includes the third sector and private sector as well as local authorities) in order to help the right people access the right information at the right time and place, to support better care.
- Exploring the use of technology to **enhance access to services in rural or remote areas** – including in supporting multidisciplinary teams to work together.
- Understanding the use of **virtual communication between health and social care professionals** during COVID, and the implications for the care of people with advanced dementia in care homes.
- Looking at **how technology is commissioned and implemented**, particularly in social care – and the way older people are involved in those decisions.

Drivers and regulation

- 3.28 In contrast to the basic science field in the UK, the technological innovations related to ageing are primarily driven by the commercial sector, with ‘ageing tech’ being increasingly promoted worldwide as a promising investment opportunity.³¹¹ Contributors to the working group’s inquiry expressed concern as to how this approach may lead to many products being developed that have little connection with the real lives and needs of diverse older adults – with the associated risks either of inappropriate products being put on the market (and actively promoted for use), or of substantial ‘research waste’ if products fail regulatory hurdles.³¹²
- 3.29 Alongside this commercially driven approach, however, there are a number of public sector drivers in the UK that provide a route for public interests to help steer the direction of commercial production (see Box 3.7). The 2017 ‘Healthy Society Grand Challenge’, for example, (see Box 1.1) has channelled public funding for technological development in this field through partnerships with the commercial sector, providing opportunity for the national innovation agency, Innovate UK, to influence the direction of innovation. The NHS AI Lab (part of NHS England’s Transformation Directorate) is similarly playing an active role in shaping how artificial intelligence can be used in the health and care sector, both through the direct provision of funding, and through its own development of ‘proof-of-concept’ tools. Major academic centres, such as the National Innovation Centre Ageing (NICA) in Newcastle, bring together academic research expertise and public input to work collaboratively with industry.
- 3.30 Nevertheless, a review of technologies being developed for use in the care sector has highlighted how, at present, innovation tends to ‘cluster’ around particular kinds of technologies (e.g., prioritising care management tools over innovations under the control of individuals), leaving many gaps.³¹³ The review recommended the introduction of a

³¹¹ See, for example, an indication on how ‘ageing’ and ‘technology’ are two of the dominant themes highlighted in future investment reports: UBS (2022) *Thematic guide: our longer term investment themes for a multi-year investment horizon*, available at: <https://www.ubs.com/global/en/wealth-management/insights/chief-investment-office/investment-opportunities/longer-term-investments.html>.

³¹² Ageing, AI, and data-driven innovation roundtable, 7 December 2021 (see Appendix 1).

³¹³ Future Care Capital (2022) *Care tech sector analysis*, available at: <https://futurecarecapital.org.uk/wp-content/uploads/2022/02/CTSA2.pdf>.

“formal demand-signalling mechanism (regional and national) for the care sector and people using care” to help focus innovation better around the needs of those using it.³¹⁴

Box 3.7: Public and partnership funding of ageing technology in the UK

In partnership with government funding through the 2017 Healthy Ageing Industrial Strategy Challenge Fund, Innovate UK’s Healthy Ageing Grand Challenge is investing up to £98 million to catalyse innovations to support people to enjoy an active and independent later life while also addressing inequalities in healthy life expectancy.³¹⁵ A part of the UK Research and Innovation (UKRI) Healthy Ageing Challenge and the Healthy Longevity Global Grand Challenge, and supported by the company Zinc, is the Healthy Ageing Catalyst Award. First started in 2020, Zinc and UKRI’s Catalyst Award funds “entrepreneurial academics who want to translate their research into impactful and scalable products, services, and interventions”.³¹⁶ Examples of other publicly funded initiatives in the UK that aim to shape the development of technologies to support ageing well, include the following.

- **The UKRI Healthy Ageing Challenge Community of Practice** and its knowledge exchange network that aims to provide a “collaborative learning community” for a range of stakeholders working across sectors to “share knowledge and insights, in relation to healthy ageing”.³¹⁷
- **NHS England** has set up the Digital Social Care information and guidance platform, a new £8 million fund to help social care providers adopt care technologies, and support for procuring digital social care records.³¹⁸ The NHS Artificial Intelligence in Health and Care Award has awarded 79 AI technologies a share of around £90 million to accelerate and support promising AI technologies for health and social care,³¹⁹ including its ‘Skunkworks’ proof-of-concept tools/targeted support for early adopters in the health and care sectors.³²⁰
- **The National Innovation Centre for Ageing (NICA)**, supported by initial investment from UK Government and Newcastle University, supports projects that help businesses co-innovate, co-develop, and commercialise meaningful products and services to help people live healthier, more productive, longer lives.³²¹ A flagship programme led by NICA is the ‘The Internet of Caring Things’, funded by the North of Tyne Combined Authority, which focuses on using technology, including sensors and data-driven strategies, to help deliver a range of approaches to support older adults in living well.³²²
- Launched in 2018 by the Care Innovation Hub, the annual **Care Innovation Challenge** (run since 2018 and recently taken over by the National Care Forum with

³¹⁴ *ibid*, at page 14.

³¹⁵ See: Department for Business, Energy and Industrial Strategy (26 January 2021) *The grand challenge missions*, available at: <https://www.gov.uk/government/publications/industrial-strategy-the-grand-challenges/missions>; and UKRI (2022) *Healthy ageing*, available at: <https://www.ukri.org/what-we-offer/browse-our-areas-of-investment-and-support/healthy-ageing/>. We note that since March 2023, the *Industrial Strategy* has transitioned into the *Plan for Growth* and its related strategies.

³¹⁶ Zinc (2022) *UKRI Healthy Ageing Catalyst Awards*, available at: <https://www.zinc.vc/programmes/catalyst/>.

³¹⁷ Innovate UK KTN (2022) *Healthy Ageing Challenge Community of Practice*, available at: <https://ktn-uk.org/programme/healthy-ageing-community/>.

³¹⁸ NHS England - Transformation Directorate blog (1 December 2021) *Launching the adult social care technology innovation and digital skills reviews*, available at: <https://transform.england.nhs.uk/blogs/launching-the-adult-social-care-technology-innovation-and-digital-skills-reviews/>.

³¹⁹ NHS England - Transformation Directorate (2022) *NHS AI Lab roadmap*, available at: <https://transform.england.nhs.uk/ai-lab/nhs-ai-lab-roadmap/>.

³²⁰ NHS England - Transformation Directorate (2022) *NHS AI Lab Skunkworks*, available at: <https://transform.england.nhs.uk/ai-lab/ai-lab-programmes/skunkworks/>.

³²¹ National Innovation Centre Ageing (2022) *Who we are*, available at: <https://uknica.co.uk/who-we-are/>.

³²² National Innovation Centre Ageing (2022) *Internet of caring things*, available at: <https://ioct.uknica.co.uk/>.

support from Think Local Act Personal) awards cash prizes to innovators that have novel solutions addressing challenges identified by the care sector.³²³

- 3.31 Given the breadth of technologies covered by the concept of ‘ageing tech’, it is perhaps unsurprising that regulation of developments in this field is also complex and evolving. Some contributors to the working group’s inquiry described it as the ‘wild west’, with many technologies falling between regulatory systems, or outside regulation altogether.³²⁴ This contrasts with the highly regulated environment in which pharmaceutical companies, for example, operate, with respect to both legislative requirements and industry-led standards such as the code of practice produced by the Association of the British Pharmaceutical Industry.³²⁵
- 3.32 Technologies specifically developed and marketed for health or care purposes are regulated by the MHRA as ‘medical devices’, an area of regulation that is currently in flux in the aftermath of the UK’s departure from the EU (see Box 3.8). Quite apart from these uncertainties around the future direction of UK regulation, however, many relevant devices and apps come under the category of ‘fitness’ or ‘wellness’ products and fall completely outside this regulatory regime.³²⁶ The situation is further complicated by the way that apps provided through standard consumer devices, such as smartphones, can increasingly be used for a range of health-related purposes. This includes both functions that might otherwise be provided through medical devices, for example monitoring for diseases such as Parkinson’s disease (which are regulated under the rubric of ‘software as a medical device’),³²⁷ and those that would be classified as lifestyle or fitness products such as step-counters that also include many other functionalities such as monitoring changes in gait. Similar challenges arise regarding the regulation of telemedicine, with a patchwork of existing regulation of professionals, services, and products not designed specifically with telemedicine in mind.³²⁸

Box 3.8: Proposals for regulatory reform of medical devices

On 26 June 2022, the Medicines and Healthcare products Regulatory Agency (MHRA) published the outcome of its wide-ranging consultation on the future of medical devices regulation in the UK,³²⁹ in the light both of well-publicised concerns about existing

³²³ Care Innovation Hub (2022) *Welcome to the Care Innovation Hub*, available at: <https://careinnovationhub.org.uk/>.

³²⁴ Ageing, AI, and data-driven innovation roundtable, 7 December 2021 (see Appendix 1).

³²⁵ Association of the British Pharmaceutical Industry (2021) *ABPI code of practice for the pharmaceutical industry 2021*, available at: <https://www.pmcpa.org.uk/media/3406/2021-abpi-code-of-practice.pdf>.

³²⁶ Medicines and Healthcare products Regulatory Agency (2021) *Borderlines with medical devices and other products in Great Britain*, available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1023171/Rev_Borderlines_with_medical_devices_and_other_products_-_V1_4_80_.pdf, at page 5. For a helpful overview, see also: TaylorWessing blog (9 June 2022) *Is it a wellness app or medical device? A critical boundary issue in the smart wearables sector*, available at: <https://www.taylorwessing.com/en/insights-and-events/insights/2022/06/is-it-a-wellness-app-or-medical-device---a-critical-boundary-issue-in-the-smart-wearables-sector>.

³²⁷ The Times (27 September 2022) *NHS smartwatches offer patients with Parkinson’s better life quality*, available at: <https://www.thetimes.co.uk/article/nhs-smartwatches-to-give-patients-with-parkinsons-better-life-quality-39tfmphrc>.

³²⁸ TaylorWessing blog (7 June 2022) *Issues with regulation of telemedicine in the UK*, available at: <https://www.taylorwessing.com/en/insights-and-events/insights/2022/06/issues-with-regulation-of-telemedicine-in-the-uk>.

³²⁹ Medicines and Healthcare products Regulatory Agency (2022) *Government response to consultation on the future regulation of medical devices in the United Kingdom*, available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1085333/Government_response_to_consultation_on_the_future_regulation_of_medical_devices_in_the_United_Kingdom.pdf. For a helpful overview, see, for example, TaylorWessing blog (15 August 2022) *MHRA response to consultation on UK regulation of medical devices*, available at: <https://www.taylorwessing.com/en/insights-and-events/insights/2022/08/mhra-response-to-consultation-on-uk-regulation-of-medical-devices>; and DAC Beachcroft (2022) *Medical Device Reform – creating a landscape for the future*, available at: <https://www.dacbeachcroft.com/en/articles/2022/june/medical-device-reform-creating-a-landscape-for-the-future/>.

standards of safety,³³⁰ and of the departure of the UK from the EU at a time when EU countries were implementing the new Medical Devices Regulation.³³¹

Areas of particular relevance to the use of technology in ageing well include the following.

- The scope of regulations to be extended to capture some non-medical products with similar risk profiles to medical devices, including some diagnostic ‘wellbeing’ tests.
- The regulation of ‘software as a medical device’ to be improved in order to provide greater clarity to developers, and assurance to patients and members of the public that they are acceptably safe, and function as intended. This will be primarily through guidance rather than regulatory change. The use of AI within products will not be treated separately from the arrangements for software as a medical device.³³²
- More detailed requirements for conducting and documenting clinical evaluation, with the aim of ensuring that products are not placed on the market without sufficient evidence of both their safety and performance.
- Post-market surveillance requirements to be strengthened and increased, ensuring better incident monitoring, reporting, and surveillance.

3.33 In addition to the regulatory functions of the MHRA, other potential routes for regulating, or influencing, how technology may be used in health or care contexts include the roles of the National Institute for Health and Care Excellence (NICE) and the Care Quality Commission (CQC) in England, and their equivalents in the other countries of the UK. One of NICE’s functions is to conduct ‘technology appraisals’, resulting in recommendations as to whether particular technologies should be made available through the NHS or social care, either to specified groups of people or more generally.³³³ While this role does not have direct regulatory impact (a NICE decision does not affect a developer’s ability to promote their product on the open market), it affects availability within the publicly funded systems, and also may be interpreted more broadly as a marker with respect to the perceived value of the innovation. The CQC, on the other hand, has a more direct regulatory role in inspecting health and care services and settings. It has, for example, recently issued new guidance clarifying that some private companies providing AI software and services for clinical use will come within the definition of providing ‘regulated activities’ and hence will be subject to the CQC’s regulatory regime.³³⁴ The way in which the use of technological innovation affects the quality of care received by older adults could also potentially come within the remit of the CQC when inspecting care services.

3.34 Beyond the sphere of regulation specifically concerned with the health and care sectors, the British Standards Institution (BSI) plays a significant role in developing standards for

³³⁰ Department of Health and Social Care (2020) *First do no harm - the report of the Independent Medicines and Medical Devices Safety Review*, available at: https://www.webarchive.org.uk/wayback/archive/20200721101148mp_/https://www.immdsreview.org.uk/downloads/IMMDSR_eview_Web.pdf.

³³¹ European Medicines Agency (2021) *Medical devices*, available at: <https://www.ema.europa.eu/en/human-regulatory/overview/medical-devices>.

³³² Medicines and Healthcare products Regulatory Agency (2022) *Software and AI as a medical device change programme - roadmap*, available at: <https://www.gov.uk/government/publications/software-and-ai-as-a-medical-device-change-programme/software-and-ai-as-a-medical-device-change-programme-roadmap>; and Osborne Clarke (29 June 2022) *New regulations are coming for medical devices in the UK*, available at: <https://www.osborneclarke.com/insights/new-regulations-are-coming-medical-devices-uk>.

³³³ The National Institute for Health and Care Excellence (2022) *Technology appraisal guidance*, available at: <https://www.nice.org.uk/About/What-we-do/Our-Programmes/NICE-guidance/NICE-technology-appraisal-guidance>.

³³⁴ Care Quality Commission (2022) *The scope of registration*, available at: <https://www.cqc.org.uk/guidance-providers/scope-registration>. See also: Osborne Clarke (8 July 2022) *Updated CQC guidance has implications for the health technology and wellbeing industries*, available at: <https://www.osborneclarke.com/insights/updated-cqc-guidance-has-implications-health-technology-and-wellbeing-industries>.

the wider consumer market, and in offering accreditation systems through which companies can demonstrate that they have met those standards.³³⁵ As illustrated above with reference to robotic technologies (see paragraph 3.27), in some cases technologies developed for the general consumer market may offer an equal, or greater, prospect of providing useful support for older adults than ‘specialist’ devices. This highlights again the importance of challenging ageist assumptions that lead to the needs and perspectives of older adults not being included in research targeting the wider public (of which, of course, they form a significant part). We return to questions of inclusive design processes in Chapter 4 (see paragraphs 4.20–4.28).

Data-driven innovation in earlier diagnosis and treatment

“An important ageing challenge will be to design and develop tools that facilitate disease diagnosis. The high rates of MLTC in older populations worldwide highlight the need for rapid and accessible diagnostic tools to detect the plethora of conditions that affect older patients.”³³⁶

- 3.35 Increasing attention – and funding – is being devoted to the aim of detecting the common diseases of older age much earlier, by combining multiple data sources with increasingly sophisticated use of AI techniques (see Box 3.9). This area of research and development potentially draws on, and combines, elements of both the fields of research and innovation described earlier in this chapter: the identification of biomarkers associated with aspects of the biological ageing process that may indicate early signs of disease (or predisposition to disease); and the use of increasingly sophisticated and portable devices for collecting relevant data in real time from people and relaying it directly to the health system.

Box 3.9: Definitions and examples of application of applied AI algorithms used in ageing research

- **Machine learning (ML)** is a branch of AI that can learn and make predictions from available data, by building a model of simple inputs, without being explicitly programmed. ML is being used with the aim of recognising specific clinical outcomes or predicting disease risk – for example identifying multiple risk factors for a prematurely ageing brain by estimating people’s brain age from their MRI scans and comparing this with their chronological age.³³⁷
- **Deep learning (DL)** extracts patterns and features from complex medical data related to a person’s health to predict disease states. DL relies on deep architectures with cascades of multiple layers (including input and output layers). ‘Deep’ thus refers to more than one hidden layer – for example the diagnosis of neurodegenerative disease from neuroimages, natural language processing, and pattern recognition.³³⁸

³³⁵ The British Standards Institution (2022) *About BSI*, available at: <https://www.bsigroup.com/en-GB/about-bsi/>.

³³⁶ The Academy of Medical Sciences, responding to our call for evidence.

³³⁷ Wagen AZ, Coath W, Keshavan A *et al.* (2022) Life course, genetic, and neuropathological associations with brain age in the 1946 British Birth Cohort: a population-based study *The Lancet Healthy Longevity* **3(9)**: e607-e16.

³³⁸ LeCun Y, Bengio Y, and Hinton G (2015) Deep learning *Nature* **521(7553)**: 436-44.

- **Deep neural networks (DNNs)** are models with multiple hidden layers between the input and output layers. DNNs are used widely to analyse different types of data, but particularly image, video, and sound.³³⁹
- **Convolutional neural networks (CNNs)** are an example of a DNN designed to imitate neuronal connections and reduce dimensionality of the data. CNNs are often used in image and video analysis.³⁴⁰
- **Reinforcement learning (RL)** is a type of goal-orientated algorithm that is trained to attain a complex objective over many steps. RL is often used in drug development with the ‘objective’ including drug-likeness of molecules.³⁴¹

3.36 Substantial public funding for this area of research has been channelled through the ‘Artificial Intelligence and Data’ Grand Challenge, launched by the Government in 2017, another of the grand challenges, alongside that of the ‘Ageing Society’, envisioned in the *Industrial Strategy* (see Box 3.10).³⁴² The mission of the challenge is to “use data, Artificial Intelligence and innovation to transform the prevention, early diagnosis and treatment of chronic diseases by 2030”, with the expressed aim of reducing the need for costly late-stage treatments, enhancing NHS efficiency, and leading to “a whole new industry of diagnostic and tech companies which would drive UK economic growth”.³⁴³ While no specific reference is made to ageing, the emphasis on prevention and earlier intervention with respect to chronic disease is clearly potentially relevant to a life-course approach to ageing well.

Box 3.10: Initiatives supported through the AI and Data Grand Challenge

- **Our Future Health** describes itself as “an ambitious collaboration between the public, charity, and private sectors to build the UK’s largest health research programme – bringing people together to develop new ways to prevent, detect, and treat disease”. It is aiming to recruit up to five million volunteers willing to share their health data, with the aim of “creat[ing] one of the most detailed pictures we’ve ever had of people’s health” in the hope that “researchers could unlock new ways to detect diseases earlier when they can be treated more easily, and more accurately predict who is at higher risk of diseases such as cancer, diabetes, heart disease, dementia and stroke”.³⁴⁴
- **The AI Centre for Value Based Healthcare** applies AI technologies to the delivery, interpretation, and reporting of medical imaging technologies, with projects exploring innovative approaches to diagnosing and treating common diseases across the life course, including cancers, stroke, and heart disease.³⁴⁵ Established in 2019, it is funded by the Department of Health and Social Care and UK Research and Innovation (UKRI), and led by King’s College London and Guy’s and St Thomas’ NHS Foundation Trust, alongside ten NHS trusts, four universities, a number of multinational industry partners including Siemens Healthineers, NVIDIA, IBM, GSK,

³³⁹ See: Myszczyńska MA, Ojamies PN, Lacoste AMB *et al.* (2020) Applications of machine learning to diagnosis and treatment of neurodegenerative diseases *Nature Reviews Neurology* **16(8)**: 440-56; and LeCun Y, Bengio Y, and Hinton G (2015) Deep learning *Nature* **521(7553)**: 436-44.

³⁴⁰ Yamashita R, Nishio M, Do RKG *et al.* (2018) Convolutional neural networks: an overview and application in radiology *Insights into Imaging* **9(4)**: 611-29.

³⁴¹ Arulkumaran K, Deisenroth MP, Brundage M *et al.* (2017) Deep reinforcement learning: A brief survey *IEEE Signal Processing Magazine* **34(6)**: 26-38.

³⁴² Department for Business, Energy and Industrial Strategy (26 January 2021) *The grand challenge missions*, available at: <https://www.gov.uk/government/publications/industrial-strategy-the-grand-challenges/missions>. We note that since March 2023, the *Industrial Strategy* has transitioned into the *Plan for Growth* and its related strategies.

³⁴³ *ibid.*

³⁴⁴ Our Future Health (2022) *About us*, available at: <https://ourfuturehealth.org.uk/about-us/>.

³⁴⁵ AI Centre for Value Based Healthcare (2022) *Projects*, available at: <https://www.aicentre.co.uk/projects>.

ten UK-based small and medium-sized enterprises (SMEs), and the Health Innovation Network.³⁴⁶

- 3.37 The importance for geroscience research of validated, and also affordable, biomarkers of the biological ageing process was reiterated to the working group in its roundtable meeting on geroscience,³⁴⁷ and we noted above the valuable role that reliable and validated markers of ageing could play in developing regulatory processes suitable for geroscience-guided clinical trials (see paragraph 3.20). Such markers, measured on a regular basis, could also potentially be incorporated into life-course health records, providing a much more complete picture of a person's health over their lifetime.³⁴⁸ Contributors to the same roundtable meeting emphasised the developing field of 'digital' as well as traditional biomarkers, drawing on data collected from many non-health sources – from the use of 'wellness' apps such as step-counters to the possible implications of the way a person types or uses a computer mouse,³⁴⁹ as well as that collected through medical devices. This expansion of what is understood by a 'biomarker' highlights both the relevance of many different research fields and funders for research in ageing,³⁵⁰ and the extent to which this data-driven field of research expands into numerous aspects of our day-to-day lives in under-appreciated ways. It also highlights potential challenges relating to the quality of the data used, and the inferences that may be made in a range of different contexts.³⁵¹
- 3.38 As illustrated in Box 3.11, this field of data-driven innovation offers promise both in contributing to improved understanding and recognition of the early signs of long-term health conditions that commonly affect us in older age, and in developing measures and indicators of the biological ageing process. However, it also raises some challenging issues that are often overlooked, in terms of how such developments in knowledge may actually translate into benefits for a particular individual. In particular, it is essential to keep in view the differences between **predicting risk** of developing a condition, **early detection** of that condition, and a **clinical diagnosis** by a health professional, associated with access to effective interventions and support. These distinctions are complicated by the way that some risk states, such as hypertension, prediabetes, and mild cognitive impairment, are gradually starting to be treated as disease states in their own right. However, there is a very important difference for a person between learning they are at 'elevated risk' of developing a condition and receiving a validated diagnosis and treatment plan for that condition.

³⁴⁶ AI Centre for Value Based Healthcare (2022) *About us*, available at: <https://www.aicentre.co.uk/about-us>.

³⁴⁷ Geroscience roundtable, 21 July 2021 (see Appendix 1).

³⁴⁸ See, for example, Hirschfeld S, Goodman E, Barkin S et al. (2021) Health measurement model-bringing a life course perspective to health measurement: The PRISM Model *Frontiers in Pediatrics* **9**: 605932; and Green S, and Hillersdal L (2021) Aging biomarkers and the measurement of health and risk *History and philosophy of the life sciences* **43(1)**: 28.

³⁴⁹ See, for example, White RW, Doraiswamy PM, and Horvitz E (2018) Detecting neurodegenerative disorders from web search signals *npj Digital Medicine* **1(1)**: 8.

³⁵⁰ See, for example, research funded by companies such as Intel and Apple: Morris M, Lundell J, Dishman E *et al.* (2003) New perspectives on ubiquitous computing from ethnographic study of elders with cognitive decline *UbiComp 2003: Ubiquitous Computing* 227-42; Intuition (2021) *About Intuition*, available at: <https://www.intuitionstudy.com/en-us/about-intuition.html>; and Apple (2022) *Empowering people to live a healthier day*, available at: <https://www.apple.com/newsroom/pdfs/Health-Report-July-2022.pdf>.

³⁵¹ Wachter S, and Mittelstadt B (2019) A right to reasonable inferences: re-thinking data protection law in the age of big data and AI *Columbia Business Law Review* 494.

Box 3.11: Examples of the use of AI and data-driven innovation in age-related conditions and to measure ageing

There has been increasing attention in developing the AI approaches described in Box 3.9, such as using deep learning (DL) and deep neural networks (DNNs), to support earlier diagnosis of age-related diseases, and to predict biological age. Examples include:

- The use of deep learning techniques to predict risk of myocardial infarction from retinal scans and basic personal information.³⁵²
- The development of a digital tool to detect neurodegenerative diseases years before symptoms of dementia present, using patterns in digital data to create a ‘digital fingerprint’ (see Box 4.12 for further information).³⁵³
- The use of AI, using DNNs, to develop ‘deep ageing clocks’ to predict a person’s ‘biological age’.³⁵⁴
- Using DL approaches to predict future wellbeing and psychological age based on psychological questionnaires. It has been suggested that the creation of a “deep learning predictor of future well-being” can be used for cognitive behavioural therapy (CBT) and online mental health applications as an initial assessment tool or to improve individual psychological support.³⁵⁵
- Applying AI approaches to imaging data and photographs for early diagnosis and predicting disease progression of age-related macular degeneration.³⁵⁶
- Using AI methods to identify and understand how multiple long-term conditions develop over the life course, with the aim of developing methods to prevent and treat them.³⁵⁷

3.39 An important factor to take into account in translating research in this area into clinical practice is that indicators that are shown to be predictive of a particular condition at population level (which is useful for service planning, for example), do not necessarily translate directly into being predictive for an individual.³⁵⁸ A key characteristic of digital tools for early detection is their potential to detect signs of disease among people who do not currently have a diagnosis or who appear to be healthy, and to do this at a large scale. This brings some forms of early detection into the realm of population screening, as opposed to individual testing initiated by a health professional in response to identified concerns. There are established criteria for assessing the appropriateness of new screening tools within the health system, recognising, among other factors, the harms of false positives and negatives, unnecessary medical interventions, increased anxiety, and both financial and environmental costs.³⁵⁹ However, it was suggested to the working

³⁵² Diaz-Pinto A, Ravikumar N, Attar R et al. (2022) Predicting myocardial infarction through retinal scans and minimal personal information *Nature Machine Intelligence* **4**(1): 55-61.

³⁵³ Edon Initiative (2019) *EDoN - Early Detection of Neurodegenerative diseases*, available at: <https://edon-initiative.org/>.

³⁵⁴ Putin E, Mamoshina P, Aliper A et al. (2016) Deep biomarkers of human aging: Application of deep neural networks to biomarker development *Ageing (Albany NY)* **8**(5): 1021-33.

³⁵⁵ Galkin F, Kochetov K, Keller M et al. (2022) Optimizing future well-being with artificial intelligence: self-organizing maps (SOMs) for the identification of islands of emotional stability *Ageing* **14**(12): 4935-58; and Zhavoronkov A, Bischof E, and Lee K-F (2021) Artificial intelligence in longevity medicine *Nature Aging* **1**(1): 5-7.

³⁵⁶ Dong L, Yang Q, Zhang RH et al. (2021) Artificial intelligence for the detection of age-related macular degeneration in color fundus photographs: A systematic review and meta-analysis *EClinicalMedicine* **35**: 100875; and Romond K, Alam M, Kravets S et al. (2021) Imaging and artificial intelligence for progression of age-related macular degeneration *Experimental Biology and Medicine* **246**(20): 2159-69.

³⁵⁷ NIHR (3 September 2021) *NIHR awards £12 million to artificial intelligence research to help understand multiple long-term conditions*, available at: <https://www.nihr.ac.uk/news/nihr-awards-12-million-to-artificial-intelligence-research-to-help-understand-multiple-long-term-conditions/28581>.

³⁵⁸ Altman DG, and Bland JM (1994) Diagnostic tests 2: predictive values *British Medical Journal* **309**(6947): 102.

³⁵⁹ UK National Screening Committee (2022) *UK National Screening Committee screening in healthcare*, available at: <https://www.gov.uk/guidance/principles-of-population-screening>. See also: WHO (2020) *Screening programmes: a short guide*, available at: <https://apps.who.int/iris/bitstream/handle/10665/330829/9789289054782-eng.pdf>.

group that these standard criteria may be insufficient, given the way that many tools are being developed outside formal health systems, drawing on multiple sources of data.³⁶⁰

- 3.40 It is also essential to recognise that early detection (however reliable) of a condition is not necessarily helpful to the individual, if this is not accompanied by access to effective therapies, or at least advice and support on how better to manage the impact of the condition on the person's life. There are well-recognised risks of anxiety and depression associated with such early detection in the absence of support, which are actively detrimental to people's wellbeing.³⁶¹ As implied in the language of the Grand Challenge (see paragraph 3.36), it is widely assumed that earlier identification of disease will lead to more effective treatments that benefit both the individual concerned and the wider health service by providing more cost-effective treatment. This may not, however, necessarily be the case – indeed a strong focus on early detection may even divert attention in hard-pressed health services from the needs of those already experiencing the effects of later-stage disease.³⁶²
- 3.41 This raises significant ethical challenges for research in this field: in particular with respect to how to develop knowledge that might in future lead to new effective therapies, without offering false promise and hope to those participating in that research (see paragraph 4.43). Rapid developments in the digital cognitive assessment of Alzheimer's at earlier stages, for example,³⁶³ in a context where, all too often, people with established dementia currently receive little or no support after diagnosis, highlight the ethical issues at stake.³⁶⁴ We now turn in more depth to a consideration of these and related ethical issues.

³⁶⁰ Comments submitted by external reviewers.

³⁶¹ The Academy of Medical Sciences, responding to our call for evidence.

³⁶² Evidently Cochrane blog (23 October 2020) *Screening: earlier detection of disease is not necessarily better*, available at: <https://www.evidentlycochrane.net/screening-earlier-detection-of-disease-is-not-necessarily-better/>.

³⁶³ Öhman F, Hassenstab J, Berron D *et al.* (2021) Current advances in digital cognitive assessment for preclinical Alzheimer's disease *Alzheimer's & dementia (Amsterdam, Netherlands)* **13**(1): e12217-e; and Adkins-Jackson PB, and Belsky DW (2022) Alzheimer's disease risk biomarkers: progress and challenges *The Lancet Healthy Longevity* **3**(9): e575-e6.

³⁶⁴ Wheatley A, Bamford C, Brunskill G *et al.* (2021) Implementing post-diagnostic support for people living with dementia in England: a qualitative study of barriers and strategies used to address these in practice *Age and Ageing* **50**(6): 2230-7.

Chapter 4

Ethical challenges

Chapter 4 – Ethical challenges

Overview of Chapter 4

Despite the broad spectrum of research and innovation explored by the working group, common themes of ethical concern were raised by diverse contributors to the inquiry.

Whose voices are heard?

- A core ethical concern that emerged across all the various forms of evidence and experience we heard was over the extent to which older adults' values and perspectives are currently insufficiently included in the way that research is prioritised, planned, and carried out. This raises a series of important questions, including **who benefits and how** from research in ageing? **Who sets the agenda and determines the need?** And **who takes part in research?** The scope for older adults to benefit from improvements in understanding the biology of ageing and from innovations in technology will continue to be limited, unless the perspectives of diverse older adults influence the aims and conduct of research, and research participants reflect the diversity of the populations who will be using the outputs.

Equitable access

- Questions of **affordability, availability, and appropriateness of design** affect older adults' abilities to benefit from effective novel interventions. Concerns were also raised about the reliability of increasingly digitised services, older adults' confidence in using them, and the risk that increasingly automated forms of support may add to existing inequalities through digital exclusion.

Choice and control

- Technological innovations, and new approaches to treatment, may increase the options open to all of us as we get older, and enable us to live independently for longer. However, the way some technologies are used may also act to limit the control that older adults have over their own lives: for example where a person's physical safety is prioritised (by others) over their own important needs and interests. Contributors to the working group's inquiry queried whether people would still be able to choose to have hands-on care, and whether they might feel 'pushed' into taking long-term preventative medications or being screened for conditions that are not currently affecting them, regardless of their own preferences.

Impact on relationships

- Concerns were expressed about the risk that data-driven healthcare and more technological approaches to care and support might have a negative impact on relationships with health and care professionals, and on human contact more generally. However, the opposite possibility was also highlighted: in particular, the scope for rehabilitative and adaptive technologies to enable older adults to keep their independence and maintain the relationships and activities that they value.

Trust and trustworthiness

- Questions of trust arose in diverse ways, including scepticism about the motivations driving research, concern over the use of data, and uncertainty about whether the implied promises associated with research could in fact be delivered.

Sustainability

- It was strongly argued that more collaborative and cross-disciplinary working would be required across the research, health, and care systems, for research benefits to be translated into practice in ways that are sustainable (in time, finances, or physical resources) over the long term. Preventative approaches need to be prioritised.

Introduction

- 4.1 In this chapter, we present an overview of the ethical issues raised with the working group by those who contributed evidence to our inquiry, using their own words where possible. This evidence took many forms, with contributions from older adults and intergenerational groups through a series of public engagement activities; from many researchers, practitioners, and people working in health and science policy who shared their expertise with us; and from participants in our public dialogue who shared their own views on ageing and the role of science and technology, and then reviewed our early findings and tentative conclusions (see Appendices 1–3). The working group was particularly struck by the extent to which clear common themes emerged from these multiple forms of input and engagement, despite the variety and breadth of research and innovation under consideration, and the diversity of experience of the contributors.

Whose voices are being heard?

How is ‘benefit’ or ‘success’ defined?

“There is a recognition that future studies of interventions must include people living with MLTC [multiple long-term conditions] to avoid limiting their applicability; the focus should move from clinical endpoints towards outcome measures such as quality of life, quality of care and treatment burden for both people living with MLTC and carers. These are what matter to patients.”³⁶⁵

“I was interested in reading about the research on changing kitchens and bathrooms with special devices. But it made me think – why not make all designs disabled user friendly, so no adaptations are needed!”³⁶⁶

“The main benefit should be the gift of time to care – medical devices which can prevent deterioration and give people more time to care should be the goal.”³⁶⁷

- 4.2 A central underlying question repeatedly emerged during this inquiry: what constitutes a ‘successful’ outcome of research, and from whose perspective should that be judged? While at first sight this issue might seem a technical one of defining successful ‘endpoints’ to studies, it raises profoundly ethical questions of who actually benefits from ‘successful’ interventions or products, and in what way – in short, whose wellbeing and interests are thought to matter. In one of the working group’s roundtable meetings exploring the role of technological developments in supporting people to live well in older age, concerns were strongly expressed that thinking about technologies themselves was the wrong starting point, as was the idea of ‘fixing deficits’. Rather, researchers should be focusing on the question of what helps people live a meaningful life (e.g., see, Boxes 2.6–2.8 for the needs and preferences expressed by those contributing to our

³⁶⁵ Owen N, Dew L, Logan S et al. (2022) Research policy for people with multiple long-term conditions and their carers *Journal of multimorbidity and comorbidity* 12: 26335565221104407.

³⁶⁶ NIHR (2018) *Help at home - use of assistive technology for older people*, available at: <https://evidence.nihr.ac.uk/themedreview/help-at-home-use-of-assistive-technology-for-older-people>.

³⁶⁷ Anonymous response to our call for evidence.

engagement projects). However, contributors to the roundtable meeting felt that current practice falls far short of this aspiration: “We’re a long way from this at present.”³⁶⁸

- 4.3 This issue emerged particularly strongly with respect to the development of technologies for use in older adults’ homes, and the very different ways these might be framed depending on whose perspectives, needs, and interests are being taken into account.³⁶⁹ One significant area of focus for technological development, for example, is that of systems designed to prevent older adults with dementia from leaving their homes at night, including by sensors that set off a loud noise if anyone goes too close to the outside door at night.³⁷⁰ From one perspective, this may be regarded as successful – for example by providing reassurance to adult children who are concerned about their parent’s physical safety, which is an important consideration. However, it achieves this success by frightening the person with dementia: indeed it was pointed out to the working group that as the person with dementia is unlikely to understand what triggers the noise, it may also make them scared to go into their kitchen at night – or even to potter around their house on their own terms.³⁷¹ Such an approach to securing physical safety, and providing reassurance to others, thus potentially comes at the cost of the emotional wellbeing of the older adult themselves – a factor that is often overlooked in the way such technologies are developed and marketed.
- 4.4 In contrast, a current research project is seeking to use sensors in the home to collect data about a person’s regular patterns of living and use artificial intelligence (AI) to make predictions about what that person might do, with the aim of using this information to develop ways to support them as their dementia progresses – for example through the use of intelligent cues that can prompt them to do the things they are likely to want to do.³⁷² Such an approach is founded on a very different concept of benefit – that of supporting a person to be and do what is meaningful to them, rather than ‘managing’ behaviours that are of concern to others.
- 4.5 While there are some positive examples of collaborative research with older adults (see Box 4.1), a rapid review of studies of the development and use of technology by older adults, conducted for the working group, suggested that at present these were in a minority.³⁷³ Few studies appear to focus on increased wellbeing from older adults’ own perspectives, with emphasis instead on outcomes such as physical ability to achieve a particular task “rather than the opinions, enjoyment, or ease of using the technology”.³⁷⁴ A related concern is that of how, and where, studies are conducted: a review of robotic

³⁶⁸ Technologies roundtable, 21 July 2021 (see Appendix 1).

³⁶⁹ See, for example, Dementia Change Action Network (2022) *Place, people, purpose and power - promoting the wellbeing of people living with dementia through personalised care and support*, available at: <https://dcan.org.uk/news/new-paper-launched-place-people-purpose-and-power/>. This makes the case for ‘people, place, purpose and power’ being key in supporting people to live well with dementia – not instead of the ‘medical model’ but as a broader way of looking at dementia. For comments by the head of the Alzheimer’s Society regarding how the focus of innovation should be support for users, not surveillance, see: The Telegraph (24 September 2022) *AI can ‘plug the gaps in the brains’ of dementia sufferers*, available at: <https://www.telegraph.co.uk/news/2022/09/24/ai-can-plug-gaps-brains-dementia-sufferers/>.

³⁷⁰ See, for example, Verywell Health (22 April 2022) *Door alarms for wandering in alzheimer's and dementia*, available at: <https://www.verywellhealth.com/safety-in-dementia-door-alarms-98172>. See also: National Institute on Aging (2017) *Home safety checklist for alzheimer's disease*, available at: <https://www.nia.nih.gov/health/home-safety-checklist-alzheimers-disease>.

³⁷¹ Roundtable meeting with members of Technology and Ageing Special Interest Group, British Society of Gerontology, 24 June 2021 (see Appendix 1).

³⁷² UK Dementia Research Institute (2022) *Meet the team: David Sharp*, available at: <https://ukdri.ac.uk/team/david-sharp>. For further research related to ‘the enactment effect’, see: Roberts BRT, MacLeod CM, and Fernandes MA (2022) The enactment effect: a systematic review and meta-analysis of behavioral, neuroimaging, and patient studies *Psychological Bulletin* **148**: 397-434.

³⁷³ See reviews of technology: Nuffield Council on Bioethics (2023) *The future of ageing: evidence reviews*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering-2>.

³⁷⁴ Kamimura T, Ishiwata R, and Inoue T (2012) Medication reminder device for the elderly patients with mild cognitive impairment *American Journal of Alzheimer's Disease & Other Dementias* **27(4)**: 238-42.

technologies noted how much of the reported research had taken place in experimental conditions, rather than in more complex real-life settings, and highlighted the need for randomised controlled trials in older adults' own homes in order to validate any claims of benefit.³⁷⁵ A systematic review of AI-guided interventions in long-term care (LTC) concluded robustly: "It is paramount that solutions included in future studies are the most appropriate for the needs of older people receiving LTC and to acknowledge that in some cases not all individuals will benefit from these technologies. Until then, AI-enhanced interventions could be considered as part of a technology development race, as opposed to being effective and acceptable solutions for LTC delivery."³⁷⁶

Box 4.1: Examples of research and innovation that take older adults' needs as the starting point

- **The SMARTech Project** is an example of an international project that aims to use SMART technology to improve the lives of older adults living in long-term care settings by understanding the needs of this group. This Canadian project is building a novel 'SMARTech' service that combines technology, person-centred assessments, and data analytics to improve the independence and wellbeing of older adults. The project intends to "seek to understand the experiences, needs, and desires for well-being among this group of older adults aging with disability", and "understand the impact of this Service on these older adults, their caregivers, and care delivery".³⁷⁷
- A UK Research and Innovation (UKRI) project called **Generating Older Active Lives Digitally (GOALD)**, is taking an "innovative intergenerational co-production approach" to the research. They aim to engage with older people not just as research participants but 'experts through experience' by creating an Intergenerational Advisory Group and co-design partners to create digital resources to facilitate online activity programmes. The Advisory Group meets regularly online throughout the project to provide feedback and advice on progress. The GOALD project began by exploring the members' views on exercise and memories of sporting activities that will feed back to the GOALD developers to shape the development of the online intergenerational activities.³⁷⁸
- **The multigenerational 4GenKitchen project**, led by National Innovation Centre Ageing (NICA) and in collaboration with kitchen designer Johnny Grey and Professor Peter Gore, intends to create a functional, comfortable kitchen that can be used by multiple generations, including older adults. To design the prototype kitchen, the project team hosted insight gathering sessions with those who have experience of living in multigenerational homes. The sessions included exploring a current working kitchen and understanding areas of tension and unmet needs as well as hearing aspirations for people's own living spaces. The experiences heard at these sessions were incorporated into the design of the 'intelligent' multigenerational kitchen.³⁷⁹

³⁷⁵ Shishehgar M, Kerr D, and Blake J (2019) The effectiveness of various robotic technologies in assisting older adults *Health Informatics Journal* **25**(3): 892-918.

³⁷⁶ Loveys K, Prina M, Axford C *et al.* (2022) Artificial intelligence for older people receiving long-term care: a systematic review of acceptability and effectiveness studies *The Lancet Healthy Longevity* **3**(4): e286-e97.

³⁷⁷ SMARTech AGE-WELL (2022) *The SMARTech Project*, available at: <https://www.livmoresmartech.com/>.

³⁷⁸ UKRI (2021) *Project: Generating Older Active Lives Digitally (GOALD)*, available at: <https://www.ageing-sbdnp.co.uk/research-projects/connectivity-and-digital-design/>.

³⁷⁹ National Innovation Centre Ageing (2021) *Ready, steady cook... the multigenerational 4GenKi*, available at: <https://www.uknica.co.uk/ready-steady-cook-the-multigenerational-4genki/>.

4.6 Strongly linked with these questions of how benefit is defined is the issue of what comparators are used in studies exploring possible uses of new technologies. Participants in the working group's Future of Ageing Open Forum, held in partnership with Greater Manchester Older People's Network (GMOPN) and Sonder Radio, highlighted the relevance of the acceptability, or otherwise, of alternatives, when discussing whether there could be any role for robots in providing care. Comments included:

- "Given 15 mins care visits and lack of training opportunities for care staff ... I'd rather have a care robot in my dotage"; and
- "Being dependent and having seen the quality of care out there ... having to depend on someone for everything this frightens the hell out of me."³⁸⁰

We return later in this chapter to questions of equitable access and choice with respect to using novel interventions and approaches (see paragraphs 4.29 and 4.32), but it is important to highlight here how expectations as to the adequacy of future support may significantly affect judgments about the relative benefits of technological approaches. This raises the question of how explicitly these issues are discussed in research exploring the possibilities of such technologies, and also of the importance of honest and open public debate about where responsibilities should lie for providing and funding support to older adults when they need it (see paragraphs 5.61–5.62).

4.7 These issues also arise, if in less immediately concrete terms, in biomedical sciences, with a range of perspectives on what constitutes a benefit from the point of view of the individual, and how this might be traded off against associated harms. Respondents to our call for evidence highlighted how "interventions given in midlife or before, that seek to change the course of the ageing process over several decades, clearly pose a very different class of risks to those inherent in short-term therapies."³⁸¹ Participants at the working group's intergenerational roundtable event held in Exeter expressed concerns about such long-term and unknowable risks, and emphasised the importance of a strong evidence base before any such interventions were made available.³⁸² There were very mixed views in response to the hypothetical question as to whether participants would take such medications if they were offered, with some who were positive about the overall aim of such an approach hesitant about when would be the right time to start ("Maybe when I'm a bit older"). Others felt it would be preferable to try to achieve the same aims through non-medicalised means, such as healthy diet and exercise, with concerns expressed about seeking to intervene in the "natural ageing process".

4.8 Members of the West Bromwich African Caribbean Resource Centre (WBACRC) similarly strongly emphasised a preference for non-medicalised approaches to healthy ageing such as exercise programmes, access to healthy nutrition, social community spaces and better transport links, in particular highlighting the need for attention (and funding) to be directed towards inequalities that affect ageing well.³⁸³ They were also sceptical about the motivations underlying geroscience research, expressing concern that the main drivers could be the interests of researchers or research institutions in

³⁸⁰ Nuffield Council on Bioethics (2022) *Open forum with members of the Greater Manchester Older People's Network, in collaboration with Sonder Radio*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/open-forum-with-members-of-the-greater-manchester-older-peoples-network-gmopn-and-other-residents-in-manchester-organised-in-collaboration-with-sonder-radio>.

³⁸¹ Professor Miles Witham and Professor Avan Sayer, responding to our call for evidence.

³⁸² Nuffield Council on Bioethics (2022) *Intergenerational roundtable event in Exeter*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing>.

³⁸³ Nuffield Council on Bioethics blog (12 July 2022) *The future of ageing – learning from the West Bromwich African Caribbean Resource Centre*, available at: <https://www.nuffieldbioethics.org/blog/the-future-of-ageing-learning-from-the-west-bromwich-african-caribbean-resource-centre>.

pursuing their own agendas, or the profit motive of commercial companies, rather than the needs of older adults. We return later to these concerns relating to trust and trustworthiness (see paragraphs 4.42–4.45). Reactions from members of Greater Manchester Growing Older with Learning Disabilities (GM GOLD) to the possibility of early interventions in how their bodies were ageing similarly highlighted questions of trust, alongside differing perspectives on whether early knowledge might be experienced as helpful or worrying (see Box 4.2).

- 4.9 In our discussion of data-driven innovation in approaches to earlier diagnosis and treatment in Chapter 3, we highlighted the scope for harm as well as benefit, particularly in identifying risk states, and in detecting disease without being able to offer effective interventions (see paragraphs 3.39–3.41). Wider concerns were raised with the working group with respect to the risks of ‘medicalising’ middle age, and what this might mean in terms of both individuals’ relationships with the health system and the sustainability of such systems long term. One participant at the Exeter workshop, for example, made a comparison with being regularly monitored for type 2 diabetes: while on the one hand it was very reassuring to be ‘in the system’, on the other hand, even when her diabetes had been brought under control she still felt treated as a ‘patient’.³⁸⁴ These considerations connect with a more general concern that “healthcare is becoming more protocolised and less patient-centred”³⁸⁵ – a point to which we return below in our discussion of relationships (see paragraph 4.40). Predictive tests, or presymptomatic detection of long-term conditions, could also have practical downsides with respect to access to financial products such as mortgages and insurance.

Box 4.2: Thoughts about predictions of biological ageing, and early interventions

Reflections from members of Greater Manchester Growing Older with Learning Disabilities (GM GOLD), when asked how they would feel about predictions of how well their bodies were ageing, or early interventions to influence biological ageing, are listed below.³⁸⁶

If you could have a blood test to find out how long you might live, would you?

- “Yes, because I want to know in person, like one to one, if I have cancer or something like that.”
- “Yes, to see how fit I am.”
- “I wouldn’t have a blood test as I have a fear of needles so if there was another way then I would.”
- “No, as it would play on my mind.”

If you could take a pill to live longer, would you?

- “No as if it was contaminated, I wouldn’t take it.”
- “To keep me as young as I can. I would have a pill that would make me younger where you wouldn’t get old, you would stay young.”
- “No because I am on too many tablets at the moment, and it might affect the tablets I am on currently.”

³⁸⁴ Nuffield Council on Bioethics (2022) *Intergenerational roundtable event in Exeter*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing>.

³⁸⁵ British Pharmacological Society, responding to our call for evidence.

³⁸⁶ Nuffield Council on Bioethics (2022) *Workshop with Greater Manchester Growing Older with Learning Disabilities (GM GOLD)*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/greater-manchester-growing-older-with-learning-disabilities-gm-gold>.

- “Yes because it is protecting your health and insides, but I would like to know what’s in it before we take them because some people can be allergic to them in your body and it can affect all your insides.”
- “Yes because I would like to see things I have not seen before in this world and go and do things I have not done before.”

4.10 Across all the various engagement and evidence-gathering activities conducted by the working group, there was a strong sense that biomedical science and technological innovation would inevitably continue to develop and bring about changes – and hence a key challenge would be to find ways for those changes to be shaped around the needs of those who would be affected. The public dialogue emphasised this approach, with a strong focus on the aim of independence and self-reliance: “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.”³⁸⁷ Other contributors focused more on the role of technology in care, suggesting how innovations should ideally free up time from routine tasks to provide the “gift of time to care”.³⁸⁸ Alongside the need for clarity as to the aims and aspirations of different forms of innovation lies the ethical imperative of a strong evidence base “to ensure the costs and efforts of implementing these measures across the healthcare system have a tangible and effective benefit and to help avoid unforeseen harms.”³⁸⁹ This reinforces yet again the importance of multiple perspectives, and the contribution of different research disciplines to capture social and psychological effects, as well as the direct health impacts, of new interventions.

Who is involved in setting the research agenda?

“By taking an approach that is inclusive of diverse groups in the design of healthcare systems, interventions, and research, these inequalities [in healthy life expectancy] can be prioritised, tackled, and minimised.”³⁹⁰

“Of particular note was the reported tendency for researchers ‘to think of elderly people as older versions of themselves – which usually means educated, middle class people who have a nice life and for whom things are relatively easy.’³⁹¹

“A specific challenge in ensuring representative voices in the field of translation or clinical research is finding ways to include older people living with frailty, who may find it difficult or burdensome to take part in PPIE [patient and public involvement and engagement] events or processes. This is not easy, and further work is required to find the best ways to reach

³⁸⁷ Nuffield Council on Bioethics (2023) *Public dialogue report on the future of ageing*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/public-dialogue-on-the-future-of-ageing>, at page 8.

³⁸⁸ Anonymous response to our call for evidence.

³⁸⁹ The Academy of Medical Sciences, responding to our call for evidence.

³⁹⁰ *ibid.*

³⁹¹ Dr Philippa Brice, PHG Foundation, responding to our call for evidence, citing: PHG Foundation (2018) *My healthy future: healthy ageing workshop*, available at: <https://www.phgfoundation.org/media/269/download/mhf-older-people-workshop-outcome.pdf?v=1&inline=1>.

*those with cognitive impairment, those who are housebound, those living in care homes, and those with sensory impairment or disabilities.*³⁹²

- 4.11 The central issue of what constitutes ‘success’ or a positive outcome in any piece of research leads directly to the question of *how* the research agenda is being set: to what extent decisions about research priorities incorporate input from older adults and wider publics, and if so, the extent to which public contributors reflect the diversity of experience across these populations. As the members of the WBACRC pointed out to us, criteria such as ‘high-quality science’ are not sufficient on their own in driving the direction of research.³⁹³ It cannot be ethical to allocate resources into areas of science and technology in ways that do not take account of the priorities and needs of the people who are ostensibly the beneficiaries.
- 4.12 As we noted at the beginning of Chapter 3, there is a growing recognition of the essential role played by public contributors in influencing the research agenda (see paragraph 3.4). A wide range of bodies within the research system, including the National Institute for Health and Care Research (NIHR),³⁹⁴ the Health Research Authority (HRA),³⁹⁵ and the Medicines and Healthcare products Regulatory Agency (MHRA)³⁹⁶ have published detailed guidance and strategies on developing meaningful relationships between researchers and public contributors, and have come together to sign a shared commitment to improve public involvement in health.³⁹⁷ As a result, there is now a growing evidence base of the benefits to research of this contribution.³⁹⁸
- 4.13 There is also an increasing number of initiatives specifically supporting the involvement of older adults in guiding and influencing research concerned with ageing, alongside examples of effective involvement of older adults in helping shape discrete research projects (see Box 4.3). Organisations such as Ageing Better,³⁹⁹ Dementia Voices,⁴⁰⁰ and

³⁹² Professor Miles Witham and Professor Avan Sayer, responding to our call for evidence.

³⁹³ Nuffield Council on Bioethics blog (12 July 2022) *The future of ageing – learning from the West Bromwich African Caribbean Resource Centre*, available at: <https://www.nuffieldbioethics.org/blog/the-future-of-ageing-learning-from-the-west-bromwich-african-caribbean-resource-centre>.

³⁹⁴ National Institute for Health and Care Research (2021) *Being inclusive in public involvement in health and care research*, available at: <https://www.nihr.ac.uk/documents/being-inclusive-in-public-involvement-in-health-and-care-research/27365>; and National Institute for Health and Care Research (2019) *UK standards for public involvement*, available at: <https://www.invo.org.uk/wp-content/uploads/2019/11/UK-standards-for-public-involvement-v6.pdf>.

³⁹⁵ Health Research Authority (24 May 2022) *Calling all patients and public contributors - can you help us put people first in research?*, available at: <https://www.hra.nhs.uk/about-us/news-updates/calling-all-patients-and-public-contributors-can-you-help-us-put-people-first-research/>.

³⁹⁶ Medicines & Healthcare products Regulatory Agency (2021) *Patient involvement strategy 2021-25*, available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1022370/Patient_involvement_strategy.pdf.

³⁹⁷ Centre for Ageing Better (14 March 2022) *Shared commitment to improve public involvement in research*, available at: https://www.ukri.org/news/shared-commitment-to-improve-public-involvement-in-research/?utm_medium=email&utm_source=govdelivery.

³⁹⁸ The Academy of Medical Sciences, responding to our call for evidence, citing: The Academy of Medical Sciences (2016) *Improving the health of the public by 2040*, available at: <https://acmedsci.ac.uk/snip/uploads/5807581429f81.pdf>; National Institute for Health Research (2009) *Exploring impact: public involvement in NHS, public health and social care research*, available at: <https://www.invo.org.uk/wp-content/uploads/2012/01/INVOLVEexploringimpactSummary2009.pdf>; and Connected Communities (2019) *Towards co-production in research with communities*, available at: https://www.dur.ac.uk/resources/geography/reframing_state/CCDiscussionPaperDurose2etal.pdf. See also: The Health Foundation blog (5 October 2022) *What have we learnt from involving and engaging with patients and the public in our health data science projects?*, available at: <https://www.health.org.uk/news-and-comment/blogs/what-have-we-learnt-from-involving-and-engaging-with-patients-and-the-public>.

³⁹⁹ Ageing Better (2021) *Stronger together: a co-production toolkit from Ageing Better*, available at: <https://agefriendlysheffield.org.uk/wp-content/uploads/2021/07/Stronger-Together-%E2%80%93-a-co-production-toolkit-Final.pdf>.

⁴⁰⁰ The Dementia Engagement and Empowerment Project (2013) *Tips for organisations wanting to consult people with dementia about written documents*, available at: <https://www.dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Consulting-about-written-documents.pdf>.

Housing LIN⁴⁰¹ have published guidance on engagement and co-production with older adults and people with dementia, and there has been a ‘call for action’ across Europe for better public and patient involvement in research concerned with brain health (see paragraph 4.17).⁴⁰² However, as illustrated earlier in this chapter, it is clear that much more needs to be done to shift the mainstream research culture so that the actual needs of older adults, from a wide range of backgrounds and experiences, are at the heart of research planning, and not simply considered (if at all) at a later stage when important decisions have already been made.

Box 4.3: Examples of older adults influencing research agendas

Stand-alone patient and public involvement and engagement (PPIE) networks that can advise on multiple projects, or identify research priorities

- **VOICE** is an organisation (part of the UK’s National Innovation Centre for Ageing) that is made up of a large network of citizens of all ages across the UK and internationally. Members of VOICE contribute their insights, experience, and ideas to steer innovation for ageing and improve health research by identifying areas of unmet needs and opportunities.⁴⁰³
- **The Birmingham 1000 Elders** is a group based at the University of Birmingham that brings together healthy ageing researchers and older adults to carry out research into how we can age more healthily. Older adults from the local area, including anyone over the age of 60, take part in and share findings of research activities, from direct involvement in studies as research participants or through participation in focus groups, to help design and shape future studies.⁴⁰⁴
- **Priority setting partnerships (PSP)**, run by the James Lind Alliance, bring together patients, carers, and clinicians to identify and prioritise evidence uncertainties in particular areas of healthcare that could be answered by research. A PSP on living well with multiple conditions in later life worked with people over 80 and their carers to identify issues of most concern to them.⁴⁰⁵

Specific examples of projects actively partnering with diverse older adults

- **The SENSE-Cog project** focused on understanding the impact of dementia, age-related hearing and vision impairments in European older adults. It ran from 2016 to 2022 and involved an EU ‘patient and public voice’ and innovative public engagement network to inform the project and communicate the findings. A series of PPIE consultation and dissemination events were held in several EU cities including, Manchester, Athens, Nice, and Nicosia.⁴⁰⁶
- **The Dementia Engagement and Empowerment Project (DEEP)** is led by around 80 groups of people living with dementia. The UK-wide network aims to connect people living with the disease to share learning and skills and contribute their views on the issues that are important to them. One of DEEP’s projects is the **Dementia**

⁴⁰¹ Housing LIN (2021) *Ageing well with assistive technology: co-producing technology solutions with older people*, available at: <https://www.housinglin.org.uk/Topics/type/Ageing-Well-with-Assistive-Technology-Co-producing-technology-solutions-with-older-people/>.

⁴⁰² Alzheimer Europe (2022) *Patient involvement in brain health – a call to action*, available at: https://www.alzheimer-europe.org/sites/default/files/2022-05/final_-_patient_involvement_in_brain_health_-_a_call_to_action.pdf.

⁴⁰³ VOICE (2022) *About us*, available at: <https://www.voice-global.org/about/>.

⁴⁰⁴ The University of Birmingham (2019) *The Birmingham 1000 Elders*, available at: <https://www.birmingham.ac.uk/Documents/college-mds/Birmingham-1000-Elders-Booklet-Feb2019.pdf>.

⁴⁰⁵ James Lind Alliance (2018) *Multiple conditions in later life: priority setting partnership*, available at: <https://www.jla.nihr.ac.uk/priority-setting-partnerships/health-with-multiple-conditions-in-old-age/downloads/Multiple-Conditions-in-Later-Life-PSP-Top-10-report.pdf>.

⁴⁰⁶ SENSE-Cog (2023) *SENSE-Cog project promoting health for eyes, ears and mind*, available at: <https://sense-cog.eu/>; and European Commission (2023) *Ears, eyes and mind: the ‘SENSE-Cog project’ to improve mental well-being for elderly Europeans with sensory impairment*, available at: <https://cordis.europa.eu/project/id/668648>. See also: Miah J, Parsons S, Lovell K et al. (2020) Impact of involving people with dementia and their care partners in research: a qualitative study *British Medical Journal Open* 10: e039321.

Enquirers initiative, developing a new approach to research that is led and controlled by people with dementia, enabling DEEP groups to carry out their own research.⁴⁰⁷

- **An online forum** has been established by the Cicely Saunders Institute at King's College, London, to bring together families, patients, and members of the public to share ideas and participate in palliative care and rehabilitation research – areas of research that are often neglected because of the sensitive context of life-threatening illness.⁴⁰⁸
- **ADMISSION** is a research collaborative that includes a geographically and ethnically diverse PPIE group of people living with multiple long-term conditions (MLTCs). Workshops with participants have focused on the lived experience of people living with MLTCs, and their insights have influenced the development and design of future research plans, with workshop members becoming co-applicants on research projects.⁴⁰⁹

- 4.14 The need for researchers, and the wider research establishment, proactively to reach out to those who are already excluded or overlooked is particularly important. Existing public contributors to research do tend to be older – not least on the basis of being more likely to have time during the working day to contribute. However, survey feedback received by NIHR has shown that its public contributors are also predominantly female, white, and heterosexual, illustrating how much more needs to be done to find ways proactively to include a much wider range of voices.⁴¹⁰ Such mapping of current contributors is an important first step in recognising whose voices are not yet being heard, and in identifying barriers and facilitators to broader, more diverse, participation.
- 4.15 Contributors to the working group's public dialogue also emphasised the need to avoid treating older adults' contribution in a silo, but rather to promote intergenerational approaches to helping shape research: "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."⁴¹¹
- 4.16 In a roundtable meeting with researchers and public contributors who had worked together on research related to ageing, contributors shared with the working group their own ideas and experiences as to how to manage collaborative processes in ways that genuinely enable people from a wide range of backgrounds and experiences to be

⁴⁰⁷ Dementia Enquirers (2022) *Dementia Enquirers*, available at: <https://dementiaenquirers.org.uk/>.

⁴⁰⁸ Brighton LJ, Pask S, Benalia H *et al.* (2018) Taking patient and public involvement online: qualitative evaluation of an online forum for palliative care and rehabilitation research *Research involvement and engagement* **4(1)**: 14; and Cicely Saunders Institute, King's College London (2019) *Your experiences contribute to our research*, available at: <https://www.csipublicinvolvement.co.uk/>.

⁴⁰⁹ ADMISSION (2022) *Patient & public involvement*, available at: <https://research.ncl.ac.uk/admissioncollab/patientpublicinvolvement/>; and Professor Miles Witham and Professor Avan Sayer, responding to our call for evidence.

⁴¹⁰ National Institute for Health and Care Research (2022) *NIHR public involvement feedback survey 2020-2021: the results*, available at: <https://www.nihr.ac.uk/documents/nihr-public-involvement-feedback-survey-2020-2021-the-results/29751>.

⁴¹¹ Nuffield Council on Bioethics (2023) *Public dialogue report on the future of ageing*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/public-dialogue-on-the-future-of-ageing>, at page 8.

involved and have their voices heard (see Box 4.4).⁴¹² Strong themes included working together from the beginning so that public contributors can help steer the direction of the whole project; being transparent about what can be influenced and what cannot; ensuring that locations are both physically and psychologically accessible; creating an atmosphere in which people feel valued and able to speak; and being constantly alert to differentials in power, and to how these can be overcome.

Box 4.4: Working together respectfully – tips from our evidence session

Four researchers and two public contributors joined the working group in February 2022 for a roundtable discussion of their experiences of coproduction in a variety of research projects concerned with the use of technology and ageing. Advice shared by contributors included the following (see also paragraph 4.12 for links to guidance from the National Institute for Health Research, Ageing Better, Dementia Voices, and others).

Approaches to meaningful partnership

- Meaningful partnership needs to involve **going on a journey together**. This is quite distinct from providing a set of options to a community but not being willing to explore additional options that would better meet people's needs and aspirations.
- Given the deep power imbalances inherent in our systems, **active steps need to be taken to create a valuing environment, with a particular focus on the needs of those who have least been listened to in the past**. Everyone needs to have a sense of security, belonging, continuity, purpose, achievement, and significance. This will require culture change within many research environments.
- **Starting as early as possible in the process is crucial** – thus avoiding the temptation to ask for endorsement of what has already been done. This can be difficult with very innovative approaches (no one knew they would value a CD until CDs were invented). But you can start with what is available (technologies, apps, strategies) – and then start to elicit what is missing; what could be improved; what people are looking for; and what is important to them (e.g., worrying about being a burden, or being concerned where data might be stored). This then feeds in to the next iteration or development.
- Importance of **house rules to ensure that everyone's voice is heard**. This can include starting with an icebreaker activity that gets everyone talking about tech and breaks down barriers – in particular the barrier caused by people thinking they don't know enough to contribute. This gets everyone to interact and ensures that everyone's opinion is recognised as meaningful.
- Using the TLC approach: **talk, listen, and change**. Nothing should be off the table, and no question is stupid. Clear ground rules may be required to ensure that discussion remains focused around the research.
- Thinking about **location** – not expecting people to come to you, but rather holding events in familiar community venues (churches, residential areas, retirement communities), working with trusted leaders. You might need to be available on a Friday evening or a Sunday morning for Muslim or Sikh participants – even though that is not when universities are usually open! Physical accessibility is also important.

And what to avoid

- Intolerance and lack of respect – it is crucial that people feel valued, and necessary accommodations are made.

⁴¹² Co-production roundtable, 22 February 2022 (see Appendix 1).

- Not being genuine in the desire for public input – there is a need for practical, intellectual, and emotional accommodation to enable authentic engagement to happen.
- Stressful environments – if people feel apprehensive, they can't give their best and will understandably back away.
- Dropping relationships when the project is done – relationships need to be long term, and not just about the research.
- Failing to disseminate the findings of research in ways that are accessible – academic papers are not accessible to most people.
- Failing to nurture people who are willing to get involved – it is important to build capability and capacity for coproduction, and also to connect people to wider opportunities outside the immediate area.
- Failing to share power, and 'professionalising' lived experience. Dialogic techniques can be used to seek people's views in a democratic space – it is for researchers to make the leap as to how that input can be used, and not for members of the public to fit themselves into the research mould.

4.17 In their 2022 'call for action' on the involvement of patients and members of the public in research concerned with brain health, Alzheimer Europe, the European Federation of Neurological Associations, and the Global Alliance of Mental Illness Advocacy Networks highlighted how a lack of such involvement routinely leads to inadequate research attention being paid to the day-to-day experiences of people living with brain conditions such as dementia.⁴¹³ The working group was similarly alerted to how many aspects of life and health that play an important role in older adults' quality of life are often overlooked in research agendas, including hearing and seeing; dental health; foot care; and continence. The voices and experiences of older adults living with impairments in any of these aspects of health could help steer the research agenda towards interventions that could help improve their quality of life. However, this will require substantial commitment from both research teams and funders, not least in going out proactively (into people's homes, including care homes) to seek people's input.

Who is involved in shaping implementation?

4.18 While inclusive approaches to the design of conduct of research studies can help ensure that older adults' needs and perspectives influence the design of the technologies being developed, this does not necessarily automatically translate into widespread adoption and use of the eventual products.⁴¹⁴ It was strongly emphasised to the working group that meaningful engagement was equally important in the way that research findings or new interventions are 'rolled out' as part of general services or healthcare provision. It was recognised that, even where research participation has been inclusive, the way that new technologies and services fit into different people's lives will differ fundamentally – not least because of significant differences between 'early adopters' of technologies (those who are likely to be involved in research and early implementation) and 'late adopters' (the vast majority).⁴¹⁵ This has implications for recruitment into studies, with a need for "purposive recruitment of expected late adopter groups and the development of

⁴¹³ Alzheimer Europe (2022) *Patient involvement in brain health – a call to action*, available at: https://www.alzheimer-europe.org/sites/default/files/2022-05/final_-_patient_involvement_in_brain_health_-_a_call_to_action.pdf.

⁴¹⁴ Fischer B, Peine A, and Östlund B (2019) The importance of user involvement: a systematic review of involving older users in technology design *The Gerontologist* **60(7)**: e513-e23.

⁴¹⁵ Woodcock A (2014) Late adopters and laggards: should we care? *The International Journal of Design Management and Professional Practice* **7(3)**: 53-61.

practical standards for design”,⁴¹⁶ and also for taking a collaborative approach to how innovative products and services are introduced into wider practice.

- 4.19 At the systemic level, this involves ensuring that participative processes in research continue into the development and roll-out of projects. At the individual level, those providing support directly to older adults need to “ask, demystify through demonstration and offer access” rather than make assumptions.⁴¹⁷ As we described in Chapter 3 (see paragraph 3.25), it is also essential to ensure that a new intervention or technology is appropriate for a particular individual’s needs: “There could be an over-reliance on devices rather than utilising, e.g. rehabilitation to empower older people to utilise their assets rather than just compensate for deficits.”⁴¹⁸

Who takes part in research?

“There is a pressing need for high quality longitudinal evidence about the multiple processes contributing to optimal ageing. This need is best met with longitudinal multidisciplinary studies that track people from middle age into retirement and beyond. The UK is fortunate in having a number of longitudinal cohort studies, but these are too small to allow detailed study of subgroups such as ethnic minorities, and few involve more than a single generation so cannot study intergenerational processes directly.”⁴¹⁹

“Those groups not being included in clinical trials are at risk of receiving substandard healthcare.”⁴²⁰

“It is also important to ensure older adults included in clinical trials are representative of genuine patients and the trials must be appropriately and accurately designed.”⁴²¹

- 4.20 In the earlier part of this chapter, we explored the ethical imperative for research concerned with ageing to be based around the needs and perspectives of older adults (and, where appropriate, intergenerational groups), and for clarity regarding who is expected to benefit from successful outcomes, and in what way. This brings us to the crucial question of *who* is recruited to take part in the research studies that underpin novel technologies and medications. The widespread exclusion from research of older adults, and in particular older adults living with multiple conditions, is a long recognised, but still unaddressed challenge across the research sector. Seeking diversity within older generations of research participants presents a further challenge: as with older public contributors (see paragraph 4.14), it is not enough simply to ‘tick the box’ by recruiting healthy people in their 60s and 70s who will not be representative of those likely to use the outputs of the research.

- 4.21 As described in Box 4.5, there are clear scientific benefits in ensuring that older adults, in particular older adults living with multiple long-term conditions (MLTCs), are adequately represented in studies of new medications that are likely to be used by this population group (see also paragraph 3.10). As we have repeatedly emphasised,

⁴¹⁶ Dr Philippa Brice, PHG Foundation, responding to our call for evidence.

⁴¹⁷ Nuffield Council on Bioethics (2023) *The future of ageing: practitioner survey*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering-2>.

⁴¹⁸ Vicki Goodwin, responding to our call for evidence.

⁴¹⁹ Professor Andrew Steptoe, responding to our call for evidence.

⁴²⁰ The Academy of Medical Sciences, responding to our call for evidence.

⁴²¹ British Pharmacological Society, responding to our call for evidence.

approaches to broader inclusion must also take account of other factors, in particular race and ethnicity⁴²² and sex and gender,⁴²³ in order to reflect the rich diversity of older generations and ensure that research takes account of the intersectional disadvantages many older adults may experience.

Box 4.5: Why biomedical research needs older participants

The British Pharmacological Society, responding to our call for evidence, set out clearly the scientific case for involving older adults in biomedical research:

“The potential changes that come with increasing age can change what the body does to a drug (pharmacokinetics), what the drug does to the body (pharmacodynamics) and [the] likelihood of negative effects of medicines. As such, the balance profile of a drug in an older adult is different to that of a younger adult. In order to address these issues, clinical pharmacology can play a key role. If appropriate data is obtained early enough, it can inform the trial enrolment, [and] dose protocol and reduce risks for older patients. It is also important to ensure older adults included in clinical trials are representative of genuine patients and the trials must be appropriately and accurately designed. To determine whether these studies are beneficial, pharmacodynamic, and pharmacokinetic data must be acquired. It will also be important to develop guidance which ensures sufficient assessment of the efficacy and safety of drugs in older patients.”⁴²⁴

4.22 Related concerns arise in the context of other kinds of research concerned with ageing well. We noted earlier the inadequate evidence base produced when studies are conducted with atypical users, such as the ‘early adopters’ of technologies (see paragraph 4.18) or in experimental conditions that do not reflect use in day-to-day domestic environments (paragraph 4.5). Given the growing role of mainstream consumer technologies in supporting people in ageing well, the question of who participates in research and consumer testing of such products is increasingly important.⁴²⁵ Where such technologies involve AI and machine learning, the dangers of built-in bias from the use of unrepresentative learning data-sets is particularly concerning, with respect to both age in general,⁴²⁶ and protected characteristics such as race and sex/gender.⁴²⁷ The same concerns arise with respect to the lack of representation in large data-sets being used for data-driven innovations in healthcare,⁴²⁸ and the lack of inclusivity in routinely collected data: that is, data collected outside research studies that may still be drawn on

⁴²² Dawson S, Banister K, Biggs K *et al.* (2022) Trial forge guidance 3: randomised trials and how to recruit and retain individuals from ethnic minority groups—practical guidance to support better practice *Trials* **23**(1): 672.

⁴²³ De Paoli M, Gardner HR, and Treweek S (2022) Another brick in the wall... no more! breaking the sex bias *Clinical Oncology* **34**(12): 796-8.

⁴²⁴ British Pharmacological Society, responding to our call for evidence.

⁴²⁵ MIT Technology Review (21 August 2019) “Old age” is made up—and this concept is hurting everyone, available at: <https://www.technologyreview.com/2019/08/21/75537/old-age-is-made-up-and-this-concept-is-hurting-everyone/>.

⁴²⁶ Rosales A, and Fernández-Ardèvol M (2019) Structural ageism in big data approaches *Nordicom Review* **40** (Supplement 1): 51-64. See also recommendations on the inclusion of underrepresented participants and community engagement projects: Multi-Regional Clinical Trials Center of Brigham and Women’s Hospital and Harvard (2021) *Achieving diversity, inclusion, and equity in clinical research: guidance document*, available at: <https://mrctcenter.org/diversity-in-clinical-research/wp-content/uploads/sites/11/2021/09/MRCT-Center-Diversity-Guidance-Document-Version-1.2.pdf>, at page 102.

⁴²⁷ NHS Race and Health Observatory (2022) *Ethnic inequalities in healthcare: a rapid evidence review*, available at: https://www.nhs.uk/wp-content/uploads/2022/02/RHO-Rapid-Review-Final-Report_v.7.pdf; and Science (13 April 2017) *Even artificial intelligence can acquire biases against race and gender*, available at: <https://www.science.org/content/article/even-artificial-intelligence-can-acquire-biases-against-race-and-gender>.

⁴²⁸ See, for example, GWAS Diversity Monitor (2022) *Total GWAS participants diversity*, available at: <https://gwasdiversitymonitor.com/>.

in research.⁴²⁹ The working group was further alerted to the importance of longitudinal cohort studies being large enough to allow for greater population representativeness, which is often not the case at present.⁴³⁰ While very large scale multi-purpose volunteer databases may appear to be able to help fill this gap, with their findings assumed to be generalisable, participants in such studies tend to come disproportionately from healthier and wealthier parts of society.⁴³¹

- 4.23 Participants in the public dialogue were reported as being “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.”⁴³²
- 4.24 Despite this enthusiasm, and the recognition of the value of including diverse older adults in the full spectrum of research covered by this inquiry, many studies continue to impose arbitrary age limits. This is often because of perceptions of older adults as being ‘vulnerable’; beliefs that older adults ‘can’t consent’; or simply because it is perceived as easier to recruit younger people (see Box 4.6). The working group also heard how older adults may be indirectly excluded as a result of a lack of imagination in overcoming barriers to participation, including difficulty travelling to additional appointments or lack of adequate digital access, despite the scope for designing research in more inclusive ways that can overcome these barriers. As one respondent to our call for evidence told us: “Often the main limitation is time and financial resources to be able to do ‘gold standard’.”⁴³³ The same respondent noted how research ethics committees can also be nervous about the inclusion of adults with a degree of cognitive impairment in research – even in studies of very direct relevance to them, such as studies of rehabilitation for older people living with frailty.⁴³⁴

Box 4.6: Inclusion and exclusion from research: insights from the call for evidence

- “It has too often been assumed that older people (like children) are incapable of balancing risks and benefits of taking part in clinical research; a mindset that goes against the presumption of autonomy.”⁴³⁵
- “People are protective and with good intentions can gatekeep for older people in terms of taking part in research (family members and health/social care professionals).”⁴³⁶
- [Key priority to] “support informed decision-making by ageing individuals themselves and where relevant by the individual as part of a network of informal and formal carers”.⁴³⁷

⁴²⁹ Office for National Statistics (2021) *Inclusive Data Taskforce recommendations report: leaving no one behind – how can we be more inclusive in our data?*, available at: <https://uksa.statisticsauthority.gov.uk/wp-content/uploads/2021/09/1618-Inclusive-Data-Taskforce-Recommendation-Report-web-v1-00.pdf>.

⁴³⁰ Professor Andrew Steptoe, responding to our call for evidence.

⁴³¹ Brayne C, and Moffitt TE (2022) The limitations of large-scale volunteer databases to address inequalities and global challenges in health and aging *Nature Aging* **2**(9): 775-83.

⁴³² Nuffield Council on Bioethics (2023) *Public dialogue report on the future of ageing*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/public-dialogue-on-the-future-of-ageing>, at page 8.

⁴³³ Vicki Goodwin, responding to our call for evidence.

⁴³⁴ Vicki Goodwin, responding to our call for evidence.

⁴³⁵ Professor Miles Witham and Professor Avan Sayer, responding to our call for evidence.

⁴³⁶ Vicki Goodwin, responding to our call for evidence.

⁴³⁷ Professor Christine Hine, University of Surrey, responding to our call for evidence.

4.25 In response to wider concerns about representation and inclusion in clinical research, in 2020 the NIHR published guidance from its INCLUDE project setting out steps to promote the inclusion in research of “under-served” groups,⁴³⁸ with similar initiatives emerging in a number of other countries.⁴³⁹ This has led to further work and tailored guidance looking at how to tackle barriers to inclusion for particular groups, including those with impaired capacity to consent (see Box 4.7).

Box 4.7: INCLUDE Impaired Capacity to Consent Framework

In 2017, the National Institute for Health and Care Research (NIHR) launched an initiative called INCLUDE that aims to produce a roadmap to steer the development of guidance and resources to increase the inclusion of under-served groups in research and trials.⁴⁴⁰ While randomised controlled trials are thought to be the gold standard for testing medical interventions or ways of providing care, some populations are often routinely excluded from trials. The NIHR defines an ‘under-served’ group as being: “a group that is less well represented in research than would be desirable from population prevalence and healthcare burden”.⁴⁴¹ ‘Under-served’ is often very study specific and varies depending on the context. However, examples presented by NIHR include people with particular demographic factors (e.g., different ethnic minority groups, LGBTQ+, and age extremes), social and economic factors (e.g., carers and socioeconomically disadvantaged people) and health status factors (e.g., mental health conditions, cognitive impairment, and pregnant women).⁴⁴²

One under-served group is people who have cognitive impairment and are unable to provide consent to participate in a trial. Trials and research involving adults who lack capacity to consent encounter specific barriers which often result in these populations being excluded from research. A recent study found barriers to inclusion are found at every stage throughout the life cycle of a trial, but predominately clustered around the early trial design decisions, including:

- complexity of legal frameworks;
- gatekeeping by health and social care professionals;
- specific recruitment issues;
- lack of relevant expertise and training in research that involves adults with impaired capacity; and
- resource intensive nature of trials involving adults lacking capacity.⁴⁴³

⁴³⁸ NIHR (January 2022) *Improving inclusion of under-served groups in clinical research: guidance from INCLUDE project*, available at: https://www.nihr.ac.uk/documents/improving-inclusion-of-under-served-groups-in-clinical-research-guidance-from-include-project/25435#The_INCLUDE_roadmap. This terminology was adopted as a result of a consensus workshop as part of the project.

⁴³⁹ See, for example, National Institutes of Health (2021) *Inclusion across the lifespan*, available at: <https://grants.nih.gov/policy/inclusion/lifespan.htm>; National Institute on Aging (2015) *Recruiting older adults into research (ROAR) toolkit*, available at: <https://www.nia.nih.gov/health/recruiting-older-adults-research-roar-toolkit>; and Crome P, Cherubini A, and Oristrell J (2014) The PREDICT (increasing the participation of the elderly in clinical trials) study: the charter and beyond *Expert Review of Clinical Pharmacology* **7**(4): 457-68.

⁴⁴⁰ NIHR (2020) *Improving inclusion of under-served groups in clinical research: guidance from INCLUDE project*, available at: <https://www.nihr.ac.uk/documents/improving-inclusion-of-under-served-groups-in-clinical-research-guidance-from-include-project/25435#examples-of-underserved-groups>.

⁴⁴¹ Cardiff University (2022) *Implementation of the ‘INCLUDE Impaired Capacity to Consent Framework’ for researchers*, available at: <https://www.cardiff.ac.uk/centre-for-trials-research/research/studies-and-trials/view/implementation-of-the-include-impaired-capacity-to-consent-framework-for-researchers>.

⁴⁴² NIHR (2020) *Improving inclusion of under-served groups in clinical research: guidance from INCLUDE project*, available at: <https://www.nihr.ac.uk/documents/improving-inclusion-of-under-served-groups-in-clinical-research-guidance-from-include-project/25435#examples-of-underserved-groups>.

⁴⁴³ Shepherd V, Hood K, and Wood F (2022) Unpacking the ‘black box of horrendousness’: a qualitative exploration of the barriers and facilitators to conducting trials involving adults lacking capacity to consent *Trials* **23**(1): 471.

Building on the work of INCLUDE and the previous development of the Ethnicity Framework⁴⁴⁴ that aims to guide researchers to think about which ethnic groups should be included in their trials, the INCLUDE Impaired Capacity to Consent Framework has been developed. The framework, which was developed with researchers and those affected by particular health conditions or disabilities, is intended to provide guidance to researchers to identify which people with impaired capacity should be included in trials; develop inclusive trial design ideas; and address barriers to the inclusion of people with impaired capacity. The initiative includes the development of accessible materials such as versions of consent forms that help people with capacity-affecting conditions or disabilities to participate in a trial, and a series of worksheets and an easy-read user guide to the framework to help trial teams facilitate the inclusion of adults with impaired capacity.⁴⁴⁵

- 4.26 The NIHR INCLUDE roadmap sets out a number of questions to encourage research funders and reviewers of grant proposals to consider, including prompting them to consider who will be the target audience of the research outcomes, how the study population correlates with that target population, and whether study outcomes are relevant to that target group.⁴⁴⁶ Respondents to our call for evidence also emphasised more tangible ways in which research funders could encourage researchers to be more inclusive in their recruitment of participants, including by providing funding specifically to cover the additional costs incurred in removing barriers to participation. These could include, for example, home-based visits by researchers; recognition that recruitment may take longer because of the need to identify likely participants and build relationships; and also the need to recruit higher numbers to allow for higher than average drop-out rates because of ill health.⁴⁴⁷ A further approach would be for funders actively to mandate both the collection of demographic data to monitor diversity of participants, and the recruitment of representative populations. The *2022 Women's Health Strategy for England*, for example, states that: "our aim is that health and care research which should, but does not, take into account sex differences does not receive public funding. We will encourage all publicly funded health research to include data on the sex breakdown of participants, keep progress under review and consider the need for further action."⁴⁴⁸
- 4.27 Work is also continuing in relation to the inclusion of people living with long-term medical conditions. Building on a report on multimorbidity published in 2018 by the Academy of Medical Sciences,⁴⁴⁹ a number of research funders including Wellcome, the Medical Research Council (MRC), and the NIHR joined the Academy of Medical Sciences in forming a "multimorbidity research interest group". As set out in Box 4.8, this has resulted in a cross-funder multimorbidity research framework, setting out multiple 'pillars' for increasing research participation by this population.⁴⁵⁰

⁴⁴⁴ Trial Forge (2022) *The INCLUDE Ethnicity Framework*, available at: <https://www.trialforge.org/trial-forge-centre/include/>.

⁴⁴⁵ Capacity Consent Research (2022) *NIHR INCLUDE Impaired Capacity to Consent Framework*, available at: <https://www.capacityconsentresearch.com/include-impaired-capacity-to-consent-framework.html>.

⁴⁴⁶ NIHR (January 2022) *Improving inclusion of under-served groups in clinical research: guidance from INCLUDE project*, available at: https://www.nihr.ac.uk/documents/improving-inclusion-of-under-served-groups-in-clinical-research-guidance-from-include-project/25435#The_INCLUDE_roadmap.

⁴⁴⁷ See, for example, Professor Miles Witham and Professor Avan Sayer, responding to our call for evidence.

⁴⁴⁸ Department of Health and Social Care (2022) *Women's health strategy for England*, available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1100706/Womens-Health-Strategy-England-print.pdf, at page 49.

⁴⁴⁹ The Academy of Medical Sciences (2018) *Multimorbidity: a priority for global health research*, available at: <https://acmedsci.ac.uk/policy/policy-projects/multimorbidity>.

⁴⁵⁰ The Academy of Medical Sciences (2020) *Cross-funder multimorbidity research framework*, available at: <https://acmedsci.ac.uk/file-download/50613213>.

Box 4.8: Working towards including people with multiple long-term conditions in clinical research

One of the aims of the cross-funder multimorbidity research framework is to “facilitate multimorbidity-inclusive clinical trials and research” by the following means.

- Addressing the problem of exclusion and inclusion criteria through engagement with regulators such as the Medicines and Healthcare products Regulatory Agency (MHRA) and the Health Research Authority (HRA).
- Reviewing of funding policies and guidance by individual funders to ensure inclusivity.
- Developing more innovative, effective, and efficient trial designs through engagement with trial units.
- Developing and testing the collection of real-world evidence and real-world trials.
- Collecting more comprehensive data, to minimise patient burden and maximise outcomes from trials.
- Improving determinants of health outcomes and multimorbidity, for example early surrogate or technical markers.
- Aligning patient reported outcome measures (PROMs) across the sector, where appropriate.⁴⁵¹

4.28 In addition to these developments within the field of biomedical research in taking a more age-inclusive approach to research participation, there are a number of relevant initiatives in the technology and AI sectors relating to inclusion more broadly. Work on inclusion by the BSI includes a general commitment to develop product standards that are “inclusive as standard”,⁴⁵² and work is continuing on a forthcoming BSI standard on the role of AI in health and care.⁴⁵³ The National Institute for Health and Care Excellence (NICE) has updated its *Evidence standards framework for digital health technologies* to highlight the risks that training data sets used in developing AI-based technologies can build in inequality;⁴⁵⁴ and the MHRA has combined with the US Food and Drug Administration (FDA) and Health Canada in producing guiding principles for good machine learning practice which include the principle that “clinical study participants and data sets are representative of the intended patient population”.⁴⁵⁵

Equitable access

“If technologies are specifically designed for and targeted to areas of greatest need – regardless of socioeconomic status – they could go some way to ‘levelling up’ health spans across the socio-economic spectrum.”⁴⁵⁶

“Researchers need to take a step forward to view the older adults not just as a frail group, but as people who need a supportive head start in

⁴⁵¹ The Academy of Medical Sciences (2020) *Cross-funder multimorbidity research framework*, available at: <https://acmedsci.ac.uk/file-download/50613213>, at pages 5-6.

⁴⁵² British Standards Institution (2022) *Inclusive as standard*, available at: <https://www.bsigroup.com/globalassets/documents/about-bsi/nsb/standards-makers/inclusive-as-standard-v2.pdf>.

⁴⁵³ British Standards Institution (2022) *BS 30440 validation framework for the use of AI within healthcare - specification*, available at: <https://standardsdevelopment.bsigroup.com/projects/2021-00605#/section>.

⁴⁵⁴ National Institute for Health and Care Excellence (2018) *Evidence standards framework for digital health technologies*, available at: <https://www.nice.org.uk/corporate/ecd7>.

⁴⁵⁵ The U.S. Food and Drug Administration, Health Canada, and the Medicines and Healthcare products Regulatory Agency (2021) *Good machine learning practice for medical device development: guiding principles*, available at: <https://www.fda.gov/media/153486/download>.

⁴⁵⁶ The Academy of Medical Sciences, responding to our call for evidence.

positive, innovative active ageing and have an innate need to be included in the digital world and not left behind.”⁴⁵⁷

“Thinking particularly of technologies to improve the health of older people through personalised prevention, the [PHG health ageing] workshop participants concluded that access should be based on need and not restricted by financial or other social barriers, otherwise they will exacerbate existing health inequalities.”⁴⁵⁸

4.29 In order to be able to benefit from the novel technologies or services that are demonstrated to be effective, people clearly need to be able to access them. Concern that access should be equitable was one of the headline conclusions of the working group’s public dialogue: “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.”⁴⁵⁹ Contributors to the working group’s inquiry highlighted a variety of different factors that might affect access including the following.

- **Affordability:** concerns about cost were raised as an issue by many different contributors, both as a theoretical concern as to the likely cost of new medications or sophisticated smart home systems, and reflecting direct personal experience, for example of having limited access to the internet and IT systems because of cost pressures.⁴⁶⁰ The difference in situation between those able to buy technological products of their own choice and those relying on access through social services was highlighted as a matter of concern, particularly as social services may often be able to offer only a limited selection of specialist devices, even if needs could be better met by mainstream consumer products.⁴⁶¹
- **Availability:** questions of availability arose both in the context of social care, as noted above, and in the context of NHS services, with one respondent to our practitioner survey commenting on the difference between research-active centres and other hospitals, where patients were much less likely to have early access to innovative interventions. Another survey respondent “worked in an NHS hospital without access to any of the technologies described in your question”,⁴⁶² highlighting how practitioners too may experience inequitable access to innovative equipment or services that could help them provide better care.
- **Appropriateness of design:** it was noted that over-complicated designs could act as barriers to access, with the added risk that difficulty in using such designs might then be blamed on older users. Design needs to be culturally appropriate,⁴⁶³ with factors

⁴⁵⁷ Sangeetha Neeraja Babu Manoharan, Centre for Ageing Research (C4AR), Lancaster University, responding to our call for evidence.

⁴⁵⁸ Dr Philippa Brice, PHG Foundation, responding to our call for evidence.

⁴⁵⁹ Nuffield Council on Bioethics (2023) *Public dialogue report on the future of ageing*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/public-dialogue-on-the-future-of-ageing>, at page 8.

⁴⁶⁰ Nuffield Council on Bioethics blog (12 July 2022) *The future of ageing – learning from the West Bromwich African Caribbean Resource Centre*, available at: <https://www.nuffieldbioethics.org/blog/the-future-of-ageing-learning-from-the-west-bromwich-african-caribbean-resource-centre>.

⁴⁶¹ Roundtable meeting with members of Technology and Ageing Special Interest Group, British Society of Gerontology, 24 June 2021 (see Appendix 1).

⁴⁶² Nuffield Council on Bioethics (2023) *The future of ageing: practitioner survey*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering-2>.

⁴⁶³ Co-production roundtable, 22 February 2022 (see Appendix 1). See also: Papadopoulos C, Castro N, Nigath A *et al.* (2022) The CARESSES randomised controlled trial: exploring the health-related impact of culturally competent artificial intelligence embedded into socially assistive robots and tested in older adult care homes *International Journal of Social Robotics* **14**(1): 245-56.

such as motor, sensory, and cognitive challenges taken into account in developing products that are easy to use.⁴⁶⁴

- **Reliability:** concerns about the reliability of access, particularly to digital services, emerged as a strong theme in the working group's engagement projects, with the convenience of online services and digital communication with family and friends compromised by fears of being 'locked out' by complicated security systems and multiple passwords (see Box 4.9). The nature and extent of this concern was closely associated with levels of **confidence** on the part of individual users, alongside the issue of whether support to use technology or solve problems would be available if necessary.⁴⁶⁵
- **Stigma:** the perceived stigma in using 'adaptive' devices designed specifically to meet the needs of older or disabled adults (exacerbated by uninspiring "big, beige and boring" design⁴⁶⁶) can lead to people delaying using technologies that could be beneficial.

Box 4.9: Wider concerns about an increasingly digitised world: contributions from the working group's engagement events

A recurrent theme at a number of the working group's engagement events was about how older adults can be locked out of services, or unable to do day-to-day things by the challenges of digital access.

- Participants at the drawing workshop with members of the Bristol Older People's Forum (BOPF) identified fears about being 'locked out', both from necessary services such as healthcare systems, and from personal contacts (such as speaking to grandchildren on Zoom) because of computer problems, forgotten passwords, or over-complicated systems. The importance of having other ways of accessing the world – involving human beings to sort things out where necessary – was strongly emphasised.⁴⁶⁷
- Members of the Greater Manchester Older People's Network (GMOPN) similarly expressed frustrations where technologies (including standard domestic appliances such as washing machines) appear unnecessarily complicated: "For example, my washing machine has 5 billion settings on it when I need 2 ... I'm not piloting the Starship Enterprise here, I just want the basics."⁴⁶⁸
- Participants at the intergenerational roundtable event, held in Exeter, raised worries about everyday services such as banking increasingly moving online, and how this might make it difficult for some older adults to access these services without the right support.⁴⁶⁹

⁴⁶⁴ Sangeetha Neeraja Babu Manoharan, Centre for Ageing Research (C4AR), Lancaster University, responding to our call for evidence.

⁴⁶⁵ See, for example, Chu CH, Yee A, and Stamatopoulos V (2022) Poor and lost connections: essential family caregivers' experiences using technology with family living in long-term care homes during COVID-19 *Journal of Applied Gerontology* **41(6)**: 1547-56; and Chu CH, Yee AV, and Stamatopoulos V (2022) "It's the worst thing I've ever been put through in my life": the trauma experienced by essential family caregivers of loved ones in long-term care during the COVID-19 pandemic in Canada *International Journal of Qualitative Studies on Health and Well-being* **17(1)**: 2075532.

⁴⁶⁶ MIT Technology Review (21 August 2019) "Old age" is made up—and this concept is hurting everyone, available at: <https://www.technologyreview.com/2019/08/21/75537/old-age-is-made-upand-this-concept-is-hurting-everyone/>.

⁴⁶⁷ Nuffield Council on Bioethics (2022) *Online workshop with members of the Bristol Older People's Forum*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/online-workshop-with-members-of-the-bristol-older-peoples-forum-bopf>.

⁴⁶⁸ Nuffield Council on Bioethics (2022) *Open forum with members of the Greater Manchester Older People's Network, in collaboration with Sonder Radio*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/open-forum-with-members-of-the-greater-manchester-older-peoples-network-gmopn-and-other-residents-in-manchester-organised-in-collaboration-with-sonder-radio>.

⁴⁶⁹ Nuffield Council on Bioethics (2022) *Intergenerational roundtable event in Exeter*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing>.

- Fears were also expressed around the way that increasing use of digital services could exacerbate existing inequalities. At the intergenerational roundtable, for example, participants raised worries about the potential barriers for older adults for whom English is not their first language, as smartphone apps become more common in everyday life.⁴⁷⁰
- Members of the West Bromwich African Caribbean Resource Centre (WBACRC) raised general feelings of fear when using certain technologies, such as “What would happen if X technology breaks?” Particular worries about using technology came from having to access assistance or support through online electronic chatbots or automated phone calls instead of speaking to a human being.⁴⁷¹

4.30 As Box 4.9 illustrates, questions of equitable access arise acutely in connection with the risks of digital exclusion. It is important not to stereotype older adults, many of whom made active use of a wide range of digital technologies both before and during the COVID-19 pandemic (see Box 4.10).⁴⁷² However, it remains the case that a significant number of those who are digitally excluded are also older, especially minoritised ethnic groups and people who are more socioeconomically disadvantaged.⁴⁷³ Any shift to offer services via digital means needs to take account of this, being alert to the risks of technological developments exacerbating, rather than reducing, current inequalities in access to services, care, or support.⁴⁷⁴ Moreover, ‘digital access’ can be a matter of degree, with people using older devices more likely to experience problems. Unpublished survey data from 1,200 UK adults in July 2022, for example, found that 26 per cent of adults over 55 with smartphones had devices that were more than 3 years old, compared with 14 per cent of those aged under 34.⁴⁷⁵

4.31 Respondents to the working group’s call for evidence highlighted the importance of a proactive focus on digital inclusion, addressing practical barriers to access and the role of continuing education.⁴⁷⁶ We also heard about research initiatives such as the Adjust Tech, Accessible Technology (ATAT) project, which actively recruited older adults with limited digital experience and supported them both in sharing their own views and in understanding those of others, resulting in the development of an innovative app and handbook geared to their needs.⁴⁷⁷ A common theme that emerges from the wider literature of the acceptability and use of technologies by older adults – whether with respect to general computer/internet use, or with respect to healthcare technologies – is that of starting with people’s needs rather than technologies (see paragraph 4.2). The

⁴⁷⁰ *ibid*, at page 4.

⁴⁷¹ Nuffield Council on Bioethics blog (12 July 2022) *The future of ageing – learning from the West Bromwich African Caribbean Resource Centre*, available at: <https://www.nuffieldbioethics.org/blog/the-future-of-ageing-learning-from-the-west-bromwich-african-caribbean-resource-centre>.

⁴⁷² See, for example, Mitzner TL, Boron JB, Fausset CB *et al.* (2010) Older adults talk technology: technology usage and attitudes *Computers in Human Behavior* **26(6)**: 1710-21; and Sangeetha Neeraja Babu Manoharan, Centre for Ageing Research (C4AR), Lancaster University, responding to our call for evidence. See also: Professor Andrew Steptoe, responding to our call for evidence, who highlights high levels of use of digital technologies among participants in the English Longitudinal Study of Ageing, albeit with “socioeconomic gradients in access to digital technology”.

⁴⁷³ The British Academy (2022) *Understanding digital poverty and inequality in the UK*, available at: <https://www.thebritishacademy.ac.uk/publications/understanding-digital-poverty-and-inequality-in-the-uk/>. See also: NHS Race and Health Observatory (2022) *Ethnic inequalities in healthcare: a rapid evidence review*, available at: https://www.nhs.uk/wp-content/uploads/2022/02/RHO-Rapid-Review-Final-Report_v.7.pdf.

⁴⁷⁴ Litchfield I, Shukla D, and Greenfield S (2021) Impact of COVID-19 on the digital divide: a rapid review *British Medical Journal Open* **11(10)**: e053440.

⁴⁷⁵ Comments submitted by external reviewers.

⁴⁷⁶ Nuffield Council on Bioethics (2023) *The future of ageing: call for evidence summary of responses*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/public-dialogue-on-the-future-of-ageing>. See also: PHG Foundation (2019) *My healthy future: health technologies and social impacts*, available at: <https://www.phgfoundation.org/media/100/download/health-tech-and-social-impacts.pdf?v=1&inline=1>, at page 19.

⁴⁷⁷ The Open University (2022) *Adjust tech, accessible technology*, available at: <https://www.open.ac.uk/health-wellbeing/projects/adjust-tech-accessible-technology-atat>; and Dr Hannah R Marston, Dr Deborah J. Morgan, Dr Gemma Wilson-Menzfeld, Ms Jessica R. Gates, and Mr Robbie Turner responding to our call for evidence.

older adults involved in the Technology in Later Life study, for example, highlighted the importance of focusing on the positive opportunities to improve health and wellbeing that technology could offer; creating peer support networks to support use; and the role of technology in enhancing intergenerational networks.⁴⁷⁸ A systematic review of the use of remote care technologies to support people with heart failure identified five factors affecting how people engage with digital healthcare: convenience; quality of care; communication; tailored information; and ease of use.⁴⁷⁹

Box 4.10: Proactive uses of digital tools by older adults

- ‘The Zoomettes’ are a UK-wide group for women living with dementia who use the online platform Zoom for peer support and friendship. The group has no more than eight members at a time on a call, with a professional facilitator also present.⁴⁸⁰
- Members who took part in the Future of Ageing Open Forum expressed strong enthusiasm for the opportunities for communication offered by technologies, particularly those used throughout the COVID-19 pandemic; for example FaceTime was described as the “best thing ever been invented”. Another participant described themselves as “a right Zoomie” and commented that “being able to physically see family members on messenger ... it does a lot for my mental health”.⁴⁸¹
- Practical guides, such as that produced by the Good Things Foundation, have been developed to help older adults get online and make support accessible, enabling them to gain confidence when using digital tools.⁴⁸²

Choice and control

“[W]hile digital technologies have considerable potential to improve wellbeing for an older population they will not always be experienced as empowering nor as promoting the kinds of active citizenship that can be significant to living well for those experiencing conditions such as dementia.”⁴⁸³

“[risks of] technologies using inaccessible language, setting unrealistic standards, or becoming a controlling force.”⁴⁸⁴

“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

⁴⁷⁸ Marston HR, Genoe R, Freeman S *et al.* (2019) Older adults’ perceptions of ICT: main findings from the Technology In Later Life (TILL) Study *Healthcare* **7**(3): 86.

⁴⁷⁹ Al-Naher A, Downing J, Scott KA *et al.* (2022) Factors affecting patient and physician engagement in remote health care for heart failure: systematic review *JMIR cardio* **6**(1): e33366.

⁴⁸⁰ DEEP: The UK Network of Dementia Voices (2022) *The Zoomettes: the story of a virtual peer support group*, available at: <https://anniversary.dementiavoices.org.uk/wp-content/uploads/2022/06/The-Zoomettes-a-group-in-the-DEEP-network.pdf>.

⁴⁸¹ Nuffield Council on Bioethics (2022) *Open forum with members of the Greater Manchester Older People’s Network, in collaboration with Sonder Radio*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/open-forum-with-members-of-the-greater-manchester-older-peoples-network-gmopn-and-other-residents-in-manchester-organised-in-collaboration-with-sonder-radio>.

⁴⁸² Good Things Foundation (2022) *Doing digital in later life: a practical guide*, available at: <https://www.goodthingsfoundation.org/insights/doing-digital-in-later-life-a-practical-guide/>.

⁴⁸³ Professor Christine Hine, University of Surrey, responding to our call for evidence.

⁴⁸⁴ Dr Philippa Brice, PHG Foundation, responding to our call for evidence citing findings of PHG Foundation (2018) *My healthy future: healthy ageing workshop*, available at: <https://www.phgfoundation.org/media/269/download/mhf-older-people-workshop-outcome.pdf?v=1&inline=1>.

*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.*⁴⁸⁵

- 4.32 As the quotations above indicate, the impact of technological innovation, both on people's choices and on their control over their own lives, was a subject of some concern among those contributing to the working group's inquiry. This issue connects closely with our earlier discussion of how 'benefit' is understood in research projects (see paragraphs 4.2–4.10): in any particular case, is the actual aim of a new technology, treatment, or service innovation to put the older adult in control and support their agency (including where their capacity is impaired) – or is it to enable others to control them or be reassured about their physical safety?⁴⁸⁶ How are legitimate concerns about physical safety balanced against broader questions of wellbeing and autonomy? And what degree of choice do people have about using, or not using, the technologies on offer? Concern was expressed in working group discussions as to how the language of 'support' can often be misused as a means of exercising restraint on people, particularly where they have impaired capacity.
- 4.33 It is important to note that these questions of choice and control cannot necessarily be answered simply with reference to the technology itself – rather, the relevant factor is likely to be the uses to which particular technologies or functionalities are put. Earlier, we highlighted two contrasting approaches to how technology might be used to enable people with dementia to live in their own homes (see paragraphs 4.3–4.4). In one, the focus was on physical safety (ensuring the person with dementia does not leave the house at night) and reassurance for others, such as family carers, especially if they do not live close by. In the second, the focus was on using AI to predict what a person might wish to do, and then providing prompts to help them achieve this, with a focus on the perspectives of the individual concerned and what might promote their wellbeing. While forms of surveillance, such as sensors, were being used in both cases, the use to which the information gained through surveillance was put was quite different.
- 4.34 It is also crucial to recognise that all these aims (promoting personal wellbeing, protecting physical safety, and providing reassurance for family and other informal carers) are legitimate and important aims. In particular, support for informal carers, who themselves often have few choices about taking on a caring role, should be regarded as a good in itself. However, this should not come at an unacceptable cost to the older adult. Making decisions about these trade-offs will never be easy, but it will be helped by being explicit about the different interests and needs at stake, and recognising how these may at times be in conflict. Of course, it is also the case that some uses of innovative technology may avoid such conflicts, particularly where they contribute to independent living in ways that are under the direct control of the older adult, and may lessen the need for personal support and care, in ways that are valued both by older adults and those close to them (e.g., see, the examples of assistive technologies described in Box 3.5).
- 4.35 While these questions of control may arise most obviously in the context of technological innovations using various forms of surveillance, related themes also emerged with respect to biomedical innovations. One contributor at the intergenerational roundtable

⁴⁸⁵ Nuffield Council on Bioethics (2023) *Public dialogue report on the future of ageing*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/public-dialogue-on-the-future-of-ageing>, at page 8.

⁴⁸⁶ See, for example, University of Essex (2022) *A digital cage is still a cage*, available at: <https://www.essex.ac.uk/research-projects/human-rights-big-data-and-technology/social-care#report>.

event in Exeter, for example, described feeling under pressure from her GP to start taking statins – a recommendation based on current research and standard medical practice but about which she felt doubtful, both because of her own family history and her sense of hesitancy of embarking on long-term medication for uncertain future good. This concrete example relating to current practice illustrated some of the hypothetical concerns expressed by roundtable participants concerning being channelled early in life into a medicalised approach to ageing (see paragraph 4.7). We consider this issue further below in the context of relationships between people and health professionals (see paragraph 4.40).

- 4.36 The importance of choice also emerged in the context of innovations being introduced in the way that health or care services operate. Concerns were expressed both about personal choice, and about the risk that introducing new systems that work for most but are difficult for others would further disadvantage those who are already disadvantaged. Common examples raised with the working group were those of digitised and automated appointment systems being introduced within the NHS, and reduced access to in-person appointments with health professionals. This highlighted the question of whether any innovation that is introduced should always be genuinely optional, with people able, in particular, to opt for direct contact with a person rather than automated or digital systems? Alternatively, should such options be reserved for those who are potentially less able to make use of innovations such as digital healthcare appointments?⁴⁸⁷
- 4.37 While some innovations may be perceived (at least initially) as leading to unwelcome changes in service, others may be widely perceived as desirable. As we noted earlier in the discussion of affordability (see paragraph 4.29), a ‘walled garden’ approach whereby social services can offer only a limited range of specified items may significantly restrict choice for some users. This concern has been raised also by the Social Care Institute for Excellence who commented in a 2020 report that: “we still seem to be somewhat stuck in buying a limited menu of services where the largest part of budgets is spent on the same things they have been for many years”.⁴⁸⁸ The concept of a ‘walled garden’, controlling access to specified products, also highlights the power and control exercised by those who determine what is included within the approved list. This issue extends beyond budgetary controls exercised by public bodies to include technology companies such as Apple whose gatekeeping role with respect to what is available via their platform may similarly be “make-or-break for many digital health products and services”.⁴⁸⁹
- 4.38 Questions of control and agency are particularly relevant in the context of ‘passive’ data collection: data that is collected from a variety of non-health sources without the active involvement, or often awareness, of those to whom it relates. Such approaches to data collection underpin much of the work on data-driven innovation, and have implications for the autonomy of older adults, and for the intersection between ‘surveillance medicine’ (related to early detection and screening) and ‘surveillance capitalism’ (related to wealth creation from the data surplus).⁴⁹⁰

⁴⁸⁷ The Academy of Medical Sciences, responding to our call for evidence.

⁴⁸⁸ Social Care Institute for Excellence (2020) *Commissioning for a better future: a starter for ten*, available at: <https://www.scie.org.uk/transforming-care/innovation/network/reports/phase-two/commissioning>, at page 2.

⁴⁸⁹ Explain this paper (2022) *Apple's foray into healthcare*, available at: <https://explainthispaper.com/apples-foray-into-healthcare/>.

⁴⁹⁰ Martinez-Martin N, Insel TR, Dagum P *et al.* (2018) Data mining for health: staking out the ethical territory of digital phenotyping *npj Digital Medicine* 1(1): 68.

Impact on relationships

“In my hypertension work, I deliberately ask whether they have a smartphone, and if they do I ask them to download a blood pressure app on which they record their blood pressure and bring the readings back to me. This makes them more aware of their condition, and thereby participate in their care.”⁴⁹¹

“There is an existing bias among people, that technology-based interventions are dehumanising or isolating in some ways. There could be some truth in it. However, in the light of cuts in public health funding and the cost of hiring service providers is expensive, it is important to take a more pragmatic approach.”⁴⁹²

“Tech, perhaps as a function, helping us develop a skill or provide support day-to-day, but it cannot be a substitute for the true human connection and that relationship and the power of this helping with our mental health and self-esteem.”⁴⁹³

4.39 The potential impact on human relationships of increasingly technological approaches to both health and care was raised with the working group in connection with a wide range of forms of research and innovation. Contributions varied from fears of a dystopian future of entirely automated care services, to considerations of how technologies could be deployed in ways that enhance both personal and care relationships. Issues raised with the working group included the following (see also Box 4.11).

- Concern about the idea of personal care and support being replaced by technological means of meeting basic needs, with risks both of receiving dehumanised support, and losing valued human contact.
- Conversely, positive support for innovations that could enable older adults to dispense with human assistance and be more independent, particularly where privacy is at stake. This was accompanied by the recognition that for most people, human contact is most important with those close to them, and that the provision of personal care by a professional should not be conflated with the ability and opportunity to maintain valued relationships.⁴⁹⁴
- Scope for technological innovations to *improve* health and care relationships – as in the way smartphone data can be used to promote people’s involvement in their own medical care, as described in the quotation about hypertension care above.
- Fears of being exploited because of the inherent risks of digital (depersonalised) technologies – for example fears of being scammed when expected to use digitised rather than human services.⁴⁹⁵

⁴⁹¹ British Pharmacological Society, responding to our call for evidence.

⁴⁹² Sangeetha Neeraja Babu Manoharan, Centre for Ageing Research (C4AR), Lancaster University, responding to our call for evidence.

⁴⁹³ Nuffield Council on Bioethics (2022) *Open forum with members of the Greater Manchester Older People’s Network, in collaboration with Sonder Radio*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/open-forum-with-members-of-the-greater-manchester-older-peoples-network-gmopn-and-other-residents-in-manchester-organised-in-collaboration-with-sonder-radio>.

⁴⁹⁴ University of Essex (2022) *A digital cage is still a cage*, available at: <https://www.essex.ac.uk/research-projects/human-rights-big-data-and-technology/social-care#report>.

⁴⁹⁵ Nuffield Council on Bioethics (2023) *The future of ageing: practitioner survey*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering-2>.

Box 4.11: Varying perspectives on robots shared with the working group

- In the working group’s expert roundtable meeting on technology, a number of potential benefits of using robots were highlighted, including for carrying out tasks that are burdensome for care staff such as lifting heavy equipment, or where people might find human support embarrassing, for example, help in the toilet. However, it was suggested that concerns arise when robots are being used for social purposes, including by designing anthropomorphising features such as humanoid shapes and smiley faces.⁴⁹⁶
- Participants at the intergenerational roundtable event felt that human beings, not robots, should be responsible for the care of older adults because human beings are social beings and need “social interactions to live a good life”, something not easily replicated by robots.⁴⁹⁷
- Participants at the Future of Ageing Open Forum voiced concerns around robots affecting social relationships among older adults and worries that older adults may “lose the social skills they would need to try and build a relationship away from this type of technology”. One participant explained that a companion robot is “not a real person, it does not have feelings, it has no history”.⁴⁹⁸
- Members of the West Bromwich African Caribbean Resource Centre (WBACRC) expressed mixed opinions about robotic technology for older adults. There was an agreement among the focus group that robots may be beneficial in providing functional support for older adults at home, such as mowing the lawn or cleaning; however some members had significant fears that an increase in care robots would lead to a potential lack of human contact.⁴⁹⁹
- Members of Greater Manchester Growing Older with Learning Disabilities (GM GOLD) members designed several ‘dream machines’ to be used in older age that were in the form of robots. These included a robot that can clean the house or help communicate their needs if they struggle to communicate themselves.⁵⁰⁰

4.40 In healthcare, the focus on increasingly data-driven approaches to care (see paragraphs 3.35–3.41) has led to anxieties that care may in future be less patient-centred, both because health professional discretion may be lost, and because of reduced opportunities for people to discuss healthcare choices one-to-one with a health professional.⁵⁰¹ The Academy of Medical Science’s inquiry *Our data-driven future in healthcare*, for example, highlighted “patient and public concern that widespread utilisation of novel technologies may result in loss of patient-practitioner interaction and lack of opportunity to discuss treatment and care options”.⁵⁰² Wider concerns have also been expressed that a shift to

⁴⁹⁶ Technologies roundtable, 21 July 2021 (see Appendix 1).

⁴⁹⁷ Nuffield Council on Bioethics (2022) *Intergenerational roundtable event in Exeter*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing>.

⁴⁹⁸ Nuffield Council on Bioethics (2022) *Open forum with members of the Greater Manchester Older People’s Network, in collaboration with Sonder Radio*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/open-forum-with-members-of-the-greater-manchester-older-peoples-network-gmopn-and-other-residents-in-manchester-organised-in-collaboration-with-sonder-radio>.

⁴⁹⁹ Nuffield Council on Bioethics blog (12 July 2022) *The future of ageing – learning from the West Bromwich African Caribbean Resource Centre*, available at: <https://www.nuffieldbioethics.org/blog/the-future-of-ageing-learning-from-the-west-bromwich-african-caribbean-resource-centre>.

⁵⁰⁰ Nuffield Council on Bioethics blog (29 September 2022) *If you could design your ‘dream machine’ to help you in older age, what would it be?*, available at: <https://www.nuffieldbioethics.org/blog>.

⁵⁰¹ British Pharmacological Society, responding to our call for evidence citing: Berntsen G, Strisland F, Malm-Nicolaisen K *et al.* (2019) The evidence base for an ideal care pathway for frail multimorbid elderly: combined scoping and systematic intervention review *Journal of Medical Internet Research* **21(4)**: e12517.

⁵⁰² The Academy of Medical Sciences responding to our call for evidence, drawing on: The Academy of Medical Sciences (2018) *Our data-driven future in healthcare: people and partnerships at the heart of health related technologies*, available at: <https://acmedsci.ac.uk/file-download/74634438>.

a ‘scan first, ask questions later’ approach, with scans ordered before clinical examination, rather than in the light of that examination, is changing the nature of medical practice and the patient/professional relationship.⁵⁰³

- 4.41 There was clear consensus across the range of contributions made to the working group’s inquiry of the importance of innovative approaches to treatment and care being developed, and deployed, in ways that complement and support existing relationships. Contributors to our practitioner survey and call for evidence, for example, highlighted how improved access to medical records and better streamlining of procedures could facilitate better care;⁵⁰⁴ and how “the use of routine data and AI alongside health and care professionals to bring the clinical judgement and shared decision making to healthcare management and prevention would be a valuable thing and give added value to clinical decision making that may not be as good with each approach individually.”⁵⁰⁵

Trust and trustworthiness

“The wealth of patient data that is collected by technologies such as home sensors, wearable technologies and artificial intelligence, must be responsibly and ethically handled by the NHS (and organisations acting on its behalf) and used to inform development of effective interventions.”⁵⁰⁶

“Loss of privacy - individuals might feel that they are ‘being watched’ ostensibly for the provision of support. Data sharing – in order to maximise the utility of this data it needs to be shared, which relies upon sufficient infrastructure being in place, but also upon public trust and acceptability.”⁵⁰⁷

“The datafication of healthcare is extending and simultaneously medicalization is expanding into further areas of everyday life as remote monitoring and smart healthcare at home expand. Older adults are a particular target of this dual datafication, with a form of “surveillance for independence” offered by systems that aim to anticipate and avert, through timely intervention, events such as falls and urine infections.”⁵⁰⁸

- 4.42 While trust and trustworthiness is often discussed in the context of the use of data in research and care, the role of trust in the wider health and research system arose as a much broader theme during the working group’s inquiry. This was expressed particularly bluntly by members of the WBACRC: “Some of the participants felt a **lack of trust in technology, public bodies, and commercial companies**, especially when considering how their personal data might be used and stored.” Participants also described “a lack of trust in research that has involved BAME [Black, Asian, and Minority Ethnic] communities, due to previous experiences and known areas of inequality among Black

⁵⁰³ Maskell G (2022) Scan first, ask questions later? *British Medical Journal* **378**: o2052.

⁵⁰⁴ Nuffield Council on Bioethics (2023) *The future of ageing: practitioner survey*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering-2>.

⁵⁰⁵ Anonymous response to our call for evidence.

⁵⁰⁶ The Academy of Medical Sciences, responding to our call for evidence.

⁵⁰⁷ Dr Philippa Brice, PHG Foundation, responding to our call for evidence, citing: PHG Foundation (2018) *My healthy future: healthy ageing workshop*, available at: <https://www.phgfoundation.org/media/269/download/mhf-older-people-workshop-outcome.pdf?v=1&inline=1>.

⁵⁰⁸ Professor Christine Hine, University of Surrey, responding to our call for evidence.

Caribbean communities. Connecting with community leaders and centres was described by many participants as a helpful method of building trust in using new technologies.”⁵⁰⁹

- 4.43 Trust and trustworthiness also emerged as a significant theme in connection with the prospect of **earlier diagnosis of conditions associated with older age**: for example in terms of what is actually being promised, and what the consequences could be if these promises turn out to be undeliverable. These issues arise particularly acutely in the context of the earlier detection of conditions for which there are currently few or no effective treatments: while earlier detection of dementias, for example, may pave the way for the development of new treatments that intervene much earlier in the disease process, this provides no answer for how better to support those who receive an early diagnosis (or prediction of elevated risk) in the absence of such treatments. It also raises serious ethical questions as to the basis on which those involved in such research take part, particularly in the light of very optimistic public statements about the benefits of earlier detection of disease (e.g., see, paragraph 3.36).⁵¹⁰ The Alzheimer’s Research UK’s Early Detection of Neurodegenerative diseases (EDoN) project is currently exploring these questions, as part of public engagement to inform the development of digital tools to help diagnose neurodegeneration earlier (see Box 4.12).

Box 4.12: Early Detection of Neurodegenerative diseases (EDoN) project

Early Detection of Neurodegenerative diseases (EDoN) is an ambitious project led by Alzheimer’s Research UK. The project is developing a digital toolkit capable of detecting the earliest signs of diseases like Alzheimer’s in people who don’t have any obvious symptoms of dementia. The toolkit uses wearable devices and smartphone apps to collect active and passive physiological and behavioural measures, like gait and cognition. Ultimately, EDoN aims to make faster breakthroughs in understanding the disease and testing potential new treatments.⁵¹¹

As part of the project, a patient and public involvement and engagement panel (PPIE) was established to provide insights to help shape the digital toolkit at an early stage of development. Alzheimer’s Research UK commissioned Vine, an insights agency specialising in qualitative research, to explore these perceptions and attitudes in more depth. The panel have agreed to take part in additional waves on consultation as the EDoN project develops and the toolkit is refined. The following key themes emerged from the engagement panel workshops.

- Panellists were positive about the concept of early detection in general, but when applied to early detection of Alzheimer’s disease, they were more receptive provided interventions are available.
- Detection via a digital toolkit prompted questions about the accuracy and practicality of using the toolkit but did not significantly increase concerns around data and privacy.
- Panellists were positive about Alzheimer’s Research UK leading the project, describing it as logical, reassuring, and adding credibility.

⁵⁰⁹ Nuffield Council on Bioethics blog (12 July 2022) *The future of ageing – learning from the West Bromwich African Caribbean Resource Centre*, available at: <https://www.nuffieldbioethics.org/blog/the-future-of-ageing-learning-from-the-west-bromwich-african-caribbean-resource-centre>.

⁵¹⁰ For a discussion of the implications of emerging treatments for people already living with Alzheimer’s disease, see, for example: Making rights makes sense blog (1 December 2022) *Does he take Lecanemab?*, available at: <https://makingrightsmakesense.wordpress.com/2022/12/01/does-he-take-lecanemab/>.

⁵¹¹ Edon Initiative (2019) *EDoN - Early Detection of Neurodegenerative diseases*, available at: <https://edon-initiative.org/>.

- The current mix of partners, collaborators and funders was well received, largely driven by the involvement of what were perceived as world-class universities.
- The panellists showed more fear and uncertainty than genuine knowledge about Alzheimer's and dementia. EDoN offers an opportunity to educate and challenge misconceptions about the disease.

- 4.44 Doubt about the **motivations and drivers behind particular research directions or technologies** also emerged as an area of concern, as highlighted in the feedback from participants in the West Bromwich discussion cited above (paragraph 4.42). Similar reflections emerged in the public dialogue: participants were not opposed to commercial entities making some money out of developments in research and technology, but they were very concerned about the idea that commercial ends could be the main driver. 'Political' motivations were seen as similarly unhelpful.⁵¹²
- 4.45 Many issues associated with trust in the **use of data in research** are of course not specific to this field of research, although questions of older adults' control over the use of their data are a particular issue, given the tendency to overlook older people's agency (see for example paragraphs 2.15–2.22 and 4.2–4.10). In June 2022, the Department of Health and Social Care launched the latest NHS data strategy in which it was recognised that “we cannot take the trust of the public for granted”, and that “public trust and confidence needed to be front and centre of the safe use and access to health and social care data”.⁵¹³ Commitments in the strategy relevant to issues raised during this inquiry include “using technology to allow staff to spend more quality time with patients” and “giving people better access to their own data through shared care records and the NHS App”. In recognition of the importance of non-NHS data in research in ageing, in November 2021, the All-Party Parliamentary Group on Longevity launched an ‘Open Life Data Framework’, which aims to create enabling conditions for public and private sectors to share data for public benefit while ensuring public trust, in particular by ensuring that individuals have the opportunity to decide what information to share with whom.⁵¹⁴

Sustainability and joined-up services

“The roots of healthier older age lie in attention to enabling healthier living and ageing from much earlier in the life course.”⁵¹⁵

“This focus [in the Welsh strategy for an ageing society] on prevention and collective action aligns closely with the aims of the Well-being of Future Generations Act and the requirement it places on public bodies to “to think about the long-term impact of their decisions, to work better with people, communities and each other, and to prevent persistent problems such as poverty, health inequalities and climate change.”⁵¹⁶

⁵¹² Nuffield Council on Bioethics (2023) *Public dialogue report on the future of ageing*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/public-dialogue-on-the-future-of-ageing>.

⁵¹³ Department for Health and Social Care (2022) *Data saves lives: reshaping health and social care with data*, available at: <https://www.gov.uk/government/publications/data-saves-lives-reshaping-health-and-social-care-with-data/data-saves-lives-reshaping-health-and-social-care-with-data>.

⁵¹⁴ All-Party Parliamentary Group for Longevity (2021) *Open Life Data Framework*, available at: <https://appg-longevity.org/open-life-data-framework>. See also: Green D, O'Shaughnessy J, Starks G *et al.* (2021) Open life data to support healthy longevity for all *The Lancet Healthy Longevity* **2(5)**: e238–e9.

⁵¹⁵ Dr Philippa Brice, PHG Foundation, responding to our call for evidence.

⁵¹⁶ Welsh Government (2021) *Age friendly Wales: our strategy for an ageing society*, available at: <https://gov.wales/sites/default/files/pdf-versions/2021/10/4/1633593161/age-friendly-wales-our-strategy-ageing-society.pdf>, at page 11.

“Without a cross-disciplinary approach, we will be unable to understand ageing and enhance the experience for the population in general.”⁵¹⁷

“The [British Pharmacological] Society advocates for investment in multidisciplinary teams and integrated care pathways, which is currently not a model we have ... the traditional research paradigm focuses on one target, one disease and one treatment – often overseen by multiple specialists in secondary care pathways.”⁵¹⁸

- 4.46 The final theme that emerged in the working group’s evidence-gathering was that of sustainability – understood broadly in the sense of a concern for how innovations delivered through research could help people live well in later life, in ways that would be sustainable for future generations. This included alertness to the dangers of building systems or approaches that would be too costly (in time, finances or resources) over the long term. It also included a strong sense that the current system, including the fragmentation of the multiple parts of the health and care system, the lack of attention paid to the health impacts of other aspects of public policy, insufficient focus on multidisciplinary work within the research sector, and the lack of cross-over between research and practice, was a barrier to delivering sustainable future services.
- 4.47 As we discussed in Chapters 1 and 2, taking a public health and preventative approach to supporting good population health is widely seen as essential in supporting people to live well in older age: not only in shifting to a system that puts greater emphasis on prevention (delivering holistic ‘healthcare’ as opposed only to reactive ‘sick care’), but also actively paying attention to the need to invest in research, services, and environments that reduce, rather than increase, the health inequalities that lead to such large differences in healthy life expectancy (see Boxes 1.2 and 1.3).⁵¹⁹ A ‘Quantum Healthy Longevity Innovation Mission’, launched in November 2022 by the National Innovation Centre for Ageing and Collider Health, makes the case that data-driven innovations, geroscience, and other emerging technologies can help achieve this aim, when underscored by principles including compassion, equitable access, and intergenerational engagement (see Box 4.13).

Box 4.13: Quantum Healthy Longevity Innovation Mission

The launch in November 2022 of a ‘Quantum Healthy Longevity Innovation Mission’ by the National Innovation Centre for Ageing and Collider Health, made the case for achieving improved health and wellbeing, more connected services, and a sustainable future through harnessing data-driven innovation, AI, and geroscience. The Mission proposes developing an AI platform that “will evolve into a world-first testbed taking science and innovation out of the laboratory and directly into people’s homes, with healthy longevity-as-a-service products and services designed and developed for unmet needs that make a real and measurable difference to people’s lives and to planetary health too.”⁵²⁰ Guiding principles underlying this approach include the following.

- Taking an ‘exposome’ approach, recognising how the multiple exposures humans face in all aspects of their lives cumulatively affect our lifelong health.

⁵¹⁷ Professor Andrew Steptoe, responding to our call for evidence.

⁵¹⁸ British Pharmacological Society, responding to our call for evidence.

⁵¹⁹ Ageing, AI, and data-driven innovation roundtable, 7 December 2021 (see Appendix 1).

⁵²⁰ Woods T, Palmarini N, Corner L et al. (2022) Quantum healthy longevity for healthy people, planet, and growth *The Lancet Healthy Longevity* 3(12): E811-e3.

- Leveraging technologies, including AI, robotics, synthetic biology, and other emerging technologies.
- Mobilising brain capital, putting a premium on approaches that protect brain health.
- Focusing on intergenerational engagement.
- Optimising digital engagement through skills development, citizen-driven co-design, and equitable access to tools such as 5G.
- Being rooted in democratisation of access, with equality, diversity, and inclusion as prerequisites.
- Ensuring compassion is the running thread.

4.48 Other respondents to the working group highlighted the need to tackle the fragmentation inherent in the current system, with the ‘single disease, single treatment’ paradigm hindering sustainable, holistic approaches both to research and to the provision of treatment and care. Critically, this paradigm also delays the translation of research findings into wider practice, further exacerbated by fragmentation within health, care, and research sectors, and between those sectors. The Academy of Medical Sciences argued that “a more collaborative approach between healthcare organisations, and indeed between all life science sectors, should also speed up the translation and adoption of innovative diagnostic developments into patient benefit in the clinic”.⁵²¹ The British Pharmacological Society emphasised to us how particularly problematic this ‘siloes’ approach to health and social care can be for older adults who generally live with multiple conditions, leading to a lack of person-centred care and exposing people to additional risks through polypharmacy.⁵²²

4.49 Recent changes in healthcare structures in England, in particular through the creation of integrated care systems (ICSs), have been welcomed as offering the prospect of more coordinated approaches to planning and providing care. Nevertheless, concern was expressed to the working group that research is insufficiently integrated into these new arrangements, suggesting that a great deal more needs to be done to maximise the translation of new knowledge into concrete benefits for older adults.⁵²³

⁵²¹ The Academy of Medical Sciences, responding to our call for evidence.

⁵²² British Pharmacological Society, responding to our call for evidence.

⁵²³ Nuffield Council on Bioethics (2023) *The future of ageing: call for evidence summary of responses*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/public-dialogue-on-the-future-of-ageing>. For a helpful overview of how ICSs will work, see: The King’s Fund (2022) *Integrated care systems: how will they work under the Health and Care Act?*, available at: <https://www.kingsfund.org.uk/audio-video/integrated-care-systems-health-and-care-act>.

Chapter 5

Developing an ethical
framework

Chapter 5 – Developing an ethical framework

Overview of Chapter 5

- Ethical reasoning needs to take into account that **ageing is a fundamental feature of human life** – not some kind of aberration from an idealised ageless norm. The equal human worth of all older adults, and our capacity to flourish whatever our age, must be the starting point of any research and policy in this field.
- The **diversity of older adults** needs to be explicitly recognised in all ageing-related research and associated policy/implementation: this includes the diversity of their background and experiences (both lifelong and in older age); of their contributions to the care and support of others; and of their own evolving needs for care and support.
- Developments in any of the areas of biomedicine and technology covered within this inquiry should be **evaluated by reference to their ability to enhance genuine opportunities to flourish** (promoting our capabilities to be and do what we value). An approach to research and innovation founded on **coproduction involving people of all ages and representing a broad range of backgrounds and experiences** will be essential in order to achieve this, particularly given the diversity of situations and goals that will influence any individual's ability to flourish.
- **Research and innovation cannot take place in a vacuum**: the scope for particular interventions, goods, or services to provide genuine opportunities to flourish will be strongly determined by structural factors including lifelong discrimination, economic situation, local environment, and social support. These factors need to be taken into account throughout the research process, with the aim of **prioritising initiatives that will reduce, not increase inequalities in older age**. They will also need to be at the forefront of policy considerations when rolling out innovations that are shown to be beneficial.
- Of central concern is the risk that unequal power relationships, whether between older adults and institutions, or older adults and other individuals, increase the likelihood of oppression, discrimination, forms of domination, social exclusion, or stigmatisation. A key question to ask with respect to any proposed novel intervention or technology should be **how it will enhance the control that older adults have over their lives, and support them in more equal relationships with those around them**.
- As populations age, the need for care and support increases. Good care cannot be reduced to 'packages of care' that can be delivered in timed segments. A care ethics approach highlights how dependency relationships generate responsibilities, with an emphasis on the role of sympathy and directly attending to concrete features of situations; caring attitudes; and responsiveness to the care needs of others. The contribution that technological developments may make to providing care should thus be understood with reference to **how technology can support, not replace, important human relationships**. In some cases, technology may offer valued alternatives to human assistance, especially where privacy is at stake.
- Research processes, the new interventions that are developed as a result of that research, and the way that these interventions are made available to the wider public all need to be demonstrably **trustworthy**. They also need to be **sustainable** in the resources they consume – including in terms of energy, time, and finance.

Introduction: the aim of an ethical framework

“What kind of society can we praise and admire? In what sort of society can we live with our conscience clear?”⁵²⁴

- 5.1 Our aim in developing an ethical framework is to identify the values, principles, and factors that are most at stake in the context of biomedical research and innovation concerned with ageing – and to bring these together in a way that provides a practical, actionable guide to policy, science, and technology. In attempting this, we need to address the question in Mary Warnock’s quotation above – posed in the context of the beginning rather than the end of life, but just as apposite. If what we want is a society where older adults are valued and are able to flourish, where their agency is respected, and where their own values and preferences guide any support they may need, what does this mean for the values and principles that should guide research and innovation relevant to ageing?
- 5.2 Earlier in this report we explored the often unconscious devaluing of older age and older adults, and the risks that these negative assumptions are then built into all sorts of areas of social policy, including within biomedical research and technological innovation (see Chapter 2, in particular paragraphs 2.1–2.3 and 2.15–2.19). In Chapter 4, we drew on contributions from older adults from many different backgrounds and experiences, from intergenerational groups, and from a variety of experts working in the field, to draw together the many ethical considerations and concerns that have come to light during this inquiry. Despite the breadth of research and innovation within scope, and the diversity of contributors and experiences, some very clear common themes have emerged. These include: the fundamental importance of older adults **being included** (in all sorts of different ways); **having their agency and contribution respected** (highlighting how older adults are not just people to whom things are ‘done’); and **remaining socially connected**. In this chapter, we explore in more depth some of the ideas and concepts that underpin these considerations, in order to develop and justify our proposed ethical approach for future research and innovation in this field.

Ethics of ageing: a challenge

“Too often, ethical analysis takes for granted the perspective of someone who is autonomous, chronologically relatively young, and in the midst of planning for a future adulthood that stretches out in front of them.”⁵²⁵

- 5.3 Ethical debates on ageing and old age in the context of biomedicine and healthcare have become increasingly prominent over the last three decades, as the implications of rising life expectancies and the age shift in the population have attracted public and policy attention. Considerable attention, for example, has been paid to questions such as the relevance of chronological age in the just allocation of scarce healthcare resources;⁵²⁶ and to how health and care services can better respect the individual autonomy and

⁵²⁴ HC Deb (23 November 1984) vol 68 cc 528-44.

⁵²⁵ Jecker NS (2020) *Ending midlife bias: new values for old age*, Volume 1 (New York: Oxford University Press), at page 8.

⁵²⁶ Eric Matthews, and Russell E (2016) *Rationing medical care on the basis of age: the moral dimensions*, 1st Edition (London: CRC Press).

agency of older adults.⁵²⁷ In recent years, discussions about the desirability and moral acceptability of biomedical and technological interventions in ageing and old age have gained particular momentum.⁵²⁸

- 5.4 However, many of these debates still express a limited and biased perspective on ageing and old age, often based on the underlying assumption explored earlier in this report – that being old inherently entails being passive and dependent. One reason for this may be that the mainstream of Western liberal bioethics has rested on largely unexamined anthropological assumptions that do not take the empirical experience of ageing and old age into account.⁵²⁹ **Indeed, many of the main strands of bioethical reasoning dominant in the Global North are implicitly based on an abstract notion of the ‘person’ or moral agent as an ageless and disembodied individual who stands outside time.**⁵³⁰ On closer inspection, **this widespread ‘reference person’ or persona often turns out to be tacitly modelled on the healthy, independent, and rational (male) individual of middle adulthood.**⁵³¹ It thus presumes a set of ‘normal’ human attributes and abilities that are not always present in the same way throughout the human life course, and indeed are not true for some people at any point during their lives. Deviations from this standardised image, such as the experience of early childhood, old age, or lifelong disability, are therefore easily perceived as special developments or even abnormal and deficient modes of being human.⁵³²
- 5.5 This midlife bias within bioethics can have far-reaching and problematic consequences. In particular, there is a danger that the standard concepts and frameworks that have been built on this reference person do not do justice to the specific interests and concerns of older people – in the same way that standardised models or ‘personas’ used in design may design in certain kinds of bias.⁵³³ (We note here that many of the same issues arise with respect to the impact on a number of other groups, in particular younger adults living with disability: while our focus here is on diverse experiences of ageing, others have presented these arguments powerfully elsewhere with respect to other aspects of life.⁵³⁴) An ethical perspective that focuses strongly on individual self-determination and distributive justice, for example, may neglect those for whom a caring, attentive, and compassionate environment is at least as important as rights to privacy or a legal entitlement to resources – especially where such rights may in practice be challenging

⁵²⁷ Agich G (2003) *Dependence and autonomy in old age: an ethical framework for long-term care* (Cambridge: Cambridge University Press); and Lesser H (Editor) (1999) *Ageing, autonomy and resources*, 1st Edition (London: Routledge).

⁵²⁸ Haltaufderheide J, Hovemann J, and Vollmann J (Editors) (2020) *Ageing between participation and simulation: ethical dimensions of socially assistive technologies in elderly care* (Berlin/Boston: De Gruyter); and Davis JK (2018) *New methuselahs: the ethics of life extension* (Cambridge, Massachusetts, London: MIT Press).

⁵²⁹ See, for example, Schweda M, Coors M, and Bozzaro C (Editors) (2020) *Ageing and human nature: perspectives from philosophical, theological, and historical anthropology*, 1st Edition (Cham, Switzerland: Springer). We note that there are many reasons why early medical ethics, in particular, was framed and developed in the way that it did, including the need to challenge power imbalances between individuals and professional elites, and the context of prevailing political trends in the 1980s and 1990s. For further discussion, see: Wilson D (2014) *The making of British bioethics* (Manchester, UK: Manchester University Press), in particular Chapter 3.

⁵³⁰ Holm S (2013) The implicit anthropology of bioethics and the problem of the aging person, in *Ethics, health policy and (anti-) aging: mixed blessings*, Schermer M, and Pinxten W (Editors) (Dordrecht: Springer Science & Business Media); and Dekkers W (2013) Do we need an anthropology of the aging person and what should it look like?, in *Ethics, health policy and (anti-) aging: mixed blessings*, Schermer M, and Pinxten W (Editors) (Dordrecht: Springer Science & Business Media).

⁵³¹ Jecker NS (2020) *Ending midlife bias: new values for old age*, Volume 1 (New York: Oxford University Press).

⁵³² Holm S (2013) The implicit anthropology of bioethics and the problem of the aging person, in *Ethics, health policy and (anti-) aging: mixed blessings*, Schermer M, and Pinxten W (Editors) (Dordrecht: Springer Science & Business Media); and Jecker NS (Editor) (1992) *Ageing and ethics: philosophical problems in gerontology* (Totowa, NJ: Humana).

⁵³³ Peine A, and Neven L (2021) The co-constitution of ageing and technology – a model and agenda *Ageing and Society* **41(12)**: 2845-66. More generally, see for example, critiques of the models long used for crash-testing: Gendered Innovations (2022) *Inclusive crash test dummies: rethinking standards and reference models*, available at: <https://genderedinnovations.stanford.edu/case-studies/crash.html>.

⁵³⁴ See, for example, Reynolds JM (2022) *The life worth living: disability, pain, and morality* (Minneapolis, MN, USA: University of Minnesota Press).

to enforce.⁵³⁵ Concerns have been expressed that the assumptions built on such a biased image of human existence contribute to discrimination against older adults, and may lead to a degradation of their moral and legal status.⁵³⁶

- 5.6 While these concerns may seem extreme and theoretical, experience of the COVID-19 pandemic, in the UK and elsewhere, has illustrated how easily this kind of ‘othering’ of older or disabled people can lead to differential and disempowering treatment. Decisions have been made, for example, about how the physical health and safety of people living in care homes should be protected, without reference to the wishes, preferences, and broader wellbeing of those individuals themselves, or those of their families and friends (see Box 2.9).⁵³⁷
- 5.7 In order to avoid such problematic distortions and their practical consequences, it has been argued that bioethics needs to engage in a critical reflection of its own underpinnings and their implications.⁵³⁸ It is increasingly recognised that we can no longer simply assume a given notion of what it is to be a moral agent without further reflection or justification. We should be especially suspicious of any apparently ‘abstract’ universal claims about bioethics that in practice serve to privilege one particular point in the human life course at the expense of others. Instead of building arguments on such abstractions, bioethical reasoning needs to embrace the diverse realities of human experience, and allow room for the many and varied facets and contexts it involves.⁵³⁹
- 5.8 One important consequence of this critique is the growing recognition of the need for a critical review of some of the fundamental concepts and principles in bioethics that have been developed on the basis of these assumptions. For example, understandings of autonomy that focus only on individual choice and independence are increasingly criticised for neglecting the way that we make important decisions about our lives in the context of our lived experience – including our physical health, our personal histories, and our personal relationships.⁵⁴⁰ In response, a number of strands of ethical thought, especially communitarian, feminist, and care ethics, have developed more nuanced conceptions of autonomy that aim to accommodate the intrinsically relational and interdependent character of human existence and to acknowledge how individual self-determination is shaped by social circumstances (see paragraph 5.23).⁵⁴¹

⁵³⁵ Lloyd L (2004) Mortality and morality: ageing and the ethics of care *Ageing and Society* **24(2)**: 235-56. See also: Lloyd L (2013) *Health and care in ageing societies: a new international approach* (Bristol, UK: Cambridge University Press).

⁵³⁶ Holm S (2013) The implicit anthropology of bioethics and the problem of the aging person, in *Ethics, health policy and (anti-) aging: mixed blessings*, Schermer M, and Pinxten W (Editors) (Dordrecht: Springer Science & Business Media); Higgs P, and Gilleard C (2016) Interrogating personhood and dementia *Ageing & Mental Health* **20(8)**: 773-80; and Hughes J, Louw S, and R. Sabat S (2005) *Dementia: mind, meaning, and the person* (Oxford: Oxford University Press UK).

⁵³⁷ Similar arguments can also be made with respect to how the law privileges middle age, see: Adkins V (2022) Jonathan Herring, law through the life course *Medical Law Review* **30(2)**: 380-7.

⁵³⁸ Holm S (2013) The implicit anthropology of bioethics and the problem of the aging person, in *Ethics, health policy and (anti-) aging: mixed blessings*, Schermer M, and Pinxten W (Editors) (Dordrecht: Springer Science & Business Media). See also the introduction of Schweda M, Coors M, and Bozzaro C (Editors) (2020) *Ageing and human nature: perspectives from philosophical, theological, and historical anthropology*, 1st Edition (Cham, Switzerland: Springer).

⁵³⁹ See: Dunn M (2018) Realizing and maintaining capabilities: late life as a social project *Hastings Center Report* **48 (Supplement 3)**: S25-S30, who argues for the need for us to “shift our bioethical imagination” to ask challenging questions about the nature of the good life in later life – and also what is owed to older people.

⁵⁴⁰ Agich G (2003) *Dependence and autonomy in old age: an ethical framework for long-term care* (Cambridge: Cambridge University Press). See also: Nuffield Council on Bioethics (2009) *Dementia: ethical issues*, available at: <https://www.nuffieldbioethics.org/publications/dementia> where a strong case was made for this more nuanced, relational approach to autonomy.

⁵⁴¹ Jennings B (2016) Reconceptualizing autonomy: a relational turn in bioethics *Hastings Center Report* **46(3)**: 11-6; and Mackenzie C, and Stoljar N (2000) *Relational autonomy: feminist perspectives on autonomy, agency, and the social self* (Oxford: Oxford University Press).

- 5.9 Some authors go further, in condemning the weight placed in contemporary liberal bioethics on principles of individual autonomy and distributive justice. They emphasise instead the moral significance of values of care, empathy, and solidarity within close personal relationships and social communities (an approach to which we examine further below – see paragraphs 5.34–5.39).⁵⁴² Yet, we suggest that it would be wrong simply to counter the predominance of the apparently ageless, disembodied, and independent ideal by conversely emphasising *only* human vulnerability, finiteness, and dependence. This latter approach may be better suited to certain groups of older people, or to the experiences of nearly everyone at the very end of their lives. But as an expression of a comprehensive view of ageing, it would lead to just as many distortions, prejudices, and negative stereotypes as the conceptions against which it was originally aimed. **Rather than replacing one biased stereotype of ageing with another, thus merely reversing the value system which informs current bioethical discourse, we need to achieve a more profound understanding of what it means from an ethical perspective to age and to be old.**
- 5.10 In this context, bioethics can benefit from both the theoretical models and the increasing wealth of empirical results of gerontological research.⁵⁴³ As we have explored earlier in this report, there is growing understanding of the scale of individual plasticity of ageing and of the sociocultural variety and diversity of older lives that bioethics needs to recognise (e.g., see, paragraphs 1.20–1.21 and paragraph 2.6). Furthermore, gerontological research has reinforced the need to view ageing and old age in the light of the entire life course (see paragraphs 2.7–2.13). This perspective counteracts simplistic notions of a distinct state of ‘being old’ that is in tension, or even in conflict, with other age groups. Instead, it directs attention to the fact that we all are ageing. **According to this holistic approach, what is needed is not a ‘special gerontological ethics’ or an ‘ethics for older people’. Rather, ethical reasoning needs to take into account that ageing is a fundamental feature of human life.**⁵⁴⁴

The capabilities approach: promoting flourishing in older age

- 5.11 We suggest that one valuable way of realising such an approach is via a form of the **capabilities approach** developed by Amartya Sen and Martha Nussbaum,⁵⁴⁵ and which forms an important element of the World Health Organization’s (WHO) approach to healthy ageing.⁵⁴⁶ The capabilities approach offers a framework for thinking about how people’s wellbeing can be supported and enhanced throughout their life course, by framing wellbeing in terms of **capabilities** and **functionings**. Functionings are what we are able to be and do – achieving the things that we value in life and that give us purpose. Capabilities are the opportunities genuinely open to us to achieve those functionings. Capabilities reflect a combination of internal and external factors: they rely both on our

⁵⁴² Lloyd L (2004) Mortality and morality: ageing and the ethics of care *Ageing and Society* **24**(2): 235-56.

⁵⁴³ de Medeiros K (2018) What can thinking like a gerontologist bring to bioethics? *Hastings Center Report* **48** (Supplement 3): S10-S4.

⁵⁴⁴ Schweda M (2016) “A season to everything”? considering life-course perspectives in bioethical and public-health discussions on ageing, in *Planning later life: bioethics and public health in ageing societies*, Schweda M, Pfaller L, Brauer K, Adloff F, and Schicktanz S (Editors) (London: Routledge). See also: Wareham CS (2018) What is the ethics of ageing? *Journal of Medical Ethics* **44**(2): 128-32.

⁵⁴⁵ See, for example, Sen A (1984) Rights and capabilities, in *Resources, values, and development*, (Cambridge, MA: Harvard University Press); Sen A (1985) *Commodities and capabilities* (Amsterdam: North Holland); Sen A (1993) Capability and well-being, in *The quality of life*, Nussbaum M, and Sen A (Editors) (Oxford: Clarendon Press); and Nussbaum M (2011) *Creating capabilities: the human development approach* (Cambridge, MA: Belknap Press of Harvard University Press), at Chapter 2.

⁵⁴⁶ WHO (2015) *World report on ageing and health*, available at: <https://apps.who.int/iris/handle/10665/186463>, at pages 27-30. See also: Wareham CS (2018) What is the ethics of ageing? *Journal of Medical Ethics* **44**(2): 128-32.

intrinsic characteristics and attributes, and on the many wider social and economic factors that either enable or hinder us in functioning as we wish.

- 5.12 A number of theorists have developed the capabilities approach in different ways, and with different emphases.⁵⁴⁷ In what follows, we have not sought to align ourselves consistently with a particular strand of capability theory.⁵⁴⁸ Rather we suggest that the broad scope of the capabilities approach provides a systematic and inclusive basis upon which we can think about what it means to age well, what it is to ‘flourish’ in older age, and thus what policies and approaches (including, but not limited to, technological and biomedical innovation) can promote our flourishing.⁵⁴⁹
- 5.13 In particular, by being deliberately non-specific about what forms of functionings and capabilities we should value (whether as individuals or as a society), the capabilities approach avoids overly prescriptive conceptions of the good life, such as ‘successful’ ageing to which not everyone can aspire (see paragraph 2.30). While recognising that there will be some commonly valued capabilities, such as being able to meet basic needs, form relationships, and contribute (see paragraph 5.20 and Box 5.1), the approach encourages us to look beyond the stereotypes of ageing we have critiqued in this report: whether these are of ageing as inevitable decline from an ideal (see paragraph 5.4–5.5), or as intrinsic dependence and vulnerability (see paragraph 5.9). In focusing instead on the ‘beings and doings’ that individuals value in later life, it underlines that “human diversity is no secondary complication to be ignored, or to be introduced later on; it is a fundamental aspect of our interest in equality”.⁵⁵⁰ Moreover, the distinction made between capabilities and functionings brings to the fore the role of choice or agency: while it can be argued that others (such as the state) have duties with respect to providing or enabling opportunities (capabilities), it is a matter for the individual to decide whether and how those opportunities are translated into particular functionings.
- 5.14 An approach based on capabilities and functionings thus contrasts with other approaches to wellbeing that may focus on specific factors such as people’s health or their access to income and material possessions. Importantly, however, it incorporates many of these factors (to the degree that they are relevant to individuals) by situating people and their personal capabilities *within* the social context which they inhabit – including elements such as their lifetime experience of inclusion, exclusion, or discrimination; their social and family relationships; their physical environment; their past and present economic situation; and their health.⁵⁵¹

⁵⁴⁷ Sridhar Venkatapuram provides a helpful overview of different strands of the capabilities approach, and in particular of the different ways it has been developed by Sen and Nussbaum, in his own elaboration of the approach in order to ground a theory of health justice, see: Venkatapuram S (2011) *Health justice: an argument from the capabilities approach* (Cambridge: Polity Press).

⁵⁴⁸ In particular, our choice of language in talking about ‘flourishing’ in older age is not drawn specifically from Nussbaum’s approach to capability, but rather from a long history within bioethics of exploration of the concept of what it is to flourish as a human being. See, for example, Cottingham J (2012) The question of ageing *Philosophical Papers* **41(3)**: 371-96.

⁵⁴⁹ For one detailed discussion of the applicability of the capability approach to ageing, see: Gopinath M (2018) Thinking about later life: insights from the capability approach *Ageing International* **43(2)**: 254-64, on which this part of Chapter 5 draws substantially. See also: Dunn M (2018) Realizing and maintaining capabilities: late life as a social project *Hastings Center Report* **48 (Supplement 3)**: S25-S30; and Falk Erhag H, Lagerlöf Nilsson U, Rydberg Sterner T *et al.* (Editors) (2022) *A multidisciplinary approach to capability in age and ageing*, Volume 31 (Cham, Switzerland: Springer Nature). See also: Ehni HJ, Kadi S, Schermer M *et al.* (2018) Toward a global geroethics - gerontology and the theory of the good human life *Bioethics* **32(4)**: 261-8.

⁵⁵⁰ Sen A (1995) *Inequality reexamined* (Oxford: Oxford University Press).

⁵⁵¹ See, for example, Yeung P, and Breheny M (2016) Using the capability approach to understand the determinants of subjective well-being among community-dwelling older people in New Zealand *Age Ageing* **45(2)**: 292-8, who drew on the New Zealand Longitudinal Study of Ageing to demonstrate the way that such factors played an important role in enabling, or hindering, older adults in drawing on external resources to live in ways that gave them satisfaction.

- 5.15 Whatever a person's talents, interests, and attributes, the genuine opportunities that they have to make use of these, in order to be and do what they value, is inextricably bound up with these social and contextual factors, which have a powerful influence on their ability to function as they wish. Thus, for example, an older adult's genuine opportunity to continue to live alone, where that is a 'functioning' that they value, may be impaired by personal factors such as increasing mobility challenges or by loss of confidence after a fall, but may be supported by external factors such as an accessible and adapted home environment, supportive neighbours, and good local shops. Similar considerations arise from the perspective of family members or friends providing informal care or support for an older adult. A person's ability to provide such support, while still maintaining their own sense of identity and capabilities to achieve desired functionings, will be affected significantly by the extent to which external financial and practical support is available (see paragraphs 5.40–5.41).
- 5.16 As these examples demonstrate, a person's ability to convert external goods or resources into capabilities may be affected by what have been described as **conversion factors**.⁵⁵² For example, the provision of a mobility scooter may not contribute meaningfully to the capabilities of a person with limited mobility if they are not able to ride it, or if the local pavements or roads do not provide a safe environment for using it.⁵⁵³ Similarly, policies designed to enable people to stay in work longer, and hence improve their financial position in retirement, will not achieve their aims in an equitable fashion if they make no provision for people in poor health or who have caring responsibilities.⁵⁵⁴ Prevailing beliefs and attitudes also act as conversion factors: as we have argued throughout this report, ageist assumptions about what it is to be old(er) and negative attitudes to older adults can be powerful factors in affecting both what opportunities are available to older adults, and how we see ourselves as we get older.⁵⁵⁵
- 5.17 **This concept of conversion factors is potentially very useful in bringing to the surface the structural nature of many of the inequalities that affect how we can live well in old age** (see paragraphs 1.20–1.21), **and which risk preventing those who are most in need of resources and services from benefitting from them.** This is particularly important in the context of research and innovation, in the light of the risks that inequitable access to the fruits of such research may, however unintentionally, further exclude already disadvantaged groups and individuals (see paragraphs 4.29–4.31). In particular, it plays an important role in justifying why priority should be given to research and innovation that meets the needs of those who are currently most disadvantaged, by highlighting the extent to which their capabilities can be constrained and limited by external factors outside their personal control.⁵⁵⁶
- 5.18 The capabilities approach continues to be developed and refined for different contexts and with different emphases by various theorists. Two such elements are of particular relevance in the context of older age. The first relates to the importance of thinking broadly about functionings, so that they encompass people's agency as well as their personal wellbeing – recognising that people value being able to act to benefit others, as well as meet their own needs.⁵⁵⁷ A practical example of this is the value placed on **continuing to contribute and be needed**, a theme that emerged strongly in empirical

⁵⁵² Sen A (2009) *The idea of justice* (London: Penguin).

⁵⁵³ Gopinath M (2018) Thinking about later life: insights from the capability approach *Ageing International* **43(2)**: 254–64.

⁵⁵⁴ *ibid.* See also: Tranzo vd Klink (2018) *Development of an instrument to measure sustainable employability: a joint contribution of a consortium*, available at: <https://research.tilburguniversity.edu/en/publications/development-of-an-instrument-to-measure-sustainable-employability>.

⁵⁵⁵ Nelson TD (2005) Ageism: prejudice against our feared future self *Journal of Social Issues* **61(2)**: 207–21.

⁵⁵⁶ This contrasts with seeing the status quo as “sad, tragic, unlucky, or reflecting the personal choice of individuals”, see: Venkatapuram S (2011) *Health justice: an argument from the capabilities approach* (Cambridge: Polity Press), at page 5.

⁵⁵⁷ *ibid.*, at page 131; and Wolff J, and de-Shalit A (2007) *Disadvantage* (Oxford: Oxford University Press), at pages 45–47.

research on capabilities in the context of disadvantage (see also, for example, Box 2.8).⁵⁵⁸ The second highlights the **precarity** of many people's lives, and how indeed this can be a particular feature of older age, as older adults come to terms with changes in their circumstances (see paragraph 2.21). It has been argued that in the context of such precarity, it is important to think about the capabilities approach in terms of people having genuine opportunities for **secure** functionings.⁵⁵⁹

Applying the capabilities approach to research and innovation

5.19 Applying these concepts to the focus of this inquiry, then, we can use the capabilities approach as follows.

- **Consider how specific developments in biomedicine and technological innovation can support older adults' capabilities and functionings – evaluating any such development by reference to its ability to provide genuine opportunities for a person to flourish, and to feel secure in their flourishing.**
- **Explore what social, political, and other action is needed to respond to, or mitigate, the inequalities resulting from the social determinants of health, which may prevent older adults from converting these potentially valuable resources into the capabilities they value.**

5.20 One practical criticism that has been made of the capabilities approach is that it is difficult to operationalise, precisely because it is non-specific about what forms of capabilities should be valued. In response, however, it has been argued that different forms of democratic procedure and deliberation can be used to elicit specific capabilities that matter to groups or individuals in specific contexts, thus illustrating how the capabilities approach and the strong emphasis that has emerged throughout our inquiry on the importance of meaningful partnerships with older people in research can be mutually reinforcing (see paragraphs 4.11–4.19). Moreover, while the value placed on some capabilities and functionings will be highly personal, there are also many commonly valued capabilities – indeed, in the context of political theory, Martha Nussbaum identified ten central capabilities that she argued should be secured for *all* citizens to enable them to flourish, and that should be regarded as rights.⁵⁶⁰ Many others have since produced variations on Nussbaum's categories;⁵⁶¹ and qualitative research with older adults has been used to inform a 'capability index' designed to provide an economic tool for the evaluation of health and social care interventions based on their impact on five capabilities (see Box 5.1).

Box 5.1: The ICECAP index of capability

Economists have drawn on capability theory and on qualitative work exploring with older adults in the UK what matters to them in terms of their quality of life, to develop the 'ICECAP' index of capability.⁵⁶² The index is based on five capabilities.

⁵⁵⁸ Wolff J, and de-Shalit A (2007) *Disadvantage* (Oxford: Oxford University Press), at pages 45-47.

⁵⁵⁹ *ibid*, at page 37.

⁵⁶⁰ Nussbaum M (2011) *Creating capabilities: the human development approach* (Cambridge, MA: Belknap Press of Harvard University Press), at Chapter 2.

⁵⁶¹ See, for example, Alkire S (2002) *Valuing freedoms: Sen's capability approach and poverty reduction* (Oxford: Oxford University Press). For the use of the capabilities approach to develop an instrument to evaluate health and social care interventions, see: Coast J, Flynn TN, Natarajan L *et al.* (2008) Valuing the ICECAP capability index for older people *Social Science & Medicine* **67(5)**: 874-82.

⁵⁶² *ibid*.

- Attachment – feelings of love, friendship, affection, and companionship.
- Role – the idea of having a purpose or ‘doing something’ that is valued, either by the individual and/or by others.
- Enjoyment – notions of pleasure and joy, and a sense of satisfaction.
- Security – feeling safe and secure, not having to worry, and not feeling vulnerable.
- Control – being independent and able to make one's own decisions.

These capabilities have been used to devise measurements of quality of life, which can then be used to compare the effectiveness, and cost-effectiveness, of different health and social care interventions.

5.21 In its detailed *World Report on Ageing and Health*, the WHO has identified a number of functionings and capabilities commonly valued by older adults (see Box 5.2), while also emphasising how the ‘beings and doings’ that people value inevitably differ. **A number of key questions have been suggested for eliciting a range of relevant capabilities in the context of particular groups or populations of older adults, which could usefully be applied when prioritising research agendas.**

- What are the valued capabilities identified by different groups of older people?
- Under what circumstances, and for whom, do social contexts enable and/or constrain capabilities?
- How do inequalities in health influence capabilities in later life and for whom?
- How does age and gender matter in shaping capabilities?
- How does social policy shape and support capabilities that older people have and value?
- What capabilities should be accounted for in social policy considerations?
- What assumptions about older people shape specific social policies and to what extent do these serve to enable or constrain capabilities? ⁵⁶³

Box 5.2: Exploration of capabilities approach in the World Health Organization's *World Report on Ageing and Health*

“The beings and doings that people have reason to value differ among individuals, and change over the course of people’s lives. Although research is limited, some of the things that older people identify as important include having:

- a role or identity;
- relationships;
- the possibility of enjoyment;
- autonomy (being independent and being able to make their own decisions);
- security;
- the potential for personal growth.

Several domains of functional ability appear crucial to allowing people to achieve these ends ... These are the abilities to:

- move around;
- build and maintain relationships;
- meet their own basic needs;
- learn, grow and make decisions;
- contribute.” ⁵⁶⁴

⁵⁶³ Gopinath M (2018) Thinking about later life: insights from the capability approach *Ageing International* **43(2)**: 254-64.

⁵⁶⁴ WHO (2015) *World report on ageing and health*, available at: <https://apps.who.int/iris/handle/10665/186463h>, at pages 29-30.

- 5.22 We return in more detail below (see paragraph 5.52) to the question of how this focus on people’s capabilities, and the structural factors that influence how resources can be converted into capabilities, should help inform the responsibilities and behaviours of those with power to influence research and/or implementation in this field. Before doing so, however, we explore some important related issues concerning relationships, power, and care.

Relationships and power

“Independent Living is not doing everything by yourself; rather, it is being in control of how things are done.”⁵⁶⁵

“When designed well, social care helps to weave together the web of relationships and support that we all need to lead the lives we want to, with meaning, purpose and a sense of belonging.”⁵⁶⁶

- 5.23 In critiquing the way in which dominant approaches to bioethics in the Global North have been built on a ‘persona’ of the independent and self-sufficient self (see paragraph 5.4), we emphasised the importance of reflecting the relational and interdependent nature of human life – throughout the life course – in our ethical reasoning. The growing body of scholarship in this field includes the development of the concept of ‘relational autonomy’, which highlights the importance of taking a holistic approach to the lives and decision-making capacities of older adults – looking at the network within which they live, their relationships and interdependencies, and how they can be supported to make their own decisions even in the context of impaired capacity, rather than assuming they will always be expected to function in isolation.⁵⁶⁷ This approach to autonomy emphasises how all of us, to different degrees and in different ways, share the making of important decisions with those who are close to us and who matter to us. For those older adults whose capacity is impaired, it recognises the role of close friends or family – whether or not taking on a role as ‘carer’ – in ‘holding’ them and anchoring them in their sense of identity.⁵⁶⁸ While the focus in this more nuanced approach to autonomy has primarily to date been concerned with the provision of care and services, it also has a key role to play in research, particularly in the context of the importance of finding ways ethically to include older adults with impaired mental capacity in research that is relevant to them (see paragraph 4.25 and Box 4.7).
- 5.24 In giving pre-eminence to older adults’ capability to form and maintain relationships, and to the role that relationships can play in enabling us to flourish in later life, it is crucial to pay attention to the way that **power** can be exercised in both personal and professional relationships, an issue to which we now turn. It is also essential to be alert to the wide diversity of family structures that exist in the UK – and to be alert to the dangers of assuming that adult children (in particular daughters and daughters-in-law) are

⁵⁶⁵ Center for Disability Rights blog (2022) *What is independent living?*, available at: <https://cdnys.org/blog/advocacy/467/>.

⁵⁶⁶ #socialcarefuture blog (2023) *A long-term framework to transform social care?*, available at: <https://socialcarefuture.org.uk/a-long-term-framework-for-changing-social-care/>.

⁵⁶⁷ This approach formed the basis of the Nuffield Council on Bioethics’ earlier work on the ethical aspects of dementia, building on work by George Agich and others, see: Nuffield Council on Bioethics (2009) *Dementia: ethical issues*, available at: <https://www.nuffieldbioethics.org/publications/dementia>. For a more recent discussion of how such approaches can help shape the law, see: Series L (2015) Relationships, autonomy and legal capacity: mental capacity and support paradigms *International Journal of Law and Psychiatry* 40: 80-91.

⁵⁶⁸ For a personal account of such ‘holding’ or ‘scaffolding’, see: Making rights make sense blog (26 March 2021) *Anchored*, available at: <https://makingrightsmakesense.wordpress.com/2021/03/26/anchored/>.

necessarily available to provide either emotional or practical support to their parents in the ways envisaged.⁵⁶⁹ There is a particular onus on statutory services and policy makers to avoid such assumptions (see paragraph 5.59).

A relational approach to equality

- 5.25 Questions of equity and (in)equality have emerged as central throughout this inquiry. In particular, we have noted the need to pay special attention to the implications of the existing backdrop of socioeconomic inequalities, often linked with ethnicity and discrimination, which strongly influence physical and mental health throughout the life course. Typically, the cumulative impacts of disadvantage and discrimination will be more prominent in older age, and are likely to play a key role in a person's ability to live well in this period of their life. This includes affecting a person's opportunities to 'convert' resources, such as new technologies, into capabilities to live the life they value (see paragraph 5.16).
- 5.26 Socioeconomic and health inequalities are examples of distributive inequality – inequalities in the distribution of material goods. Traditionally, the ideal of equality has been viewed primarily in these distributive terms: a belief in equality has been understood as the belief that there is something, such as income or health, that everyone, so far as possible, should have in equal quantities.⁵⁷⁰ However, in the past two decades, this idea has been challenged by the concept of a **social or relational understanding of equality**. It is argued that equality is a social and political ideal – not about distributions but rather about how individuals relate to each other.⁵⁷¹ These two understandings of equality are not necessarily mutually exclusive, and many theorists embrace a more complex understanding of equality as encompassing both relational and distributive aspects.⁵⁷² We have already touched briefly above on the ethical imperative of addressing distributive inequalities in the way that research and innovation in ageing is prioritised (see paragraphs 5.16–5.17). Here we consider further the relational aspects of equality as they relate to ageing and research concerned with ageing.
- 5.27 The ideal of relational equality has been fleshed out in a number of different ways that are relevant to our inquiry. One key aspect and central focus in the literature is on **social status and relations between individuals**. This includes both how individuals behave towards each other, and attitudes they have about each other. A society of equals has been described as a society that is “not marked by status divisions such that one can place different people in hierarchically ranked categories, in different classes for instance”, and where “people regard and treat one another as equals”.⁵⁷³ In a similar vein, equal social relations have been described as relations that are “unstructured by differences of rank, power or status”.⁵⁷⁴ As we note below (see paragraph 5.30), this concept of equality is not so much a practical political manifesto, as rather a critique of, and challenge to, the way that relationships of power and status affect how we engage with one another. In healthcare, for example, language used unthinkingly by health

⁵⁶⁹ Ageing Without Children blog (11 October 2022) *The perfect storm for people ageing without children*, available at: <https://www.awwoc.org/post/the-perfect-storm-for-people-ageing-without-children>.

⁵⁷⁰ Cohen GA (1989) On the currency of egalitarian justice *Ethics* **99(4)**: 906-44.

⁵⁷¹ Voigt K (2020) *Relational egalitarianism* (Oxford: Oxford University Press). See also: Anderson ES (1999) What is the point of equality? *Ethics* **109(2)**: 287-337; and Schemmel C (2021) *Justice and egalitarian relations* (Oxford: Oxford University Press).

⁵⁷² See, for example, Wolff J, and de-Shalit A (2007) *Disadvantage* (Oxford: Oxford University Press), at pages 3-5; Stemplowska Z (2011) Responsibility and respect: reconciling two egalitarian visions, in *Responsibility and distributive justice*, Knight C and Stemplowska Z (Editor) (New York: Oxford University Press); and Fraser N (1995) Recognition or redistribution? a critical reading of Iris Young's justice and the politics of difference* *Journal of Political Philosophy* **3(2)**: 166-80.

⁵⁷³ Miller D (1997) Equality and justice *Ratio* **10(3)**: 222–37.

⁵⁷⁴ Scheffler S (2005) Choice, circumstance, and the value of equality *Politics, Philosophy & Economics* **4(1)**: 5-28.

professionals about patients – often as shorthand – is increasingly recognised as belittling or demeaning, reflecting unacknowledged differentials in power.⁵⁷⁵ Similar themes are emerging in current debates about the future of adult social care: for example in the suggestion of the need for a “covenant between people, places and government”, embedding more equal relationships with respect to the development and ownership of social policy in this area.⁵⁷⁶

- 5.28 Treating each other as equals has also been linked to the idea of ‘testimonial injustice’.⁵⁷⁷ Testimonial injustice characterises a situation where a hearer disregards or dismisses the testimony of a speaker because of the speaker’s identity, and could be described as an instance of the hearer failing to respect the speaker as an equal.⁵⁷⁸ The lack of attention paid to the views and wishes of many people living in care homes during the COVID-19 pandemic, to which we drew attention earlier, for example, could be categorised as a form of testimonial injustice (see Box 2.9 and paragraph 5.6). Conversely, **respecting another person as an equal involves taking their testimony seriously**. This requires those with power and influence to take active steps to find ways to hear from groups who are routinely marginalised – and to respond to what they hear.⁵⁷⁹
- 5.29 Another important strand in the literature focuses on the implications of the ideal of relational equality for **how social and political institutions should treat individuals**. Institutions can play an important role in creating the conditions that are conducive to individuals relating to one another as equals, for example through the culture and behaviours that they inculcate as employers.⁵⁸⁰ In the specific context of research, for example, earlier work by the Nuffield Council has highlighted how employment factors such as short-term contracts, job insecurity, and pressure to publish have a negative impact on the overall culture of research.⁵⁸¹ Additionally, relational equality implies certain directly applicable requirements of institutions. These include that they “should be equally responsive to the interests and concerns of, and equally accountable to, all citizens”,⁵⁸² and that their actions must express “equal concern and respect” for all individuals as well as a “collective understanding of all citizens as equal members of the state, all equally part of ‘us’”, across differences such as race, ethnicity, gender, and religion.⁵⁸³
- 5.30 A more specific and unified positive account of the ideal of relational equality and its requirements is yet to be provided, and some theorists have expressed scepticism that this can be achieved.⁵⁸⁴ Rather, the most valuable contribution and insight of this perspective may be found in its analysis of the **kinds of relations that are incompatible with social equality**, such as oppression, discrimination, forms of domination, social

⁵⁷⁵ Abbasi K (2022) Mind your language to catalyse the patient revolution *British Medical Journal* **377**: o1071.

⁵⁷⁶ #socialcarefuture blog (2023) *A long-term framework to transform social care?*, available at: <https://socialcarefuture.org.uk/a-long-term-framework-for-changing-social-care/>.

⁵⁷⁷ Fricker M (2007) *Epistemic injustice: power and the ethics of knowing* (Oxford: Oxford University Press).

⁵⁷⁸ Roessler B (2015) Autonomy, self-knowledge, and oppression, in *Personal autonomy and social oppression*, Oshana M (Editor) (New York: Routledge).

⁵⁷⁹ See, for example, Nuffield Council on Bioethics (2020) *Research in global health emergencies: ethical issues*, available at: <https://www.nuffieldbioethics.org/publications/research-in-global-health-emergencies>. For a related discussion in the context of dementia and the importance of responding to people with dementia as ‘thou’, see: Flicker L (1999) Dementia reconsidered: the person comes first *British Medical Journal* **318(7187)**: 880.

⁵⁸⁰ Voigt K (2020) *Relational egalitarianism* (Oxford: Oxford University Press).

⁵⁸¹ Nuffield Council on Bioethics (2014) *The culture of scientific research*, available at: <https://www.nuffieldbioethics.org/publications/the-culture-of-scientific-research>.

⁵⁸² Anderson E (2010) *The imperative of integration* (Princeton, NJ: Princeton University Press), at page 2.

⁵⁸³ Anderson ES, and Pildes RH (2000) Expressive theories of law: a general restatement *University of Pennsylvania Law Review* **148(5)**: 1503-75.

⁵⁸⁴ Wolff J (2015) Social equality and social inequality, in *Social Equality*, Fourie C, Schuppert F, and Wallimann-Helmer I (Editors) (Oxford: Oxford University Press).

exclusion, and stigmatisation.⁵⁸⁵ In one analysis of structural oppression and the consequent disadvantages and injustices it inflicts on affected groups, for example, it is suggested that oppression does not necessarily involve conscious and intentional oppression of one group by another, but may be reflected in the “often unconscious assumptions and reactions of well-meaning people in ordinary interactions, media and cultural stereotypes, and structural features of bureaucratic hierarchies and market mechanisms – in short, the normal processes of everyday life”.⁵⁸⁶ **Thinking about relational equality may thus be particularly valuable in enabling us to identify what structures, systems, and behaviours should be avoided, or need to be amended, because of their detrimental effects (however unintended) on equal relationships, whether between individuals or between institutions and individuals.** One very practical example in which this kind of oppression is routinely exercised, for example, is through the use of language as discussed in Chapter 2 (see paragraph 2.17 and Box 2.5) and above (see paragraph 5.27).

- 5.31 This relational equality perspective is closely affiliated with many of the key questions of (in)equity that underpin our inquiry. We suggest that it provides a useful lens, alongside that of the capability approach, through which to explore the ethical implications of the way that developments in biomedical science and technology may affect relationships in later life. It is particularly valuable in **bringing to the surface often hidden questions of unequal power relationships**, prompting us to consider either what might be required to rebalance these, or (as we discuss further below – see paragraphs 5.34–5.43) how to ensure that relationships of care that may have intrinsically unequal aspects are not thereby oppressive.
- 5.32 A key concern that has arisen throughout our inquiry has been the need to **challenge ageism and ageist assumptions**. As we saw in Chapter 2 (see paragraphs 2.15–2.19), typical characterisations of the ‘problems’ of ageing will often be based on discriminatory assumptions about old age, such as in the frequent discounting of older adults’ contributions to society when they are not part of the paid economy. Ageism can also be reflected in the neglect or marginalisation of older adults’ interests, in denigrating attitudes about older adults such as patronisation or victimisation, or simply in assuming that all older adults are the same. Thinking about the role that biomedical science and technological innovation can play in supporting people’s capabilities to live the life *they* value is one important tool in pushing back against ageist assumptions about the needs and preferences of older adults (see paragraph 5.19). Another, drawing on this discussion of relational equality, is to ask explicitly how a proposed development, innovation, or policy will affect power relationships between older adults and the institutions or individuals on whom they draw for support. **A key question for any researcher to ask is, therefore, to what extent will the particular technology, or medical intervention, enhance the control that older adults have over their lives, and support them in more equal relationships with those around them?**
- 5.33 Relatedly, questions about intergenerational equity go beyond questions about distributions of material benefits and costs between the generations, such as income, healthcare, or workforce participation, to encompass **questions about social status and how different generations relate to and regard one another**. Participants in our public dialogue strongly emphasised the importance of intergenerational interactions in sharing knowledge and learning from one another, changing attitudes of younger people

⁵⁸⁵ Young IM (1990) *Justice and the politics of difference* (Princeton: Princeton University Press); Anderson ES (1999) What is the point of equality? *Ethics* **109**(2): 287-337; and Anderson E (2012) Equality, in *The Oxford handbook of political philosophy*, Estlund D (Editor) (Oxford: Oxford University Press).

⁵⁸⁶ Young IM (1990) *Justice and the politics of difference* (Princeton: Princeton University Press), at page 41.

towards older adults, and challenging ageist assumptions.⁵⁸⁷ The general value of such connections in enhancing understanding of ageing and promoting intergenerational friendships similarly emerged as a strong theme in the intergenerational roundtable discussions we held in Exeter. Cross-generational social activities, places such as churches, and volunteering opportunities that bring people of different ages together were all highlighted as playing an important role in people's lives, especially for older adults without close family, and younger people without grandparents living nearby.⁵⁸⁸

Care ethics and its implications for research

- 5.34 In exploring the concept of a 'society of equals' (see paragraph 5.27), and the associated focus on how biomedical research and technological innovation can support older adults in being in control of their lives, it is also crucial to recognise how equal power relationships will not always be possible. Many relationships of care have inherently unequal aspects, for example with respect to knowledge and understanding of the likely trajectory and treatment of a particular medical condition, or with respect to the relative powerlessness of a person who depends on the support of others for fundamental physical needs. The way that support needs are planned for and met (e.g., through the employment of 'personal assistants' by adults with physical disabilities, terminology which strongly challenges traditional assumptions about 'carers') can do much to minimise the impact of unequal power relationships on those drawing on care or support to live their lives.
- 5.35 However, there is also an important strand of thought, under the rubric of 'care ethics' or an 'ethic of care', that seeks to understand and promote the positive aspects of this caring relationship as part of a wider shift within bioethical thinking that emphasises the emotional and psychological aspects of moral thinking.⁵⁸⁹ Recognising that dependent relationships are fundamentally part of the human condition, care ethics seeks to analyse what responsibilities might be associated with providing that care, to ensure that inherent imbalances of power are managed in ways that are positive both for those receiving and for those giving care, through continuing to promote the ideal of 'equal voice' regardless of dependency.⁵⁹⁰ As such, it is an important aspect of ethical reasoning that takes account of ageing and (inter)dependency as a fundamental feature of human life (see paragraph 5.10). Strikingly, as noted above, empirical work exploring what might constitute universal core capabilities drew out the fundamental human importance of being able express care for, and be attentive to, others (see paragraph 5.18).
- 5.36 In the context of ageing, care ethics focuses on **relational dimensions of ageing** and on concepts of **vulnerability, dependence, and non-abandonment**, and can be captured in the notion that "dependency relationships generate responsibilities".⁵⁹¹ Important elements of care ethics that help elucidate the nature of those responsibilities include **the role of sympathy and directly attending to concrete features of**

⁵⁸⁷ Nuffield Council on Bioethics (2023) *Public dialogue report on the future of ageing*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/public-dialogue-on-the-future-of-ageing>, at page 8.

⁵⁸⁸ Nuffield Council on Bioethics (2022) *Intergenerational roundtable event in Exeter*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing>.

⁵⁸⁹ Care ethics emerged from critiques of justice-focused approaches to moral development and was originally developed by scholars such as Carol Gilligan (1982), Nell Noddings (1984) and, later, by Kittay (1999, 2002), Slote (2007) and others.

⁵⁹⁰ See, for example, Ethics of Care (2011) *Carol Gilligan interview*, available at: <https://ethicsofcare.org/carol-gilligan/> where Carol Gilligan strongly emphasises this aspect of 'equal voice' alongside other aspects of care ethics that tend to receive more attention.

⁵⁹¹ Collins S (2015) *The core of care ethics* (London: Palgrave-Macmillan).

situations; caring attitudes; and responsiveness to the care needs of others.⁵⁹²

These are complemented by a focus on human dignity, with its emphasis on ‘recognition’ and the value of all humans. The lens of care ethics has the potential, then, to describe and illuminate our human-to-human relationships in the context of our ageing bodies. It stands in stark contrast to the idea of care as a set of services or tasks, which can be ‘packaged’ and ‘delivered’ in 15-minute slots.

- 5.37 Given the vast diversity of contemporary societal ageing it is unsurprising that there are significant differences in older adults’ engagement with care. Many live independently, and may make significant contributions to the care of others: this includes through family relationships (caring, for example, for partners or for their own parents, providing childcare for grandchildren, or contributing financially to care costs); and in the wider community (whether within the paid workforce or in a wide range of voluntary roles).⁵⁹³ Others experience, to different degrees and at different times in later life, the impact of life-limiting health conditions, disability, and frailty, that may lead to the need for support or care from others – while often still continuing to provide support themselves, particularly for a partner. These different experiences and aspects of care have been categorised into four dimensions or phases of care, including the concept of ‘caring about’: these illustrate the complexity and reciprocal nature of many caring relationships (see Box 5.3).⁵⁹⁴

Box 5.3: Dimensions of care

- **Caring about** – recognising that care is necessary and involves having concern
- **Care-giving** – delivering care to another.
- **Taking care of** – taking responsibility for care of another, for example, in arranging care and support.
- **Care-receiving** – being on the receiving end of care.

- 5.38 Crucially, these reciprocal aspects of care, and the recognition of the many ways in which care can be proffered and expressed, strongly challenge the notion that being older, and in need of some form of care and support, is necessarily and negatively associated with being a burden on others. Care ethics helps illustrate how such relationships between older adults and caregivers (whether professional or informal) can shift from a dependency-led approach to something more approaching a partnership “where caregiver and care recipient are both participants engaged in a shared, social process of exercising their agency together or alongside each other”.⁵⁹⁵ It also highlights the multiple nature of the roles being played simultaneously by older adults: a person who is receiving care may also be proffering it to others, and will almost always be ‘caring about’ others. As we discuss below, technological innovations can potentially play an important role in such partnerships – including by supporting caregivers in their own exercise of care, and in some cases providing preferred alternatives to human assistance, particularly where privacy is at stake.⁵⁹⁶

⁵⁹² Gallagher A (2017) Care ethics and nursing practice, in *Key concepts and issues in nursing ethics*, Scott PA (Editor) (Cham: Springer International Publishing); and Tronto J (1993) *Moral boundaries: a political argument for an ethic of care* (New York: Routledge).

⁵⁹³ The King’s Fund (2021) *Key facts and figures about adult social care*, available at: <https://www.kingsfund.org.uk/audio-video/key-facts-figures-adult-social-care>.

⁵⁹⁴ Tronto J (1993) *Moral boundaries: a political argument for an ethic of care* (New York: Routledge).

⁵⁹⁵ Dunn M (2018) Realizing and maintaining capabilities: late life as a social project *Hastings Center Report* **48 (Supplement 3)**: S25-S30.

⁵⁹⁶ See, for example, #socialcarefuture (2021) *Reach for the stars*, available at: <https://socialcarefuture.org.uk/reach-for-the-stars/>.

- 5.39 A further important perspective associated with this reciprocal aspect of care is provided by the Islamic ethical understanding that caregivers are spiritually *indebted* to care receivers: the opportunity to provide care is seen as having parallels with charitable giving, where those who give charity are grateful to those who receive for enabling them to fulfil a debt that is owed.⁵⁹⁷ Such an approach again helps disrupt and challenge assumptions about the nature of a care relationship, and reinforces how complex and nuanced the balance of power and obligation can be between those who give and receive care.⁵⁹⁸
- 5.40 It is also essential to recognise that providing and receiving care can be challenging – particularly where those providing informal care and support for older adults do not have adequate support themselves, or where they are expected to take on caring roles because of the lack of other sources of care, regardless of their own personal circumstances and preferences. Both paid and informal care is predominantly provided by women, and the work involved – both emotional and practical – is routinely overlooked and under-rewarded.⁵⁹⁹ A core aspect of care ethics is that of respect and recognition for the work involved in giving care, highlighting the responsibilities of others (particularly the state) with respect to reciprocal duties to ensure that those providing care are adequately supported and recognised in return.
- 5.41 While most attention within care ethics has, unsurprisingly, focused on the practice of care, a number of elements in the brief account above provide important steers towards the development of an ethical approach to research and innovation in the context of ageing. In particular, in foregrounding the essential role of human relationships in the giving and receiving of care, it provides a clear steer as to the proper focus of technological innovation in the field of assistive technologies. The aim of such technologies must be to support older adults to live the lives they value, and to enhance the way that care can be provided and received, without jeopardising or undermining valued relationships. Where appropriate, the aim could, and should, also be to support carers in their role of providing care, enhancing their own opportunities to flourish (see paragraph 5.15). In cases of potential conflict between those sets of interests, it will be important always to keep both in mind: neither can simply trump the other.
- 5.42 More broadly, in the context of biomedical research (and particularly in research concerned with earlier diagnosis and treatment of age-related conditions), care ethics reiterates the importance of a nuanced understanding of the impact such diagnoses may have on people's lives. Being classed as a lifelong 'patient' on the basis of an early diagnosis, or indeed on the basis of an assessment of high risk of developing a particular condition, has consequences, many of which may lie outside the health and care sector, such as access to financial products or travel insurance. However, it also changes relationships within that health and care sector, creating scope for vulnerability and dependency that would not otherwise have been experienced in the same way. Care ethics prompts us to think, in advance of creating systems that entail such new

⁵⁹⁷ Sahih Muslim Book 6 Hadith 101, available at: <https://sunnah.com/muslim:720>; and Sahih al-Bukhari Book 56 Hadith 106, available at: <https://sunnah.com/bukhari:2891>.

⁵⁹⁸ See the discussion of dependency in the WHO's World Report: WHO (2015) *World report on ageing and health*, available at: <https://apps.who.int/iris/handle/10665/186463>, at page 68.

⁵⁹⁹ Peters M, Rand S, and Fitzpatrick R (2020) Enhancing primary care support for informal carers: a scoping study with professional stakeholders *Health and Social Care in the Community* **28(2)**: 642-50. See also: House of Commons Library (2022) *Informal carers*, available at: <https://researchbriefings.files.parliament.uk/documents/CBP-7756/CBP-7756.pdf>, at page 8.

relationships, of the responsibilities that arise as a result, in particular of how such early interventions can be managed in ways that empower the individual.

5.43 Finally, care ethics draws our attention to the practices of researchers and research teams and the nature of the encounter between researchers and participants, including responsibility to those who might be excluded from research participation. In particular, it points to the central role of respectful and sensitive relationships between researchers and participants – particularly where the situation of potential participants puts them at risk either of exclusion or of exploitation because of factors such as impaired cognitive abilities, limited mobility, socioeconomic disadvantage, or other kinds of social inequality.

Trustworthiness and sustainability

5.44 Questions of **trust and trustworthiness**⁶⁰⁰ emerged strongly in the working group's engagement with older adults and in our intergenerational public dialogue regarding perceptions of ageing-related research and innovation (see paragraphs 4.42–4.45). Aside from much broader questions of trust in research processes themselves,⁶⁰¹ issues raised with the working group that were specific to the outcomes of research concerned with ageing included the following.

- Distrust or suspicion with respect to the **motivations** lying behind many areas of research or innovation: for example with respect to the commercial drivers of some research, and the uses to which data obtained through technologies such as remote monitoring might be put by others. Such concerns might relate to fear of actual harm (e.g., that data could be misused or devices brought to market without proper checks and balances), or more broadly to an awareness of how interests other than user benefit may be driving stakeholders.
- **Lack of trust in one's own ability** to cope with increasingly digital systems – for example without getting locked out through complicated password requirements or being scammed.
- In parallel with this self-doubt, lack of trust that such systems will be **designed in ways that are accessible** and usable by non-experts, or that they will be **sufficiently reliable** to provide the continuing support required.
- Lack of trust or confidence in the **claims made about likely future benefit** of innovative approaches – for example with respect to earlier diagnosis of age-related conditions, or preventative approaches to good health based on interventions emerging from geroscience. This might be based on wider attitudes or beliefs about scientific procedures and the way that evidence is obtained and interpreted; or on more specific concerns about who is making the claims and the motivations behind these claims.⁶⁰² There can also be an important distinction between confidence in the likely value of the research to the wider population, and its likely applicability to oneself.⁶⁰³
- Lack of trust or confidence **that promises will necessarily be honoured** – for example that effective treatments or services will be provided in response to earlier

⁶⁰⁰ For a discussion of the relationship between trust and trustworthiness, see: O'Neill O (2018) Linking trust to trustworthiness *International Journal of Philosophical Studies* **26(2)**: 293-300.

⁶⁰¹ We recognise that wider questions of trust in the whole endeavour of research are also important. See, for example, discussions of trust in children and clinical research: Nuffield Council on Bioethics (2015) *Children and clinical research: ethical issues*, available at: <https://www.nuffieldbioethics.org/assets/pdfs/Children-and-clinical-research.pdf>.

⁶⁰² See, for example, the discussion of public trust in vaccine development: Nuffield Council on Bioethics (2021) *Vaccine access and update*, available at: <https://www.nuffieldbioethics.org/assets/pdfs/Vaccine-access-and-uptake.pdf>.

⁶⁰³ See, for example, the discussion of defining the purpose of genetic test evaluations: PhG Foundation (2007) *Moving beyond ACCE: an expanded framework for genetic test evaluation*, available at: <https://www.phgfoundation.org/media/109/download/Moving%20beyond%20ACCE.pdf?v=1&inline=1>.

diagnosis, particularly in the context of resource pressures in the health and care services.

- 5.45 These concerns, or claims, highlight a number of distinct aspects of trust, covering relationships with, or attitudes to, inanimate objects and one's own abilities to engage with them, systems, services, and people. Reliance on a particular object or technology to function as expected is generally distinguished from trust, on the basis that trust inherently involves making oneself vulnerable to the actions or behaviours of others.⁶⁰⁴ However, in the context of many of the assistive, monitoring, and communications technologies covered in this inquiry, it could be argued that a decision to rely on the technology itself does indeed engage vulnerability because of the potential personal or health consequences of malfunction – for example if relying on remote monitoring in place of in-person check-ups. Moreover, reliance on these technologies is necessarily also associated with the perceived trustworthiness of those responsible for developing and maintaining the technology, and, importantly, the trustworthiness of the wider system within which it is used. Thus, for example, the extent to which potential users of a new technology may be willing to use it are likely to be associated with their trust in:
- the supplier, for example through brand recognition or other association with quality;
 - the regulatory systems that purport to provide assurance that a particular technology is safe and fit for purpose;
 - the context in which it is being offered, for example whether this is within the NHS, on general sale in shops, or through targeted commercial marketing; and
 - any relevant relationships – for example if the technology is recommended by a known and respected health professional, family member or friend, or will be used in the context of an ongoing relationship with a trusted professional.
- 5.46 These interconnected questions, of trust in the ability of a particular technology reliably to deliver what is promised, in the context of systems and relationships that also need to demonstrate their trustworthiness, also apply to developments arising out of biomedical research. The promises of benefit deriving from geroscience (see paragraph 3.6) rely heavily not only on the evidence emerging from the research itself, but also on people in the future being willing to take novel medications, perhaps decades before actually experiencing any symptoms or difficulties. Similarly, if claims as to the benefits of earlier diagnosis are not realised, or if support is not available in response to such earlier diagnosis (see paragraph 3.40–3.41), then people would have little reason to come forward – indeed, very good reason for not doing so. The risks of over-promising in such circumstances are two-fold: both that potential benefits of living longer with lesser engagement with care services may be lost, and that valuable resources (in terms of money, time, and indeed public trust) may be squandered in promoting benefits that prove to be illusory.
- 5.47 What, then, might be needed to help engender the (well-founded) trust necessary, so that any benefits arising out of biomedical or technological research aiming to enable people to live better in older age can be realised? **We suggest that the starting point for demonstrating trustworthiness (on the part of the many and various stakeholders in this field) is that of the *motivations* that underlie the research and innovation agenda itself, alongside the *manner* in which research is conducted and its outcomes are then made available to wider publics.** Research and innovation

⁶⁰⁴ Baier A (1986) Trust and antitrust *Ethics* **96(2)**: 231-60; and Segers S, and Mertes H (2022) The curious case of “trust” in the light of changing doctor–patient relationships *Bioethics* **36(8)**: 849-57.

that takes as its starting point the needs and wishes of its target audience, and is guided by the question of what will best provide genuine opportunities for a person to flourish in older age, is well placed to earn trust in its outputs (see paragraph 5.19). Similarly, both research itself, and the translation of that research into practice, is most likely to be seen to be worthy of trust if it has involved its target audience (with due regard for the diversity of potential users and beneficiaries) throughout the process. Those responsible for setting the research agenda (particularly funders, both public and private), and for influencing how new technologies and treatments are then made available, will need to be able to demonstrate how they have been guided by concern for promoting flourishing in older age, with a particular focus on addressing conversion factors that affect how those who are currently most disadvantaged may be able to benefit (see paragraphs 5.16–5.17).

- 5.48 At the individual level, it will be important for novel treatments or technologies to be suggested in the context of a trusted and equal relationship with health or care professionals; in the context of choice (including the genuine option of non-technological alternatives); and with the assurance of any necessary continuing support (see paragraph 5.32). At the level of policy, regulatory systems need to be fit for purpose so that marketing authorisations of novel interventions can be relied upon: not only with respect to safety but also with respect to their underlying purpose, providing clarity as to whom they will benefit, and how this has been evidenced. And underpinning all these considerations lies the importance of an **ethic of responsible promising** on the part of all stakeholders: the need for all concerned, from governments and funders (both public and private) to individual research teams and service providers, not to promise what they cannot deliver.
- 5.49 Implicit in our concern with the trustworthiness of the products, systems, and relationships that underlie research and innovation in the field of ageing, is the question of their **sustainability**: the extent to which these can be relied upon and be maintained over time, at both the individual and societal level. As we noted above (see paragraph 5.18), precarity can be an important feature of older age, as both social and biological changes force a reassessment of what matters most in one's life. At the level of the individual, confidence in the sustainability of the supports and services (whether formal or informal, technological or human) that enable older adults to continue the 'beings and doings' they value, is essential for secure functioning.
- 5.50 At a policy level, questions of sustainability arise in multiple ways. The possible benefits of geroscience are predicated on the idea of intervening earlier in the way that our bodies age, in order to reduce the impacts of biological ageing on our later lives. If successful, this offers positive prospects of reducing the extent to which people need to draw on care and support from others to live their lives as they get older. However, it also potentially medicalises people's lives from middle age onwards, or even earlier, with implications not only for people's preferences and willingness to accept such interventions, but also for the infrastructure and the continuing costs entailed. Similarly, any innovations in the earlier diagnosis of common age-related conditions (including the early detection of elevated risk) will only be able to offer actual benefit if earlier interventions are both effective and available. These long-term commitments inevitably raise the question of how affordable – and hence sustainable – they would be long term. Policymakers who are emphasising the future benefits of these areas of research need to address the risk of creating systems that may simply be unaffordable in the future – or indeed that might divert resources from other recognised needs, including those of older adults currently in need of support. Building such considerations (and planning) into the research agenda is an ethical imperative.

5.51 Beyond questions of financial sustainability lie even more fundamental questions of the sustainability of physical resources and the link with the climate crisis (see Box 2.3). This consideration brings added weight to the ethical importance of **prioritising preventative approaches, at all stages of life**: by definition, these will always be more sustainable at both personal and societal level than lifelong medical intervention, or belated response to acute crises.⁶⁰⁵ We have drawn attention earlier to the very low priority given to preventative research (see paragraph 2.13) despite the strong evidence base for the significant role that preventative approaches, throughout the life course, can play in enabling us to live well in later life. There is a clear need for research funders (including those who drive the commercial innovation agenda in this space) to start ensuring that questions of sustainability, in terms of physical as well as financial resources, play a central role in decisions about research priorities. We return to this issue in the next chapter (see paragraph 6.38 and Recommendation 11).

Thinking about responsibilities

5.52 Drawing all the threads together from across the discussion in this chapter, we put forward the following claims that we suggest should underpin the use of biomedical developments and technological innovation in response to the needs of older people.

- Ethical reasoning needs to take into account that **ageing is a fundamental feature of human life** – not some kind of aberration from an idealised ageless norm. The **equal human worth of all older adults** must be the starting point of any research and policy in this field.
- The **diversity of older adults needs to be explicitly recognised in all ageing-related research and associated policy/implementation**: this includes the diversity of their background and experiences (both lifelong and in older age); of their contributions to the care and support of others; and of their own evolving needs for care and support.
- Developments in any of the areas of biomedicine and technology covered within this inquiry should be **evaluated by reference to their ability to enhance genuine opportunities to flourish**. An approach to research and innovation **founded on coproduction involving people of all ages and representing a broad range of backgrounds and experiences** will be essential in order to achieve this, particularly given the diversity of situation and goals that will influence any individual's ability to flourish.
- **Research and innovation cannot take place in a vacuum**: the scope for particular interventions, goods, or services to provide genuine opportunities to flourish will be strongly determined by structural factors including lifelong discrimination, economic situation, local environment, and social support. These factors need to be taken into account throughout the research process, with the **aim of prioritising initiatives that will reduce, not increase inequalities in older age**. They will also need to be at the forefront of policy considerations when rolling out innovations that are shown to be beneficial.

⁶⁰⁵ We recognise that there cannot be an absolute 'bright-line' distinction between prevention and treatment (with diet and exercise, for example playing a role in both).

- Of central concern is the risk that unequal power relationships, whether between older adults and institutions, or older adults and other individuals, lead to oppression, discrimination, forms of domination, social exclusion, or stigmatisation. A key question to ask with respect to any proposed novel intervention or technology should be **how it will enhance the control that older adults have over their lives and support them in more equal relationships with those around them.**
- The essence of care is found in caring relationships and cannot be reduced to 'packages of care' that can be delivered in timed segments. A care ethics approach highlights how dependency relationships generate responsibilities, with an emphasis on the role of sympathy and directly attending to concrete features of situations; caring attitudes; and responsiveness to the care or support needs of others. **The contribution that technological developments may make to providing care should thus be understood with reference to how technology can support, not replace, important human relationships.** A key element of such responsiveness is sensitivity to circumstances where technological approaches may indeed be preferred, particularly where they can help support privacy. Technology may also provide much needed support for both paid caregivers and informal carers, potentially freeing up time which can be spent in ways that enable both older adults and those supporting them to flourish.
- Research processes, the new interventions that are developed as a result of that research, and the way that these interventions are made available to the wider public all need to be demonstrably **trustworthy**. They also need to be **sustainable** in the resources they consume – including in terms of energy, time, and finance.

5.53 As indicated in the diagram opposite, these claims can be presented in the form of an ethical framework and tool to help all those concerned with the development, conduct, and implementation of research relating to living well in older age to think through the ethical implications of their work.

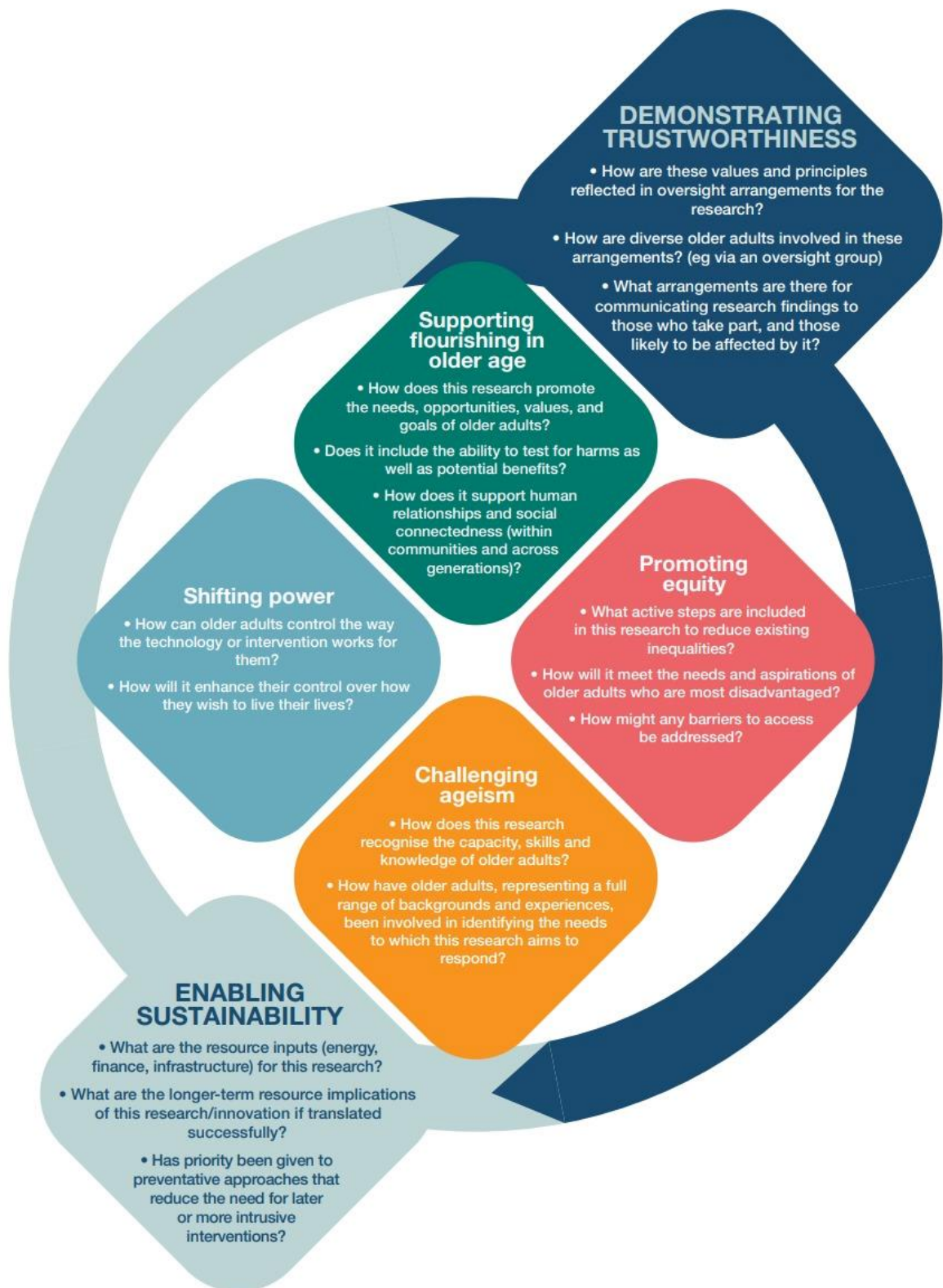


Diagram by Lou Dunn.

Applying those responsibilities

“A careful balance should be struck between personal, environmental and societal roles in terms of improving the health outcomes of the country in an equitable manner.”⁶⁰⁶

“Policy-makers have a pivotal role in directing how innovations are developed and used for health to maximise benefits – and minimise harms – for individual groups and society.”⁶⁰⁷

“[L]ate life is best understood as a ‘social project’ – an aspect of all of our lives that we are all invested in, and for which we all have diverse, everyday responsibilities.”⁶⁰⁸

“The way that responsibilities are exercised by others may also have a significant impact on individual freedoms. Decisions by the Government, by regulatory authorities, by individual care homeowners, and by insurers, during the COVID-19 pandemic have had a very direct impact on care home residents’ abilities to make their own choices – for example preventing them from deciding for themselves how to balance their risk from infection with the importance of remaining in direct contact with family and friends.”⁶⁰⁹

5.54 Making ethical claims makes no difference to people’s lives if there are no means by which these claims can be translated into action in the real world. This highlights the crucial importance of identifying both *where* relevant responsibilities lie, and then whether the systems and structures through which those responsibilities can be exercised (including willingness to act and to commit adequate resources) are fit for purpose. In an earlier inquiry concerned with research in global health emergencies,⁶¹⁰ the Nuffield Council on Bioethics made a strong argument for recognising a wide range of ‘duty-bearers’ with responsibility for the ethical conduct of research. In particular, we argued that the policies and practices of bodies such as governments, research funders, research institutions, and journals, have a powerful effect on the scope for researchers ‘on the ground’ to act ethically – and also for the outcomes of research to be translated into practice in an ethical manner.

5.55 In the context of research concerned with ageing, the evidence presented throughout this report suggests that the range of ‘duty-bearers’ in this field is similarly wide – especially when considering not only the research process itself, but also extending our view to the broader context and aim of enabling and empowering people to live as well as possible in later life. Critically, while we return to the roles and responsibilities of individuals, we argue that it is crucial to recognise both the limitations of those responsibilities, and the way that they interlock with, and depend upon, the responsibilities of many other stakeholders. Below we make the case, briefly, for who

⁶⁰⁶ The Academy of Medical Sciences, responding to our call for evidence.

⁶⁰⁷ Dr Philippa Brice, PHG Foundation, responding to our call for evidence, citing PHG Foundation (2018) *My healthy future: healthy ageing workshop*, available at: <https://www.phgfoundation.org/media/269/download/mhf-older-people-workshop-outcome.pdf?v=1&inline=1>.

⁶⁰⁸ Michael Dunn, responding to our call for evidence.

⁶⁰⁹ Alex Ruck Keene, responding to our call for evidence.

⁶¹⁰ Nuffield Council on Bioethics (2020) *Research in global health emergencies: ethical issues*, available at: <https://www.nuffieldbioethics.org/publications/research-in-global-health-emergencies>.

these ‘duty-bearers’ are, and the nature of their responsibilities, before moving on in Chapter 6 to make specific recommendations for action.

- 5.56 Starting with the role of the state, in the form of the government and public sector, we draw on other work by the Nuffield Council, concerned with the ethics of public health,⁶¹¹ to **highlight the enabling role of the state, in providing the conditions that make personal/familial choices and agency possible**. Many of the areas of action identified earlier as key in enabling people to live longer in good health, and to flourish despite declining health (see paragraphs 1.19–1.24), fall quite outside scope for individual influence, and require public policy action. These include, for example, aspects of housing and environmental planning, transport infrastructure, and employment, welfare, and pensions policies, as well as the adequacy of health and social care provision.
- 5.57 In the light of our earlier discussion of the capabilities approach, we develop this argument further by arguing for the state to recognise its **duty to facilitate a society where older people are able to realise their capabilities and pursue their life plans, and hence have genuine opportunities to flourish**. One self-evident way in which this responsibility can be exercised is through the priority given to the many environmental and social factors highlighted above – and no policymaker concerned with responding to the needs of an ageing society can afford to ignore them. In our specific context of research and innovation, factors such as accessible housing and local environments, adequate income in retirement, and health and care services that provide preventative, and not simply crisis, care, are powerful examples of the ‘conversion factors’ necessary to enable older adults to take advantage of any offered innovations in medicine and technology in order to flourish.⁶¹²
- 5.58 Characterising these wider environmental and social factors as ‘conversion factors’ also reiterates a further important duty of the state, put forward in our work on public health: that of aiming to **reduce unfair health inequalities within the population**.⁶¹³ As we discussed above, consideration of conversion factors brings to light *structural* inequalities that disadvantage particular individuals or groups. Given the public policy emphasis placed on the role of science and innovation in helping meet the aim of reducing inequalities in healthy life expectancy (see paragraph 1.4), there is a particular onus on government to take seriously the risk that some developments and innovations may actually make these inequalities worse – and to be prepared to prioritise action necessary to prevent this. One very practical example of this would be in responding to the realities of the digital divide, and the real-life consequences for a significant minority of people of being excluded from digital services for reasons such as cost, accessibility, or lack of confidence.⁶¹⁴
- 5.59 In emphasising the role of the state in this way, it is important to reiterate that this does not equate to all services being provided by the state, or, indeed, for the pattern of those services being imposed in a ‘top-down’ manner. There is a crucial role for local

⁶¹¹ Nuffield Council on Bioethics (2007) *Public health: ethical issues*, available at: <https://www.nuffieldbioethics.org/publications/public-health>.

⁶¹² See, for example, Dunn M (2018) Realizing and maintaining capabilities: late life as a social project *Hastings Center Report 48 (Supplement 3)*: S25-S30, where a powerful argument is made for adequate investment in health and social care in order to support older adults’ capabilities. Dunn further emphasises that *how* these services are made available is key: if they are genuinely to support older adults maintain capabilities they value, then they need to enable older persons to exercise their ‘navigational agency’, rather than simply to facilitate their participation in a set of fixed social activities.

⁶¹³ Nuffield Council on Bioethics (2007) *Public health: ethical issues*, available at: <https://www.nuffieldbioethics.org/publications/public-health>, at paragraph 2.44.

⁶¹⁴ See, for example, Department for Health and Social Care (2022) *A plan for digital health and social care*, available at: <https://www.gov.uk/government/publications/a-plan-for-digital-health-and-social-care/a-plan-for-digital-health-and-social-care>.

communities, including local government, the voluntary sector, and self-organised groups such as ‘community circles’⁶¹⁵ in the provision of appropriate support, based around the needs and personal situation of each older adult. However, national policymakers do play a key role in setting the overarching policy and approach: with respect to the research and innovation agenda (e.g., see, Box 1.1); with respect to the manner (top-down or bottom-up) in which policies around care and support, including the role to be played by technological innovation, are determined;⁶¹⁶ and, crucially, with respect to the overall resources to be made available. In thus setting the frame and resources in which services will be delivered, it is particularly important that national policymakers keep in view the rich diversity of ageing within the UK, and are careful to avoid assumptions about the automatic availability of family support that disadvantage and jeopardise the wellbeing of the many older adults in the UK without such support.⁶¹⁷

5.60 Other important stakeholders who could be characterised as ‘duty-bearers’ include the following.

- The many elements that make up the **research sector**: those involved in **research policy (funders, regulators, ethics committees, and journals)** who exercise power over what research gets done or published, and how that research gets done; **research institutions** who strongly influence the culture in which researchers operate; and **research teams** themselves.
- **The commercial sector**: both at the level of individual research- and innovation-led companies who can choose to be part of solutions rather than part of the problem;⁶¹⁸ and across the sector, building on initiatives such as Business for Health (see Box 2.2) to recognise the multiple ways in which the private sector influences health and wellbeing across the life course, not least as employers.
- **Health and care providers** whether public, private, or third sector: in the way they understand their responsibilities in supporting older adults to flourish, rather than simply in delivering ‘packages of care’; and in the institutional culture they create that supports or hinders relational equality with those who draw on their services.
- **Professional institutions** including those responsible for professional education, who set standards and expectations for health and care professionals, and thereby play a key role in the culture in which services are provided to older adults.

5.61 In addition to these institutional or professional duty-bearers, we suggest that **all of us** have a stake in ageing, and in how our society responds to the opportunities and challenges of longer life. As older adults, families and friends, we all have a degree of responsibility in how we navigate the role of innovative technologies and medical developments in our lives. But this responsibility is not limited to later life: the life-course approach highlights how we need to think from early adulthood onwards about the responsibilities we all have to our future selves, taking responsibility for the choices we

⁶¹⁵ Community Circles (2022) *How we work*, available at: <https://www.community-circles.co.uk/>.

⁶¹⁶ See, for example, #socialcarefuture (2022) *How can community power create a brighter social care future?*, available at: <https://socialcarefuture.org.uk/how-can-community-power-create-a-brighter-social-care-future/> for a robust critique of traditional top-down thinking about social care.

⁶¹⁷ See, for example, the critique by the organisation Ageing Without Children, of claims by successive secretaries of state for health and social care that “Health and social care begins at home. Family first, then community, then the state.”: Ageing Without Children (6 October 2021) *New charity launches to help those ageing without family*, available at: <https://www.awwoc.org/about-3-2>.

⁶¹⁸ See, for example, the parallel discussion of the role of private companies providing cosmetic procedures: Nuffield Council on Bioethics (2017) *Cosmetic procedures: ethical issues*, available at: <https://www.nuffieldbioethics.org/assets/pdfs/Cosmetic-procedures-full-report.pdf>.

make where we do have genuine agency and control, while also recognising the many ways in which our lives are shaped by external factors over which we have relatively little influence. More broadly, it has been argued that a new social compact is required “in which population aging is held to be a shared ethical concern ... [and in which] each and every member of a society will recognize that they possess wide-ranging justice-related duties to ensure that older people are provided with real-world opportunities to exercise their agency in the world.”⁶¹⁹ We return in our final chapter to the way in which this claim intersects with the enabling role of the state (see paragraphs 6.5–6.11 and Recommendation 2).

5.62 Drawing on the suggested need for a ‘new social compact’, we offer some final reflections on intergenerational thinking. There are many important reasons for taking a life-course approach to ageing – in terms of how as individuals we understand and engage with the way our bodies are ageing; of how we all (whatever our age) act as citizens, relatives, and friends in relation to older adults within our society, not least in continuing to recognise the contribution they make; and of how the many duty-bearers listed above exercise their responsibilities to promote policies and deliver services in ways that enable everyone to flourish in later life. This perspective also provides an emphatic answer to concerns about intergenerational inequity and the alleged unfairness of prioritising the needs of one generation over another. Quite apart from the fact that we will all, one day, be old (unless we are unfortunate enough to die prematurely), applying the life-course approach so that research and policy consider investment and the provision of effective interventions at *all* points of that life course illustrates how ageing is, indeed, everyone’s concern.

⁶¹⁹ Dunn M (2018) Realizing and maintaining capabilities: late life as a social project *Hastings Center Report* 48 (Supplement 3): S25-S30.

Chapter 6

Recommendations

Chapter 6 – Recommendations

Overview of Chapter 6

This chapter lays out 15 recommendations, aimed at different stakeholders, that will need to be addressed for our proposals for the ethical conduct of research in ageing to be realised in practice. We reiterate that research and innovation can only ever be part of a wider approach to supporting people to live well in older age, especially with respect to addressing structural inequalities, and that current pressures in public services will have an inevitable impact on researchers' and practitioners' ability to innovate.

- **All research stakeholders** are encouraged to use the ethical framework and toolkit to guide their thinking and their processes – particularly when scrutinising funding applications and making decisions about the translation of research into practice. An interactive tool on our website provides further prompts and support for those directly involved in research and implementation.
- The **Government** is urged to establish a cross-governmental strategy to support the aims of achieving five extra healthy years for all and narrowing the inequitable gap in healthy life expectancy, and to support this strategy with an intergenerational public advisory forum. It should also ensure that any new screening or testing programmes for age-related diseases must be accompanied by properly funded services and support for those diagnosed.
- **Research funders** are encouraged routinely to expect meaningful collaboration between researchers and older adults in any research they fund concerned with ageing; to fund the necessary engagement infrastructure and expertise; to establish minimum demographic datasets to ensure that diversity of inclusion in studies is measured; and to take active steps to encourage partnership working between researchers and practitioners. We further recommend that funders explicitly take a public health, life-course approach to research funding, recognising the importance of preventative approaches, and prioritising the needs of those who are currently most disadvantaged.
- All the **UK Research and Innovation (UKRI) funding councils** are encouraged to support interdisciplinary ageing research through the new Ageing Networks.
- The **Health Research Authority (HRA)** is encouraged to work with the **National Institute for Health and Care Research (NIHR)** and other partners to identify good practice in involving older adults with impaired mental capacity in research, and to support ethics committees to feel confident in reviewing such research proposals.
- The **Medicines and Healthcare products Regulatory Agency (MHRA)** is urged to continue working with funders and others to address the challenges that may hinder older adults with multiple long-term conditions being included in research relevant to them, and if necessary to consider mandating such inclusion.
- The **British Standards Institution (BSI)** is encouraged to work with the **MHRA, Innovate UK**, and other stakeholders to develop accredited standards that promote ethical and inclusive research practices with respect to technologies designed to support people to live well in older age.
- **Providers of undergraduate education for health professionals and biomedical scientists** are urged to ensure that their students gain a rounded, interdisciplinary understanding of ageing, including the ethical considerations set out in our ethical framework and toolkit.

Introduction

- 6.1 In the light of the wide-ranging evidence received over this two-year inquiry (Chapters 1–4) and the working group’s own ethical analysis of this evidence and resulting framework (Chapter 5), we now turn to the practical changes that will be necessary if this ethical framework is to be realised in practice. We begin with a strong endorsement of the overarching aim set out in 2017 by the Ageing Society Grand Challenge: that of seeking to achieve five years of extra healthy life for all, with particular emphasis on reducing inequalities. This is a policy aim that we hope to see reiterated and maintained in future government policies. We accompany this endorsement with the caution that science and technology can only ever be *one* part of the wider approach required to achieve this, especially with respect to addressing issues of structural inequality. Indeed, many of the respondents to our call for evidence commented in strong terms on the need to address broader aspects of social policy, or indicated how wider social and structural change will be essential in order for developments in biomedical sciences and technologies to make a difference (see Box 6.1). Given the remit of our inquiry, our recommendations will focus more narrowly on changes in policy and practice relating to biomedical sciences and technologies – but we reiterate again the importance of the bigger picture.
- 6.2 We also highlight the crucial intersection between research and innovation, and the general pressures in the health and social care systems.⁶²⁰ A number of commentators have highlighted how currently health and social care services simply do not have the resources or headspace to innovate effectively: thus, a failure to address these underlying challenges will undermine the impact of the policy focus on innovation.⁶²¹ While specific challenges affecting the health and care sectors, such as the pay, conditions, and training of the social care workforce, is outside the working group’s remit, the confidence of direct health and care staff in facilitating research or in helping implement positive findings is clearly essential for successful innovation.⁶²² Moreover, while there is evidence of the active benefits to staff of being involved in research, and using this to improve the services they offer, they cannot do this in the absence of a supportive environment.⁶²³ Those seeking to promote or undertake research and innovation in the provision of health and care similarly need to take these contextual, non-technological, aspects of their research into account, if they are to have the impact that they hope.

Box 6.1: Issues identified as essential by call for evidence respondents

- “Broader policy approaches towards levelling up health in relation to housing, education, employment, diet, activity, and other social and physical determinants of health will also remain vital, and potentially have much greater impact.”⁶²⁴

⁶²⁰ See, for example, Ham C (2022) The government should be honest with the public about its public spending choices *British Medical Journal* **379**: o2514.

⁶²¹ See, for example, Institute for Public Policy Research (2022) *Sustainable healthcare: practical steps to build back better in the English NHS*, available at: <https://www.ippr.org/files/2022-06/sustainable-healthcare-may-2022.pdf>; and Homecare Association blog (22 May 2022) *Homecare – the need to change public opinion*, available at: <https://www.homecareassociation.org.uk/resource/homecare-the-need-to-change-public-opinion.html>.

⁶²² For an overview of implementation challenges, see: UK Parliament POST (2022) *Innovation in adult social care*, available at: <https://researchbriefings.files.parliament.uk/documents/POST-PN-0670/POST-PN-0670.pdf>.

⁶²³ NIHR Yorkshire and Humber Patient Safety Translational Research Centre blog (13 August 2019) *Beyond the outcomes: the benefits of the ‘process’ of doing applied health research*, available at: <https://yhpstrc.org/beyondoutcomes/>.

⁶²⁴ Dr Philippa Brice, PHG Foundation, responding to our call for evidence.

- “Infrastructure needs to be adapted to support the needs of older people, from devices within the home, changes to the built environment, suitable public transport arrangements etc.”⁶²⁵
- “There are clear failing[s] in how the state has approached ageing, and in particular concerning the responsibility to meet the care needs of many older people in our society. These need to be addressed as a matter of priority.”⁶²⁶
- “The current health and care system is characterised by: health inequalities in older age; a lack of integration across systems; barriers to accessing appropriate care; and barriers within physical and social environments ... Bridging the gap between health and social care stretches beyond funding integration, but also encompasses reforming commissioning practice, data and information practice and service delivery.”⁶²⁷
- “Ensuring social care is appropriately resourced to care for an ageing population and support innovations in care will be vital.”⁶²⁸
- “Provide investment for NHS workforce planning and training that recognises the growing need to address the specific care needs of older and elderly patients.”⁶²⁹
- “Health-orientated policies or initiatives should be coupled with support for higher priority issues for individuals residing in more deprived areas, like debt and insecure housing.”⁶³⁰
- “Poor health is locking far too many people out of working, caring or volunteering.”⁶³¹

Guiding principles

6.3 In the previous chapter, we developed an ethical toolkit, in the form of a series of prompts and questions, as a practical means for translating the ethical values and principles that we argue should underlie ageing-related research and innovation (see page 127). While we are aware of individual research teams and practitioners whose current work does indeed embody many of these approaches (e.g., see, Boxes 4.1, 4.3, 4.4, 4.7, and 4.8), it will take system-level action to enable them to become embedded as standard in everyday practice. As the Nuffield Council on Bioethics has argued in earlier reports, responsibility for conducting research ethically cannot rest simply with those ‘on the ground’.⁶³² The structures, culture, and incentives built into the wider research ecosystem have a powerful influence on the approaches and behaviours that individual researchers and practitioners are able and empowered to adopt in their own practice.

⁶²⁵ David Gems, responding to our call for evidence.

⁶²⁶ Michael Dunn, responding to our call for evidence.

⁶²⁷ Anonymous response to our call for evidence.

⁶²⁸ The Academy of Medical Sciences, responding to our call for evidence.

⁶²⁹ British Pharmacological Society, responding to our call for evidence.

⁶³⁰ The Academy of Medical Sciences, responding to our call for evidence.

⁶³¹ International Longevity Centre UK, responding to our call for evidence.

⁶³² Most recently in Nuffield Council on Bioethics (2020) *Research in global health emergencies: ethical issues*, available at: <https://www.nuffieldbioethics.org/publications/research-in-global-health-emergencies>. See also our exploration of the wider culture of the research ecosystem in Nuffield Council on Bioethics (2014) *The culture of scientific research*, available at: <https://www.nuffieldbioethics.org/publications/the-culture-of-scientific-research>.

Recommendation 1

We recommend that everyone with influence over research and innovation concerned with ageing, from individual research teams and practitioners to governments and funders, takes account of the ethical framework and toolkit presented in this report to guide their thinking. In particular, we recommend that the toolkit is used as a guide in processes for scrutinising funding applications, for the ethical review of research in this area, and when making decisions about the translation of research into practice.

We restate here our conclusion in Chapter 1 that reducing inequalities in the ability to live well in older age should be a core, indeed primary, aim of research and innovation in this field.

- 6.4 Below, we explore what future action will be needed, by many different stakeholders, if this approach to research that seeks to influence our experience of ageing is to be realised in practice. We look first at the role of national government; then at those who exercise ‘soft power’ in different ways within the UK research environment; and then at the scope for mandatory approaches through regulation. Finally, we turn to the challenges of implementation.

General challenges: role of national government

- 6.5 A common thread throughout this inquiry, and across all the areas of science and technology that we have explored, has been the importance of challenging the pervasive (albeit often unconscious) effects of ageism – including ‘compassionate ageism’ (see paragraph 2.20). Alongside the welcome increase in policy attention to the needs of older adults (see Box 1.1), and positive examples of thoughtful and respectful research partnerships between researchers and older adults (see Box 4.3), negative assumptions about older age and older people remain common. These are not, of course, a specific feature of the research sector – they derive from deeply embedded societal attitudes. Inevitably, however, they permeate the way that research is approached, from the exclusion of older people from many research studies (see paragraph 4.24 and Box 4.6) to the development of assistive or surveillance technologies that focus on physical safety alone without consideration of the need of every individual to have opportunity to flourish.
- 6.6 The focus of some high-profile research funders in the US and the way that research in this area is sometimes reported in wider media, adds to this problem – for example in the use of terminology such as ‘cures’ for old age, with its conflation of biological and chronological ageing and implied negativity about advanced chronological age (see paragraphs 2.4–2.5). More widespread is the common stereotyping of older people as lacking agency and inherently vulnerable, which has been further exacerbated during the COVID-19 pandemic. **In order to challenge this mindset and help create a much more inclusive and differentiated conception of later life, both in research and elsewhere, there is a need for national-level leadership, supported by direct involvement of older adults able to reflect the vast diversity of ageing experience, as part of intergenerational public input into this universally important area of policy.**

- 6.7 When the Ageing Society Grand Challenge was first launched in 2017, it was clear that this was envisaged as a cross-governmental initiative, in line with the government response to the preceding UK Foresight review on the *Future of an Ageing Population*.⁶³³ However, it is striking that there are currently no cross-governmental commitments or structures within the UK Government to support the wider implementation of policies necessary to support the aim of improving healthy life expectancy, particularly among those who are most disadvantaged. The policy is now ‘owned’ only by the Department for Health and Social Care, even though the relevant areas of policy connect with the areas of responsibility of many other government departments. This is problematic: partly because it frames flourishing in later life primarily in terms of health and care, and partly because it risks neglecting the crucial role played by many other government departments in influencing both how we age throughout our lives, and how we experience our later life. The extent to which the new Office for Health Improvement and Disparities will be able to take an ‘all of government’ approach to healthy ageing is currently unclear.⁶³⁴
- 6.8 In 2021, the House of Lords Science and Technology Committee expressed concern as to the prospects of achieving the aims of the Ageing Society Grand Challenge by the target date of 2035, and argued for the need for the Government to establish a cross-governmental strategy and roadmap, clearly identifying the responsibilities of individual departments, to maximise its chance of success.⁶³⁵ **We share the Committee’s disappointment at the lack of cross-government action to date, and support their recommendation, reiterating the central importance of coordinated action across many elements of social policy (health, social care, transport, housing, planning, welfare and more) to complement and enable the benefits that science and innovation may offer.**
- 6.9 A number of other organisations have similarly called for cross-governmental action in relation to ageing, with a variety of emphases. The All-Party Parliamentary Group (APPG) on Longevity, for example, focuses specifically on the importance of preventative approaches across the life course, calling for a Cabinet-level board, supported by a Cabinet Committee, to enable joined-up work across government on health improvement in whole population health, with sustained action over 15 years.⁶³⁶ The Centre for Ageing Better calls for a cross-departmental strategy to coordinate government activity “to address the ageing population” in general, alongside specific reference to the need to “level up the dramatic and growing inequality in the way we experience later life”.⁶³⁷ A Health Promotion Taskforce was briefly established in 2022 as a Cabinet Committee with terms of reference to “drive a cross-government effort to improve the nation’s health,

⁶³³ 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/816458/future-of-an-ageing-population.pdf.

⁶³⁴ The King’s Fund blog (13 October 2022) *The Office for Health Improvement and Disparities: one year on*, available at: <https://www.kingsfund.org.uk/blog/2022/10/office-health-improvement-and-disparities-one-year>.

⁶³⁵ House of Lords Science and Technology Select Committee (2021) *Ageing: science, technology and healthy living*, available at: <https://publications.parliament.uk/pa/ld5801/ldselect/ldstech/183/183.pdf>, at paragraph 379.

⁶³⁶ All Party Parliamentary Group for Longevity (2021) *Levelling up health*, available at: <https://static1.squarespace.com/static/5d349e15bf59a30001efeaeb/t/6081711f326bde0eea34a3f6/1619095840963/Levelling+Up+Health+Report+Digital+Final+2.pdf>, at page 16.

⁶³⁷ Centre for Ageing Better (2022) *The state of ageing 2022*, available at: <https://ageing-better.org.uk/sites/default/files/2022-03/The-State-Ageing-2022-report.pdf>, at page 15. See also: Express (15 August 2022) *Daily Express calls for ‘forgotten’ older people to be given a voice in government*, available at: <https://www.express.co.uk/news/uk/1655542/daily-express-OAPs-government-voice-campaign>.

supporting economic recovery and levelling up” but was disbanded in November 2022 as part of a general restructuring of Cabinet Committees.⁶³⁸

- 6.10 However, a further crucial part of this jigsaw is the role older adults can and should play at this strategic level: both in influencing these wider policy concerns, and more specifically in steering the way in which bioscience and technological innovation may influence our experience of ageing. One example of such an approach at the broad policy level is found in Wales, where the Senedd includes Ministerial Advisory Forums that enable older adults and organisations representing older people to comment on and shape policy within the Welsh Government (see paragraph 1.24). We commend this approach, while suggesting that it is important for the contribution of today’s generation of older adults to be expanded to include intergenerational insights – reflecting both the reality of the life-course approach to ageing (the impact on later health and function of much earlier experiences and behaviours), and the needs and wishes of future generations of older adults. In particular, it is important to provide opportunities to communicate a bolder vision of what growing older could look like, challenging ‘solutions’ based on the ageist assumptions that we have critiqued earlier in this report.
- 6.11 **If research and innovation relating to ageing is truly to challenge and transcend some of the socially embedded ageism that we have highlighted throughout this report, we suggest that those responsible for policy in this field need not only to work in a coordinated manner across government, but also to ensure that older adults are involved in shaping that policy. Moreover, given the emphasis we have placed throughout this report on the importance of taking a life-course approach to ageing policy – recognising that ageing is something happening to all of us all of the time, and that our later life is strongly influenced by our lifetime experiences – broader intergenerational input into such policy will also be crucial.**

Recommendation 2

We recommend that a cross-governmental strategy to support the delivery of the 2017 Ageing Society Grand Challenge aims, as recommended by the House of Lords Science and Technology Committee, should be supported by an intergenerational public advisory forum including both older adults and contributors from across younger generations.

The remit of the forum, made up of a diverse membership of both individuals and representative organisations concerned with ageing, would be to put the experience of older adults at the heart of policymaking, challenge ageist assumptions, and encourage a broader life-course approach to ageing policy.

- 6.12 In developing such an approach, we also draw attention to the crucial role played by those who act as ‘bridge builders’ between national-level policy and institutions, and local practice. The *Women’s Health Strategy for England*, for example (see Box 1.1), has been

⁶³⁸ UK Parliament (2022) *Health Promotion Taskforce - Question for Department of Health and Social Care (UIN HL7645, tabled on 4 April 2022)*, available at: <https://questions-statements.parliament.uk/written-questions/detail/2022-04-04/HL7645>; and UK Parliament (2022) *Health Promotion Taskforce - Question for Department of Health and Social Care (UIN 59000, tabled on 10 October 2022)*, available at: <https://questions-statements.parliament.uk/written-questions/detail/2022-10-10/59000>. Due to the disbanding of the Health Promotion Taskforce in 2022 the terms of reference can only longer be found under the list of Cabinet Committees, however the terms of reference have been discussed in: NHS Confederation (2022) *Moving from silos to system improvement: what healthcare leaders want to see from the health disparities white paper*, available at: <https://www.nhsconfed.org/publications/moving-silos-system-improvement>.

supported by the appointment of a Women's Health Ambassador to help catalyse change,⁶³⁹ and we have earlier drawn attention to the role of Older People's Commissioners in some parts of the UK (see paragraph 1.24). Initiatives such as the *Quantum Healthy Longevity Innovation Mission* (see Box 4.13) provide further mechanisms for bridging the gap between high-level policy and practice on the ground. We return later in this chapter to these important questions of implementation and translation (see paragraphs 6.49–6.61).

Research policy: funders, regulators, ethics committees, and journals

6.13 From the very beginning of this inquiry, the working group took the view that it was essential to approach issues of ageing and science/technology through a lens of (in)equality, in order to be alert to how different groups, or subgroups, within the population might be affected in different ways by innovation. This might arise, for example, through the development of effective interventions that were accessible or affordable only to part of the population – or, more subtly, through a failure to recognise existing disadvantage that might be further exacerbated by technological innovation or biomedical developments. In our discussion of the capabilities approach, in particular, we noted how the concept of 'conversion factors' brings to the fore the significance of structural inequalities in hindering people from being able to access opportunities to flourish – and hence the need for research actively to seek to reduce those inequalities (see paragraphs 5.16–5.17). In what follows, we consider first how older adults with diverse experiences of ageing can influence the research agenda (building on the discussion earlier in this chapter regarding influence at national policy level); and then we explore the specific challenges of achieving more diverse participation within research studies.

Working in partnership with older adults and intergenerational publics

6.14 The central importance of working in respectful partnership with people of all ages, ensuring that older adults are appropriately represented – both throughout the full trajectory of research, and in the way that new products or services are subsequently made available – emerged as a powerful theme in the contributions we received to this inquiry. In our ethical analysis, we identified a number of grounds underpinning the intrinsic importance of respectful engagement with older adults, with a particular emphasis on the imperative of promoting the voice and influence of those who are most marginalised (see, in particular, paragraphs 5.20 and 5.28). In brief, meaningful partnerships with older adults, reflecting diverse experiences of ageing and older age, are essential throughout the research process in order to ensure that research:

- listens to, and acts on, the perspectives of those who are affected by, and will draw on, the research; and hence is soundly based on an understanding of actual, rather than presumed, needs and priorities;
- pays special attention to the needs and priorities of those who are most disadvantaged;
- is conducted respectfully with older research participants and older potential beneficiaries of research on a basis of equality; and

⁶³⁹ Department of Health and Social Care (17 June 2022) *Dame Lesley Regan appointed Women's Health Ambassador*, available at: <https://www.gov.uk/government/news/dame-lesley-regan-appointed-womens-health-ambassador>.

- avoids testimonial injustice – the disrespect and inequity involved in silencing, or failing to hear, the voices of those who will be affected by the outcomes of the research.

6.15 This responsibility rests not only with individual research teams, with respect to how they approach prospective research projects, but crucially with many other stakeholders within the research system who influence how studies are prioritised and funded; how they are designed and conducted; and how results are disseminated and acted upon. Some examples are given below.

- **Research funders, whether public, charitable, or commercial**, are in a position to mandate and support meaningful collaborative practices, including through requiring evidence of partnership arrangements in their application requirements; ensuring that review panels include necessary expertise on collaborative approaches and give due weight to this factor in making judgments about what research should be funded; and by ensuring that plans for meaningful collaboration throughout the full research trajectory are properly costed in terms of both time and money.
- **Regulators such as the Medicines and Healthcare products Regulatory Agency (MHRA)** could prompt, or even require, research sponsors to provide evidence of their partnership with diverse older adults as part of their licensing procedures for new products where these are likely to be used by older adults. They can also encourage, or in the longer term mandate, the use of patient reported outcome measures as part of the evidence demonstrating effectiveness of new products, thus ensuring that the real-life effects on older adults' daily lives are captured as part of the evidence base for authorising a new product.⁶⁴⁰
- **Research ethics committees** could expect applications for ethical review to include evidence of how researchers have worked with older adults in developing research proposals, along with proposals for continuing partnership working throughout the project, and require robust justifications if this is not the case.
- **Academic professional bodies** are in a position to develop standards and expectations around respectful partnerships with public contributors, as part of setting standards for good research practice on the part of their members.
- **Academic journals** similarly have the power to expect submitting authors to provide evidence of such collaborative practices, and to require robust justification for where it is absent.

6.16 As we have noted throughout this report, older adults, like every age cohort, are an extremely heterogeneous population, whose experience of later life is influenced not only by personal characteristics (including ethnicity, disability, sex/gender identity, sexuality, and religion), but also by the accumulated lifetime effect of how these and broader socioeconomic factors have conferred advantage or led to discrimination throughout their lives. Moreover, any group of older people may potentially span four or more decades in age, experiencing a very broad range of states of health. In seeking to work together with older people to plan and conduct research that addresses their key concerns, researchers will therefore need to be alert to the need for diversity among their public contributors. The nature of the research will affect the breadth of input required – for example a study relevant to a small subgroup of the population may have different demands from a study that potentially has the capacity to affect outcomes for everyone.

⁶⁴⁰ See, for example, Medicines & Healthcare products Regulatory Agency (2021) *Patient involvement strategy 2021-25*, available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1022370/Patient_involvement_strategy.pdf.

Moreover, for some forms of research, focusing specifically on influences on ageing earlier in the life course, younger or multigenerational public input may be most appropriate. The guiding principle for researchers, as indicated in our discussion above (see paragraph 6.14), should be whether the voices of those who are most marginalised or disadvantaged have been included.

- 6.17 **We warmly welcome steps taken by a number of major research stakeholders within the UK, including the National Institute for Health and Care Research (NIHR), UK Research and Innovation (UKRI), Health Research Authority (HRA), and MHRA to support and promote meaningful partnership with patients and publics (see paragraphs 4.12–4.13) and urge them to pay particular attention to the need to ensure that the most marginalised groups of older adults are included.**

Recommendation 3

We recommend that research funders, regulators, research ethics committees, and journals should all routinely expect to see meaningful collaboration with older adults as part of their work with public contributors in any research seeking to influence our experience of ageing. In particular, they should expect to see evidence that the public contributors to any research project reflect the diversity of those likely to be affected by it, including those who are most disadvantaged. Funders should ensure that both timescales and budgets make proper allowance for a partnership approach.

- 6.18 *How researchers work in partnership with older adults (or with multigenerational groups) will similarly vary depending on the nature of the research. Different approaches are likely to be appropriate for highly translational research such as that being conducted in the field of smart home technologies, from those helpful for laboratory research seeking better understanding of the underlying biological mechanisms of ageing. Yet even the earliest ‘discovery’ research is implicitly informed by understandings and assumptions of what matters to people in older age (see paragraphs 2.23–2.30). The input of older adults at this level – as for example in the ‘priority setting partnerships’ conducted by the James Lind Alliance – can be highly influential in steering research in ways that are more likely to be valued by those they seek to benefit (see Box 4.3). Such input is valuable not only to individual research teams, but also ‘upstream’ to research funders, in helping identify priority areas for funding.*
- 6.19 We discussed in Chapter 4 the considerable developments that have been taking place in the way that researchers work in partnership with public contributors (see paragraphs 4.12–4.13). Nevertheless, it remains the case that adapting research approaches so that they genuinely involve sharing power with public contributors will require a major cultural shift, and is highly challenging for many working in the sector. In addition to identifying the levers (‘sticks and carrots’) available to those who exercise power in the research sector (as in Recommendation 3 above), it is also important to recognise that much more practical support will be required for research teams in achieving this shift. This includes:
- creating and funding the **infrastructure** necessary to support partnership working consistently across the whole of the UK – including not only organisational structures and systems, but most importantly the necessary expertise, particularly that brought by specialist community engagement practitioners, who can help mediate effective partnerships between researchers and public contributors; and

- enabling researchers to develop **confidence in different ways of working** – not least by ensuring that the attitude and skills needed to work in partnership with public contributors are supported and developed during relevant undergraduate courses.⁶⁴¹

- 6.20 Despite strong commitment across the UK research sector to the value and importance of public involvement and engagement in research, the COVID-19 pandemic illustrated how easily such commitments could fall away under external pressures. In response to this experience at the start of the pandemic, the Health Research Authority developed a ‘matching service’ to connect researchers with willing public contributors, and the rapid increase in engagement in response to this service demonstrated the value to researchers of such signposting services.⁶⁴² The network of ‘Young People’s Advisory Group’s (YPAGs)’, established and funded by the National Institute for Health Research, NHS Scotland, and other NHS bodies provide another model, whereby researchers seeking specialist input (in this case specifically from children and young people) know where to seek it.⁶⁴³ National, regional, and local engagement networks, such as Vocal,⁶⁴⁴ VOICE, and the Thousand Elders provide further examples of systems and structures that enable researchers to seek input and support from public contributors across a range of ages (see Box 4.3).
- 6.21 One possible approach to ensuring that researchers working on studies relevant to ageing are readily able to draw on the lived experience of a sufficiently diverse group of older adults might be to establish a dedicated UK-wide network of older adults’ advisory groups and intergenerational advisory groups – potentially linking in with the 11 ageing research networks recently announced by the Medical Research Council (MRC) and Biotechnology and Biological Sciences Research Council (BBSRC) (see Box 3.3). Other approaches might include building on existing models of older people’s engagement (see Box 4.4) or (for larger projects) ensuring that project funding explicitly includes budgets for setting up bespoke advisory and partnership arrangements. **While appropriate funding models and structures may vary, an essential element will be to ensure that any such advisory mechanisms are constituted to include a diverse membership, with a particular emphasis on including the voices of those who are currently most likely to be excluded from research.**

Recommendation 4

We recommend that public research funders with a remit to support research in ageing should collaborate to establish and fund the infrastructure (systems, staff, expertise) necessary to support partnerships between research teams and public contributors able to contribute diverse understandings and experiences of older age.

⁶⁴¹ The Academy of Medical Sciences, responding to our call for evidence. See also: The Academy of Medical Sciences (2019) *From subjects to partners: putting patients at the heart of medical research: report of a roundtable on 12 June 2019*, available at: <https://acmedsci.ac.uk/file-download/95794119>.

⁶⁴² Health Research Authority (2021) *Public involvement in a pandemic: lessons from the UK COVID-19 public involvement matching service*, available at: <https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/public-involvement-pandemic-lessons-uk-covid-19-public-involvement-matching-service/>.

⁶⁴³ GenerationR: young people improving research (2014) *About*, available at: <https://generationr.org.uk/about/>.

⁶⁴⁴ VOCAL (2022) *Who we are*, available at: <https://wearevocal.org/who-we-are/>.

Inclusive and diverse research: participation

6.22 The evidence we received throughout the project highlighted a number of fundamental challenges with respect to research participation being sufficiently wide to capture the impact of novel interventions or technologies on different groups or subgroups of the population. At the most basic level, we were told that there is often a lack of granular data regarding factors such as the ethnicity or age of research participants;⁶⁴⁵ and information about a person's family or social situation (potentially highly relevant with respect to access to informal support) is almost never collected.⁶⁴⁶ This means that, even if a study has included a diverse cohort of participants, differential impacts or experiences cannot be captured in the analysis. This adds to the likelihood that the particular needs of those who are most disadvantaged will not be identified, let alone addressed. These concerns arise across the board for research covered by the scope of this inquiry, from the role of the life sciences in extending healthy life expectancy and improving diagnostics to adaptive, communications, or monitoring technologies that aim to support people to live well in later life.

Recommendation 5

We recommend that funders of research in ageing should require (and fund) researchers to collect a minimum demographic dataset about research participants. Further work may be required to specify such a data set, but it should include as a minimum age, sex/gender, ethnicity, socio-economic status, and nature of access to informal social support. They should then make use of this data in future grant rounds, to fund research that specifically aims to fill identified gaps in the coverage of the diversity of experiences of older adults. Research ethics committees should expect robust justification if researchers are not planning to collect, or analyse, such demographic data.

6.23 Poor rates of inclusion of marginalised or minoritised groups, compounded by the lack of data highlighted above, represent an important challenge to the integrity of all kinds of research, including research relevant to ageing. In addition to these challenges of inequity in research representation that arise across the life course, particularly with respect to race and ethnicity, we explored in Chapter 4 how some groups of older adults have historically been systematically excluded from research for reasons directly associated with the health impacts of biological ageing (see paragraphs 4.24–4.27). This includes:

- those with multiple long-term conditions (MLTCs), despite the fact that this will apply to most people as they get older (and indeed that this group may represent the majority of users of new treatments and interventions);
- people with impaired capacity, who are often excluded altogether; even studies specifically concerned with people with impaired capacity may exclude those without a family member or carer to support them;
- people with mobility or sensory impairments; and
- people living in care homes, both because of default assumptions about their interest in, or capacity to, take part in research, and because of practical constraints such as the lack of good connections between the research and care home sectors.

⁶⁴⁵ Ageing, AI, and data-driven innovation roundtable, 7 December 2021 (see Appendix 1).

⁶⁴⁶ Meeting with Ageing Without Children, 22 March 2022 (see Appendix 1).

- 6.24 As we explored in Chapter 5, this is unethical as well as being poor science – an example of testimonial injustice (paragraph 5.28) that, far from protecting older adults living in more vulnerable situations, leads to them being more likely to experience harm as a result of adverse drug interactions, unresearched side effects, or a lack of understanding how interventions might fit into their day-to-day lives. While this exclusion of a large proportion of the older population is a challenge in all kinds of research, tackling this problem becomes particularly important in the light of the potential for advances in geroscience to intervene in the underlying causes of biological ageing, both earlier and later in life. Older adults should not be excluded from the benefits that research in this field may be able to bring.
- 6.25 The reasons why older people, and in particular those living with MLTCs, are currently often excluded from research fall into a number of categories (see paragraph 4.24 and Box 4.7).
- Concern that **research participation would be burdensome** or otherwise inappropriate – particularly, but not exclusively, for older adults in frail physical health or with impaired capacity.
 - **Practical constraints** – for example where arrangements would need to be made for home visits, or monitoring in a care home, rather than expecting research participants to travel to research sites or hospitals.
 - Factors linked with the **study design** – because it is easier to design a study in which all the participants are living only with the one condition being studied; or out of concern about possible increased levels of risk because of the complexity of a participant's medical conditions.

These different barriers are likely to need addressing in different ways, and by different stakeholders.

- 6.26 Similar concerns about exclusion from research have long been recognised in another generational cohort – children and young people – where for many years fears about exploiting research participants led to a lack of research, and hence a lack of evidence-based healthcare. Many of the concerns cited were very similar to those described above with respect to involving older people in research, deriving both from anxiety about vulnerability and exploitation, and a lack of willingness to think about how study designs and requirements could be designed around the needs of younger participants. Over the last two decades, however, this has changed significantly, both through regulatory action and through challenging previous ethical assumptions. Research sponsors are now required to include a 'paediatric investigation plan' when researching new medications which could potentially benefit children as well as adults; and ethical concerns have been reframed around the need to work *with* children and families to design studies in ways that meet their needs and do not add to any existing vulnerabilities.⁶⁴⁷ While we should be very wary of drawing inappropriate comparisons between childhood and older age, we nevertheless suggest that there is a great deal to learn from progress in paediatric research, regarding practical measures that can challenge simplistic and harmful responses to concerns about potentially vulnerable research participants.
- 6.27 **We conclude that there is a need for proactive measures by a wide range of stakeholders to reverse the assumptions that lead to many older adults being**

⁶⁴⁷ See: Nuffield Council on Bioethics (2015) *Children and clinical research: ethical issues*, available at: <https://www.nuffieldbioethics.org/assets/pdfs/Children-and-clinical-research.pdf>, at chapter 3.

excluded from research – starting from the point that inclusion should be the norm, and that any proposal to exclude older adults from research that offers a prospect of benefitting them needs to be justified. Routine partnerships with diverse older adults in the prioritisation, planning, and design of studies as recommended in Recommendations 3 and 4 above, should provide an important first step in challenging overprotective or unthinking exclusion of older people from studies. In addition, we highlight the important role of a number of stakeholders within the research ecosystem in tackling more structural barriers to participation, including the following.

- **Funders**, who have the ability to mandate an inclusive approach to participation for the studies that they fund, and who are also well placed to ensure that budgets are adequate to meet the additional costs that may be involved in more inclusive approaches to recruitment: for example to cover higher drop-out rates; or to overcome practical barriers to participation such as arrangements for researchers to visit participants at home, and the adaptation of materials for those with impaired vision or hearing.
- **Regulators**, who can reinforce the need for data submitted for licensing authorisations to reflect the population that the product for which authorisation is being sought is likely to serve.
- **Research ethics committees**, who are well placed to require justification for any apparently arbitrary age limits, and to probe what additional steps researchers are planning to take in order to ensure that, where relevant to the research topic, an appropriately diverse group of older adults will be enabled to participate. Members of ethics committees may themselves need more support in understanding how some older adults, particularly those with impaired capacity, can be enabled to participate in research if they wish to do so.

6.28 As we outlined in Chapter 4, considerable work is already underway in related fields. A number of research funders, for example, have come together to develop a ‘cross-funder multimorbidity research framework’, with the explicit aim of facilitating clinical trials that involve people living with MLTCs, both through making the case for the importance of inclusion, and by working with regulators and researchers to develop innovative and flexible ways to conduct trials (see Box 4.8). While this initiative is not specific to older adults, it offers significant prospect of tackling the ongoing scientific and regulatory challenges that hinder older adults living with a number of different conditions from being invited to take part in research.

6.29 **We welcome current initiatives that are bringing together funders, researchers, and regulators to explore how people with MLTCs can be included in clinical trials, so that study cohorts are representative of the population that may potentially benefit from the intervention being studied. We highlight the importance of all these discussions, and initiatives, explicitly including the needs of older adults, who represent a significant part of the population of people living with multiple long-term conditions.**

6.30 One response to our call for evidence went further, and drew on the existing model of paediatric investigation plans (PIPs) to put forward the idea of ‘multimorbidity investigation plans’ or ‘elderly investigation plans’. Such an approach, if implemented on a similar basis to PIPs, would *require* sponsors of research into novel treatments to

include research participants living with other long-term conditions as a necessary part of a clinical trial in order to obtain authorisation to market the new product.⁶⁴⁸

Recommendation 6

We recommend that the Medicines and Healthcare products Regulatory Agency (MHRA) continue actively to engage with funders and researchers in addressing the challenges that may hinder older people with multiple long-term conditions being included in research relevant to them. If necessary, we encourage the MHRA to consider whether a mandatory approach should be explored, mandating the inclusion of data obtained through the participation of older research participants, and/or participants living with multiple long-term conditions, as part of licensing authorisations, where new products will be relevant to the older population.

- 6.31 It was clear from many contributors to the inquiry that ethics committees are often concerned about proposals to include older adults with impaired mental capacity in research studies, and may feel that the safer option would be to exclude them.⁶⁴⁹ Yet, as we argued above, such an approach risks overlooking the particular needs and perspectives of those living with cognitive decline, and also removes an opportunity to exercise agency where this might be possible with appropriate support. This hesitancy highlights the need for greater support and training for ethics committee members, so that they are aware of existing good practice in this area, such as the INCLUDE Impaired Capacity to Consent Framework (see Box 4.7), and can have greater confidence in making judgments about the proposals put to them. Knowledge that research proposals have been developed with the support of diverse older adults, including those with a degree of cognitive impairment (see Recommendation 3 above) should also enable ethics committees to be more confident as to whether a research proposal is sufficiently inclusive in its recruitment criteria, and has the necessary resources in place to support potential participants appropriately.

Recommendation 7

We recommend that the Health Research Authority (HRA), working with funders such as the National Institute for Health and Care Research (NIHR), takes the lead in identifying and disseminating examples of good practice in the inclusion of older adults, particularly older adults with impaired mental capacity, in research. These should be shared with ethics committees to support them when scrutinising relevant research proposals.

- 6.32 In addition to this ‘ethical nervousness’ often experienced at the prospect of involving people who have traditionally been regarded as vulnerable in research, practical constraints also clearly play a significant role in limiting the extent to which researchers feel able to reach out to a wider range of potential research participants. Designing research in ways that do not require participants to travel to hospitals or research centres, or otherwise fit around the needs of participants rather than researchers, requires

⁶⁴⁸ British Pharmacological Society, responding to our call for evidence.

⁶⁴⁹ Co-production roundtable, 22 February 2022 (see Appendix 1); and Nuffield Council on Bioethics (2023) *The future of ageing: call for evidence summary of responses*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/public-dialogue-on-the-future-of-ageing>.

additional time and money, as well as the recognition that this is important. Other issues cited to the working group included a lack of links between researchers and care services (both for people living in care homes and for those living with MLTCs or frailty in their own homes), with the result that people with significant support needs are only likely to be drawn into research if they are admitted to hospital with acute illness. This lack of connection between research and social care is exacerbated by the fragmented nature of the sector, and by historically poor data linkages between the NHS and services organised by local authorities.⁶⁵⁰ Building long-term relationships to create such links between research teams and local care systems will be crucial in order to reach out to older adults living with substantial support needs, but similarly takes time and money on the part of researchers.

Recommendation 8

We recommend that research funders provide dedicated funding to support research teams and engagement practitioners in developing relationships with older adults in their communities and with the care sector, in order to build up the connections and expertise necessary to enable older adults with care and mobility needs to participate in research.

- 6.33 Inclusive data sets become even more important where they are used for ‘training’ artificial intelligence (AI) models, because of the risk of bias and exclusion being built into the way that algorithms work. Major long-term datasets used for such purposes (including large-scale volunteer studies and population cohort studies) need to represent the current diversity of experiences of ageing. They also need to take account of the malleability of ageing, so that, where appropriate, AI models can reflect the possibility of living better as a result of actions taken to intervene in the ageing process.

Recommendation 9

We recommend that the researchers and research funders responsible for large-scale volunteer databases and cohort studies proactively review how these studies might need to be adapted to ensure that they capture both the breadth of diversity in the ageing process, and the scope to intervene positively in the ageing process.

Funding policy: drivers and priorities

- 6.34 As we explored in Chapter 3, the current research funding situation in the UK is something of a patchwork, with public and charitable funding for biomedical research mainly directed towards single disease pathways, limited venture capital to help translate basic geroscience research into clinical trials, and a market-driven technology sector (see paragraphs 3.13–3.15 and paragraph 3.28). In line with our endorsement of the House of Lords Science and Technology Committee’s recommendation with respect to the need for a cross-governmental strategy on improving health life expectancy and reducing inequalities, **we conclude that there is a strong need to promote a**

⁶⁵⁰ Roundtable meeting with members of Technology and Ageing Special Interest Group, British Society of Gerontology, 24 June 2021 (see Appendix 1).

coordinated and multidisciplinary approach to ageing research funding, underpinned explicitly by ethical prioritisation criteria.

- 6.35 We are aware that the need for such a coordinated approach has long been debated within the UK, and that the most pragmatic approach is likely to be to build on existing initiatives, rather than seeking to create brand-new structures. Recent commitments by a number of the UK funding councils to support better coordination and collaboration across the spectrum of research in ageing are particularly timely, as was the (time-limited) work of UK SPINE. In particular, we welcome the creation of 11 new UK Ageing Networks, established by the BBSRC and the MRC to bring together researchers from 28 UK universities and a wide range of disciplines (see Box 3.3). Such networks can play a crucial role in bringing together many different disciplines to support collaboration, mutual respect, and appreciation of different research paradigms across the many different areas of research relevant to ageing well. Developing and maintaining close relationships between these networks and policy officials responsible for overseeing the Ageing Society Grand Challenge targets will be crucial, so that the scope for geroscience to contribute to these targets is kept in view.

Recommendation 10

If the initial two-year funding allocation for the UK Ageing Networks demonstrates proof of concept, we recommend that all the relevant funding councils within UK Research and Innovation (UKRI) should commit to long-term joint funding of the UK Ageing Networks to ensure a truly interdisciplinary approach.

- 6.36 A coordinated approach is, however, only the first step: the values that will underpin that approach are even more important. Throughout this report, we have argued for an approach to research that is based on seeing ageing as part of the life course, not as something separate and distinct (see paragraphs 2.9 and 5.10); promoting the opportunities of everyone to flourish as they get older, with a particular concern for the structural inequalities that may hinder people in accessing such opportunities (see paragraph 5.19); and ensuring that research agendas speak to different generations, with an emphasis on sustainability and preventative approaches at all ages (paragraph 5.51).
- 6.37 In the global context, as we discussed in Chapter 3, significant funding for research, both in the life sciences and technological sectors, continues to come from the private sector. In the context of biomedical sciences, major investments by US companies such as Calico, Altos, and the SENS Foundation, have led to an emphasis, at least in public-facing communication, on life extension over improving healthy life expectancy (see paragraph 3.16 and Box 3.4). Although at the level of basic science these areas are far from distinct, with developments in one area potentially contributing usefully to the other, nevertheless this narrative can undermine public trust and understanding as to the aims of geroscience (see paragraph 4.44). As we explored in Chapters 3 and 4, concerns similarly arise with respect to the drivers and priorities of the technology sector: parts of the 'ageing tech' sector have been described as being a wild west, with devices developed in response to perceptions of commercial gain, rather than genuinely in response to the needs of current or future older generations. The development of mainstream devices (which may often be as, or more, effective in meeting older adults' needs) are by their nature market-driven, and (despite the size of the 'grey market') can be designed in ways that may inadvertently exclude older users.

6.38 Given the very different drivers and levers at play, we focus below on the approach we believe public and charitable funders should take, returning to the issue of commercial funding primarily in the context of our discussion of the role regulation can play in shaping the sector (see paragraphs 6.40–6.47). We do, however, highlight how strategic decisions taken with respect to public funding can have wider influence, through partnerships with industry (see Box 3.7).

Recommendation 11

We recommend that public and charitable funding for research in ageing within the UK (including that directed via partnership approaches with the commercial sector) should be based explicitly on a public health, life-course approach. Such an approach would:

- **recognise the importance of interventions and support across the life course and into later life to enable people to live as healthily as possible, with a particular focus on preventative approaches;**
- **prioritise the needs of those who are currently most disadvantaged, with a particular focus on addressing structural and institutional barriers to ageing well; and**
- **see scientific and technological innovation as an important complement to, but not substitute for, wider social policies that are fundamental to supporting people in ageing well.**

6.39 Further considerations and practical suggestions regarding the prioritisation of future research agendas that emerged throughout our inquiry included the following.

- The importance of **targeting research on areas of greatest need**, which may not always correlate with the ‘exciting’ science – while there will always be a role for discovery science, there is an ethical imperative for this to be accompanied by a commitment to funding research that clearly responds to current need. We highlight in particular how some areas of health of particular concern to many older adults, including dental health, foot health, and continence, are routinely overlooked (see paragraph 4.17).
- The scope for building on current practice in some funding streams by **developing requirements for applicants to demonstrate how their research will contribute to the Ageing Society Grand Challenge**.
- The essential role of **meaningful partnerships with patients and wider publics in setting priorities** (see paragraphs 6.14–6.17). Priority setting partnerships provide a valuable example of ways of including the wider public among many other stakeholders in identifying priority research needs for particular subgroups within the population.
- Specific attention to be paid to the **risk that innovations that increase healthy life expectancy for some might also increase inequalities** – accompanied by proactive plans within research proposals as to how these risks can be mitigated.
- Recognising the need to **incorporate criteria with respect to sustainability** – recognising the scope for some kinds of intervention to jeopardise the environment.
- **Including evaluation**, both within research programmes and in implementation plans, to ensure that any unintended consequences of a particular direction of travel are identified in time respond to them.

The role of regulation

6.40 A common theme across the diverse areas of research and innovation that we explored in this project is that potentially valuable developments do not necessarily fit within current regulatory frameworks. A key challenge for translational geroscience is the question of how either repurposed or novel treatments can be licensed when they are not targeting a named ‘indication’ (a condition such as cardiovascular disease or a particular cancer), but are rather seeking to intervene in the hallmarks of ageing. In the technological field, significant definitional challenges arise when determining not only *how* but *what* to regulate. Given the increasing scope for using and adapting mainstream technological devices (from voice-operated digital systems in the home to the use of smartphones for routine medical monitoring), clear dividing lines between technologies designed for health or care purposes and technologies in general use become impossible to draw. Proportionate and effective regulatory approaches are clearly important in themselves – but as noted above (see paragraph 6.38) they also have an important role as a lever that public decision makers can use to influence commercial research that would otherwise be subject only to market drivers.

Regulatory challenges in geroscience

6.41 The working group is aware of considerable ongoing work across the ageing life sciences sector exploring the particular regulatory challenges of licensing medicines that aim to intervene in the underlying processes of biological ageing (see paragraphs 3.17–3.20). While many of the challenges under consideration appear to be primarily technical in nature, relating for example to the need to find ways to conduct clinical trials within feasible timescales, and with meaningful endpoints (measures of success), these issues are in fact underlain by ethical questions, in particular relating to the way in which older adults’ own perspectives inform these decisions (see paragraphs 4.2–4.10). A further fundamental challenge relates to the scope for this area of science to tackle the underlying causes of multiple diseases, such as the role of inflammation in contributing to numerous age-related conditions, in the context of a regulatory system designed to license new treatments for specific diseases or conditions (‘indications’). Possible solutions being explored include scope to use biomarkers related to biological ageing as measures of the effectiveness of new or repurposed medicines, alongside ‘composite’ success measures, such as increasing the time between the onset of a first medical condition associated with ageing and the onset of a second or subsequent condition. However, they have also included the idea that ‘ageing’ itself should be designated as an ‘indication’ to facilitate the licensing of interventions that aim to intervene directly in the biological ageing process.

6.42 We highlighted in Chapter 2 how the word ‘ageing’ is commonly used to indicate both chronological ageing and biological ageing – and how the conflation of these two meanings can lead to negative and harmful assumptions about being old in years (see paragraphs 2.4–2.6). This is not simply a semantic point: a theme that has recurred throughout this inquiry is how detrimental assumptions and stereotypes about older adults can and do influence how research agendas are set, and, crucially, what outcomes are regarded as ‘successful’ or as demonstrating ‘benefit’ for older adults. When language such as ‘curing’ or even ‘treating’ ageing is used, this reinforces existing ageist attitudes that getting older in years is inherently a bad thing – an assumption that we have challenged on both empirical and ethical grounds throughout this report.

- 6.43 It should be recognised that it is perfectly possible for individuals to use the language of ‘treating ageing’ to mean intervening to delay the processes of biological ageing, and at the same time be highly critical of ageist attitudes and assumptions. Indeed, the main rationale for many scientists working in this field is precisely to help enable more of us to flourish in our older age, supported in doing so by the enjoyment of better health. However, **the term ‘ageing’ is so widely understood in general usage as indicating getting older in years, that we suggest it would be quite wrong to appropriate it for regulatory purposes as an indication. Classifying ageing as a disease, regardless of the scope for resolving a regulatory conundrum, would send a wider societal message about the negative status ascribed to being older, and would fly in the face of the many existing examples of good practice where scientific innovation has supported opportunities to flourish in later life.**
- 6.44 **We welcome the collaborative approach being taken by the many stakeholders (regulators, researchers, funders, industry) to find regulatory solutions that will support the effective conduct of geroscience-guided clinical trials, and the appropriate licensing of interventions found to be effective in improving and extending healthspan. We also highlight the importance, both in public communication and in choice of regulatory language, of selecting terminology carefully.** Alternative terminology already used in the sector, such as ‘intervening in the way the body ages’, ‘understanding the causes of age-related illnesses’, and ‘developing treatments to improve the health of older people’ convey to wider publics the aims of this important field of science without stigmatising the state of being old or the process of getting older.⁶⁵¹

Regulatory challenges in technology

- 6.45 The regulatory challenges arising in the context of technological innovation are rather different from those described above in the life sciences sector. Many devices that potentially have a role in supporting people to age well, from apps that are badged as having ‘lifestyle’ rather than ‘health’ purposes, to many day-to-day adaptive or communications technologies, are neither classified as ‘medical devices’ nor specific to ageing. Technologies that are explicitly developed for health or social care purposes *are* regulated as medical devices, but this is far from a settled field, with innovations such as ‘software as a medical device’ and developments in the use of AI putting pressure on existing regulatory frameworks (see paragraphs 3.31–3.32).
- 6.46 As the above very brief account makes clear, this is a highly complicated, and evolving, regulatory space. Our particular concern with the use of innovative technologies to support people in living well in later life intersects with many developments that primarily or additionally target other markets: these include, for example, products for a wide range of other medical purposes; technologies used by younger disabled adults; and products designed for the general consumer market. It is beyond the scope of this report to enter into the general debate on how the regulation of these diverse forms of technology should respond to the increasingly blurred boundaries emerging from factors such as ever-increasing digitalisation, the use of smart technologies, and developments in AI. Rather, we focus here on the specific challenges that we identified in Chapter 4, and in response to which we set out six attitudes and principles that we believe will promote the ethical development and use of technologies that aim to support people to live well in

⁶⁵¹ See, for example, UK SPINE Knowledge Exchange (2022) *For the public*, available at: <https://www.kespine.org.uk/public>.

older age (see the full decision-making tool in Box 6.1). To reiterate, we argued that research should be carried out in such a way as to:

- support flourishing in older age;
- challenge ageism;
- promote equity;
- shift power;
- demonstrate trustworthiness; and
- enable sustainability.

6.47 **We suggest there is a strong need to provide pathways and incentives that will:**

- **support researchers and companies involved in technological research and innovation to keep these principles in view at all times;**
- **provide recognition for those working in this way; and**
- **enable older adults and those supporting them to identify products that have been ethically developed.**

One way this could be achieved is through the development of accredited standards, building on the principles and supporting prompts and questions set out in our decision-making tool. Such an approach could build on existing work by the British Standards Institution, the body responsible for settings standards within the UK, for example in the area of inclusive design (see paragraph 3.34). It would have the further advantage of working both as a voluntary, aspirational scheme for those wishing to be credited for the way they have developed their products, and also being available for use by many other stakeholders within the research system, including funders in their expectations of grant-holders; the MHRA in their consideration of the evidence required for authorising new medical devices to go on the market; and National Institute for Health and Health Excellence (NICE) in the recommendations made as to the use and availability of new products and devices within the NHS.

Recommendation 12

We recommend that the British Standards Institution (BSI), the Medicines and Healthcare products Regulatory Agency (MHRA), Innovate UK, and other stakeholders should collaborate to develop accredited standards that promote ethical and inclusive research practices with respect to technologies designed to support people to live well in older age. We commend our ethical framework and tool as a starting point for such standards.

Support for researchers and research teams

6.48 The ethical approach to research in ageing that we have developed in this report represents a major shift in approach for many research teams working in this sector. We have argued that many different stakeholders have a responsibility to enable this shift in approach to be realised, with a particular emphasis on the responsibilities of those with the power to influence the culture and incentives that govern the research ecosystem (see paragraphs 5.52–5.53 and paragraph 6.3). However, researchers and research teams themselves also have a part to play: while they cannot necessarily influence the ‘sticks and carrots’ of the research ecosystem, they have personal and professional responsibility for the way that they frame and approach their own research, and the way

that they engage with older adults in the conduct of that research. In order to support researchers and research teams, we have developed further prompts and questions to our toolkit, aimed specifically at those directly involved in the conduct of research studies (see Box 6.2 and the interactive version of the toolkit online⁶⁵²; see also Box 6.5 for a similar tool for those responsible for implementation). We return in the final section of our report to other ways in which researchers could and should be supported through a more multidisciplinary approach both to education and practice (see paragraphs 6.58–6.61).

Box 6.2: An ethical approach to research: things to think about for research teams

Additional reflections for researchers, complementing the ethical toolkit.

Supporting flourishing in older age

- Involve potential users or beneficiaries of your research from the beginning – not least in identifying what would be of value to them. Don't assume you know what they need or value.
- Be explicit about success criteria in your study – who benefits and how? If the direct beneficiary is not older adults, how will older adults benefit indirectly – and what will be needed to ensure these indirect benefits are achieved? For example, innovations that streamline administrative tasks can help provide the gift of more time – but this is not a benefit to older adults if used simply to cut caregivers' hours.
- Think about complementary approaches – what does technology do well, and what can humans do better? If the introduction of technology removes valued social contact (even indirectly – for example through remote rather than in-person consultations), how can this be replaced in other ways?

Challenging ageism

- There are not many generalisations you can make about older adults except that they are a very heterogeneous group. Reflect on your own assumptions about ageing, and how these might influence your own work.

Promoting equity

- Be inclusive: reach out to diverse stakeholders, with a particular focus on those who are currently most marginalised, and recognise that involvement can take many different forms. Seek help from community engagement practitioners.
- Challenge yourself about who you imagine using your research – recognising the risk of working with stereotypes or majority-only populations in mind.

Shifting power

- What is needed to ensure that your research offers the prospect of empowering, not controlling, older adults?
- How can you mitigate against the risk that your research might be used to limit older adults' choices and agency?

Demonstrating trustworthiness

- Ensure your engagement with older adults is ongoing and iterative, creating 'feedback loops' so that people know how their comments have been taken on board. Be clear about what can, and can't, change as a result of engagement, and don't promise what you can't deliver.

⁶⁵² Nuffield Council on Bioethics (2023) *Ethical framework and toolkit*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/ethical-framework-and-toolkit>.

Enabling sustainability

- Be alert to the dangers of treating assistive technologies as something quite different from technologies in general use. Is there any reason why generally available technology can't meet the needs of older people through inclusive design?

Implementation

“Getting the right balance between social policy, health policy, and innovation and technology-based approaches is critical, and this will best be achieved by taking a proportionate and evidence-based approach to enable robust evaluation of all measures under consideration, to demonstrate their efficacy in practice.”⁶⁵³

- 6.49 While the primary focus of our inquiry has been on research and research practice, the subsequent translation of research findings into practice is an essential part of the picture.⁶⁵⁴ A key ethical consideration when undertaking research is the scope to create social value: in short, to offer the prospect of improving people's lives (e.g., see, paragraph 4.11 regarding the practical and moral hazards of failing to pay attention to the practical impact of research on the lives of participants). Effective translation of research findings is thus a matter of ethical concern for a number of reasons. It maximises the practical benefits of research, avoiding the scenario of effective interventions not being accessible or available or of multiple wasteful reinventions of the wheel. It avoids the adverse consequences of poor implementation that we highlighted in Chapter 4. Crucially, failing to act appropriately on the findings of research treats participants' contributions disrespectfully. It may also have a chilling effect on scope for research to contribute to improved practice in the future, by undermining both participants' and practitioners' willingness to engage in future research.
- 6.50 In the context of innovative technologies, for example, we highlighted risks that assistive devices might be used inappropriately, disempowering people rather than enabling them; that technologies might be used to benefit others, such as professional or family caregivers, in ways that were detrimental to older adults; or that potential benefits might not be realised because of a failure to adapt technologies to the specific, and changing, needs of individuals (see paragraphs 4.32–4.38). In the context of life sciences research, questions arise about access not only to novel diagnostics or treatments themselves but also to appropriate follow-up advice and support. Earlier diagnosis without any accompanying follow-up support or effective treatment may be actively harmful, as may a 'protocolised' approach to healthcare that fails to account for individual values, needs, or preferences (see paragraph 4.43).
- 6.51 Many of the conclusions and recommendations relating to research set out earlier in this chapter, especially those relating to meaningful involvement of older adults with a wide range of backgrounds and experiences, apply equally to implementation. In this final section of our report, we look briefly at two specific areas relevant to implementation: effective translation, and effective and respectful interdisciplinary working. We are aware

⁶⁵³ Dr Philippa Brice, PHG Foundation, responding to our call for evidence.

⁶⁵⁴ See, for example, Witham MD (2019) Bridging the gap between the laboratory and the clinic for patients with sarcopenia *Biogerontology* **20**(2): 241-8.

that there is an extensive literature on both these topics, and we touch here only on those aspects that emerged in our inquiry and are relevant to our ethical approach.⁶⁵⁵

Effective translation

“There should be greater funding and support for translation of effective interventions into policy and practice. It isn’t just a case of this works, just do it!”⁶⁵⁶

- 6.52 As we have emphasised throughout this report, one of the essential criteria for research to meet the needs of older adults is for the research to be carried out in partnership with potential future users and beneficiaries of research findings. A second element of that partnership approach lies in the relationship between researchers and other practitioners who will be involved in supporting the roll-out and continuing use of new interventions that are shown to be effective. Yet much more needs to be done to support closer connections between researchers and practitioners, even within the health and care fields, let alone across the wider social environment (housing, planning, transport, etc.) that influences our ability to live well as we age.
- 6.53 Many research funders currently encourage, or even require, researchers to demonstrate in their grant applications how they plan for their research to lead to change in practice, an approach that has been given extra weight in university research by requirements to demonstrate ‘impact’ as part of the Research Excellence Framework requirements.⁶⁵⁷ Grant proposals respond to these expectations in diverse ways: from simply setting out how researchers plan to share research findings with relevant stakeholders, to evidence of much more active engagement with practitioners from the start of the project, with plans for translation and evaluation built in from the beginning. While appropriate models will depend very much on the nature of the research, highly translational research such as innovative technologies will inevitably benefit from strong connections between research and practice, just as they benefit from partnership with older adults as the ultimate end-users.
- 6.54 We suggest that those funding research concerned with ageing, including the commercial sector, should consider ways in which they could be much more proactive in encouraging and supporting closer links between research and implementation. **One way in which funders can support genuinely integrated working between researchers and practitioners is to create funding calls that actively require partnership working, with applications to be made jointly by researchers and practitioners.** This model has proved very successful in other areas of research, with the funder Elhra, for example, funding partnerships between researchers and humanitarian workers to conduct research for health in humanitarian crises.⁶⁵⁸ The Dunhill Medical Trust (see Box 6.3) has just started developing a similar model in ageing research.

⁶⁵⁵ See, for example, The Health Foundation (2018) *The spread challenge*, available at: <https://reader.health.org.uk/the-spread-challenge>.

⁶⁵⁶ Vicki Goodwin, responding to our call for evidence.

⁶⁵⁷ UKRI (2022) *How Research England supports research excellence*, available at: <https://www.ukri.org/about-us/research-england/research-excellence/ref-impact/>.

⁶⁵⁸ Elrha (2018) *Research for health in humanitarian crises*, available at: <https://www.elrha.org/programme/research-for-health-in-humanitarian-crises/>.

Box 6.3: The Dunhill Medical Trust: funding approach

The Dunhill Medical Trust (DMT) has a history both of funding academic and clinical research into ageing and ageing-related diseases, and of supporting community-based organisations working to enhance the lives of older adults. In their 2020–2025 strategic framework and priorities, the DMT brought together these two work streams with the combined aim of developing “innovative, evidence-led and best practice ways of delivering housing, care and support for older people and in driving the systemic change needed to secure a healthier later life for us all”.⁶⁵⁹ This involves:

- developing cross-sector partnerships between researchers and community-led organisations;
- supporting evidence-informed community programmes, with a strong focus on age-friendly environments and connecting older adults to their wider community;
- providing targeted funding to community-led organisations to enable them to develop their own capabilities, including with respect to impact evaluation;
- being proactive in supporting networks and relationships, particularly between academic and practitioner communities; and
- proactively sharing outcomes of research grants and community-based projects.

As well as considering the quality and feasibility of the proposed work, the DMT also take a principle-based approach to funding: in order for their research idea to be considered as fundable, applicants need to demonstrate that they have the appropriate expertise within their team; how it will address equity, diversity, and inclusion; what they are planning to do to create real impact; and how all those in the team, especially early career researchers, will be supported as part of the project. Some grant calls explicitly require equal partnerships between academics and community organisations, and the application process involves a short video to illustrate the partnership approach planned.

Recommendation 13

We recommend that research funders should take active steps to promote closer working between the researchers they fund and those directly involved in providing the services that the research aims to influence. Possible approaches include creating grant opportunities directly aimed at partnerships between researchers and practitioners.

6.55 While such approaches may seem most obvious in areas of applied research concerned with adaptive technologies, they are also highly relevant in the biomedical sector, especially in the context of developments in early diagnosis. There is an ethical imperative to ensure that research findings can be rapidly translated into services if innovations in one area could actively cause harm when not rapidly accompanied by effective interventions (see paragraph 4.43). Particular emphasis is currently being placed on the scope for research to lead to earlier detection of particular health

⁶⁵⁹ The Dunhill Medical Trust (2020) *Remarkable research for healthy ageing: our strategic framework and priorities for 2020 to 2025*, available at: <https://dunhillmedical.org.uk/wp-content/uploads/2022/10/2020-25-Strategic-Framework-and-Themes.pdf>. See also: The Dunhill Medical Trust (8 April 2022) *Awards announcement: building and developing suitable living environments and communities for an ageing population*, available at: <https://dunhillmedical.org.uk/news/awards-announcement-building-and-developing-suitable-living-environments-and-communities-for-an-ageing-population/>; and The Dunhill Medical Trust (2022) *TAPPI: Phase 2 – from Principles to Implementation: Call for proposals for locality-based organisations*, available at: <https://dunhillmedical.org.uk/wp-content/uploads/2022/03/22-03-TAPPI2-call-Local-Orgs-guidelines-FINAL.pdf>.

conditions, including detecting a person's increased risk of developing a condition later in life. It is vital that the evidence base for such 'early detection' or screening is robust – in particular in demonstrating benefit over later detection – especially given the risk that early detection may divert resources away from those with later stages of the condition. As the value of such early detection depends very much on the availability of effective support or treatment, it is equally important that any research in this field is accompanied from the very beginning by planning for how such support or treatment will be provided. This is only likely to happen through effective partnerships between research teams and service providers, along with commitment from policy-makers to ethical and effective translation of research findings.

Recommendation 14

We recommend that, following existing good practice in screening policy, any new screening or testing programmes associated with age-related conditions should only be rolled-out if accompanied by robust, properly funded, services that offer meaningful support to people who receive such diagnoses and their families and those who provide care and support.

Flexibility at local level

- 6.56 We have made the case for the enabling role of the state and the public sector (see paragraphs 5.56–5.59), but this should not be conflated with a top-down approach to the roll-out of new interventions or innovative technologies.⁶⁶⁰ Local flexibility and responsiveness are crucial, both at the level of responding appropriately to the needs and priorities of different communities, and at the level of individual support. The 2022 white paper *Health and social care integration: joining up care for people, places and populations* (applicable to England) makes a strong case for such integrated working among public sector organisations alongside the introduction of integrated care systems and promised reform of the adult social care sector.⁶⁶¹
- 6.57 Responsive systems and services are also most likely to draw on a combination of public, private, and community-led providers: innovative examples of the latter include the development of 'community circles' who help support individuals through leveraging person-centred support from friends and volunteers, as a valuable piece of the jigsaw alongside paid-for services.⁶⁶² If innovative technologies and approaches are to be successfully deployed within this complex web of people and institutions providing care and support, funding for implementation and evaluation will need to be appropriately flexible. In particular, this will involve cooperation between funding sources from many different streams, including diverse research funders, different parts of the NHS, local authorities, and local community resources. **We highlight the importance of key parts of the public sector (including, but not limited to, the health, social care, and housing sectors) having the flexibility to collaborate and pool budgets so that they can focus on using innovation to meet needs in the most appropriate way for the person concerned, rather than being concerned where budgetary responsibility lies.** Such flexibility also needs to include scope to support small community-led

⁶⁶⁰ See, for example, Ham C (2022) Politicians must behave differently and support NHS leaders to change cultures and improve patient care *British Medical Journal* **377**: o1437 for a critique of the problems of top-down management approaches.

⁶⁶¹ Department of Health and Social Care (2022) *Joining up care for people, places and populations* available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1055687/joining-up-care-for-people-places-and-populations-web-accessible.pdf.

⁶⁶² Community Circles (2022) *How we work*, available at: <https://www.community-circles.co.uk/>.

initiatives that are sensitive to the needs of diverse older adults and may be particularly well placed to support take-up of, and confidence with, innovation, especially given the importance of human support in tailoring technological options to a person's needs (see paragraph 4.31).

Interdisciplinary and interprofessional working

“Without a cross-disciplinary approach, we will be unable to understand ageing and enhance the experience for the population in general.”⁶⁶³

“The thing with disability services is that other services should be helping people as it's a growing population. More and more people are getting older and services are not actually catered and services like organisations are not getting involved in helping people and are restricted to one service and all services should be helping.”⁶⁶⁴

- 6.58 Alongside the difficulties of navigating different institutions and funding streams to embed research findings and effective innovations, there are the well-recognised challenges of working across professional ‘silos’ – within the healthcare system (e.g., between medical specialties or across different clinical professionals) and, to an even greater degree, across the health, social care, housing, and other sectors. The existence of many different professional pathways, from the beginning of undergraduate education onwards, contributes to the lack of awareness of the malleability of ageing among many professionals working in this field, leading to the ‘it’s your age’ fatalism that is all too prevalent in the health sector, and indeed in parts of the research sector (see paragraph 2.6). Different methods and mindsets in different disciplines can compound these challenges, leading to a lack of confidence in evidence generated by different disciplines or professions.
- 6.59 Many of our call for evidence respondents highlighted the importance of interdisciplinary working (both within research and between the research sector and the health and care sectors) as being essential: both for meaningful research, informed by knowledge of practice, and for the effective translation of successful research findings.⁶⁶⁵ Such interdisciplinary working also plays an important role in recognising where there are gaps in evidence – pointing both to where more research is needed, and to where caution should be exercised with respect to assumptions about the benefit of particular interventions or innovations. It is also necessary for ongoing evaluation, enabling the evidence base to be improved by understanding how innovations work in different contexts. Interdisciplinarity is an important element of the 11 Ageing Networks supported by the BBSRC and MRC (see Box 6.4).
- 6.60 Good practice examples cited to the working group for improving interdisciplinarity in the context of care and practice in relation to ageing included the following.

⁶⁶³ Professor Andrew Steptoe, responding to our call for evidence.

⁶⁶⁴ Nuffield Council on Bioethics (2022) *Workshop with Greater Manchester Growing Older with Learning Disabilities (GM GOLD)*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/greater-manchester-growing-older-with-learning-disabilities-gm-gold>.

⁶⁶⁵ Nuffield Council on Bioethics (2023) *The future of ageing: call for evidence summary of responses*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/public-dialogue-on-the-future-of-ageing>.

- Developing regional ‘hubs of engagement’ between health and social care professionals and researchers.
- Encouraging funders to design schemes to support greater mobility between different sectors, including academia, industry, public health, the NHS, and local authorities.
- Providing for dedicated research time in health and care professional contracts.
- Setting clear targets for research activity by NHS trusts or in integrated care systems.
- Ensuring that undergraduate curricula for all health and care practitioners equip them better to engage in research.

Box 6.4: Multidisciplinary working with a public focus

The Lifelong Health multidisciplinary research theme at Queen Mary University of London is taking a collaborative approach to supporting healthy ageing throughout the life course, bringing together basic science research with active collaboration with local partners in East London to address health inequalities. The connections between research and practice are regarded as particularly important, and the Lifelong Health theme includes an education arm, focused on supporting the next generation of researchers interested in ageing.

Directors of the Lifelong Health theme are also partnering with researchers at the University of Liverpool, London School of Hygiene and Tropical Medicine, University of Birmingham, and Newcastle University to form one of the 11 new Ageing Networks funded by Biotechnology and Biological Sciences Research Council (BBSRC) and Medical Research Council (MRC) (see Box 3.3). The ‘CELLO’ network (An interdisciplinary ageing alliance: cellular metabolism over a life course in socioeconomic disadvantaged populations) will have a particular focus on disadvantaged populations and the need for research to narrow the gap of health inequalities. In addition to exploring genetic and environmental factors affecting how cells age from an early age, the CELLO network is actively engaging with local partners to provide research expertise in community projects. Initiatives include working with Hackney Council to evaluate the impact of regeneration projects on older residents, supporting a health inequalities ‘sandpit’ to identify key priorities for tackling local health inequalities, and hosting a stand at Queen Mary’s annual ‘Festival of Communities’ to engage local families with their research.

- 6.61 The working group felt that professional education (from undergraduate level onwards) has a particularly important role to play in creating more interdisciplinary approaches to ageing, particularly in increasing awareness of the malleability of ageing, and the importance of a life-course approach; promoting more holistic and coordinated approaches to the care and support of older adults; and making best use of research and innovation.

Recommendation 15

We recommend that providers of undergraduate education for health professionals and biomedical scientists ensure that their students gain a rounded, interdisciplinary, understanding of ageing, including the ethical considerations set out in our ethical framework and toolkit.

Supporting practitioners responsible for implementation

6.62 At the beginning of this chapter, we recognised how hard it is to introduce innovations in a context of time, resource, and financial pressures (see paragraph 6.2). Practitioners seeking to introduce innovative approaches, technologies, or services into practice need tools and support to do so in an ethical and evidence-informed manner. We conclude this report by providing further focused prompts and questions as an addition to our toolkit, aimed specifically at those responsible for translating research into practice. We hope that these tools (also made available in an interactive form through our website⁶⁶⁶) will help translate the ethical values and principles that have emerged through this inquiry, informed by the expertise and knowledge of so many contributors, into a practical tool for future use (see Box 6.5).

Box 6.5: An ethical approach to implementation: things to think about

Additional reflections for practitioners responsible for implementation, complementing the ethical toolkit.

Supporting flourishing in older age

- Think about relationships and social connectedness – how can you ensure that the innovation you are introducing will enhance, and not detract from, relationships that are important to the older adult concerned?
- Be explicit about success criteria when implementing – who benefits and how? If the direct beneficiaries are not older adults, how will older adults benefit indirectly – and what will be needed to ensure these indirect benefits are achieved? For example, innovations that streamline administrative tasks can help provide the gift of more time – but this is not a benefit to older adults if used simply to cut caregivers' hours.
- Think about complementary approaches – what does technology do well, and what can humans do better? If the introduction of technology removes valued social contact (even indirectly – e.g., through remote rather than in-person consultations), how can this be replaced in other ways?

Challenging ageism

- There are not many generalisations you can make about older people except that they are a very heterogenous group. Reflect on your own assumptions about ageing, and how these might influence your own work and how you implement innovative approaches, technologies, or services into practice.

Promoting equity

- Be inclusive: reach out to diverse stakeholders, with a particular focus on those who are currently most marginalised, and recognise that involvement can take many different forms. Seek help from community engagement practitioners.
- Be clear about the evidence base for the proposed innovation – and ensure there is implementation research/ ongoing evaluation, including consideration of equity and resource requirements.

Shifting power

- What is needed to ensure that the changes you are implementing offer the prospect of empowering, not controlling, older adults?
- When implementing novel approaches, ensure genuine choice, offering alternative forms of care/services when preferred (avoiding technology as an 'enforced default').

⁶⁶⁶ Nuffield Council on Bioethics (2023) *Ethical framework and toolkit*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/ethical-framework-and-toolkit>.

- What are the pros and cons of specialist technologies and devices versus generally available technology?

Demonstrating trustworthiness

- Ensure your engagement with older adults is ongoing and iterative, creating 'feedback loops' so that people know how their comments have been taken on board. Be clear about what can, and can't, change as a result of engagement, and don't promise what you can't deliver.

Enabling sustainability

- What are the pros and cons of specialist technologies and devices versus generally available technology?
- Consider if universal design includes scope for personalisation/adaptability. What support will be available for doing this?
- Think about what arrangements are in place to meet the need for adaptation over time, including continuing technical or other support.

Appendices

Appendix 1: Method of working

Background

On 24 July 2020, The Nuffield Council on Bioethics launched its project on the future of ageing. The Council appointed a working group for the project on 10 December 2020. The working group met 11 times (in person and online) between December 2020 and September 2022.

Call for evidence

To inform its deliberations, the working group launched a call for evidence in June 2021, which received 21 submissions. Further details of the call for evidence are available in **Appendix 2**.

Roundtable meetings

The working group held a series of roundtable meetings with a wide range of individuals and representatives of organisations, the details of which can be found below.

Roundtable on understandings of ageing, 10 June 2021

The purpose of the meeting on understandings of ageing was to explore how attitudes to ageing influence research and innovation and how more positive attitudes to ageing could be promoted within the research and innovation context.

- **Laia Becares**, Senior Lecturer in Applied Social Science, University of Sussex (provided a presentation as was unable to attend)
- **Stefania Ilinca**, Researcher, European Centre for Social Welfare Policy and Research
- **Louise Lafortune**, Senior Research Associate, Cambridge Institute of Public Health
- **Jeremy Myerson**, Chair of Design, Royal College of Art
- **Jing-Bao Nie**, Professor, Bioethics Centre, University of Otago

Roundtable with members of Technology and Ageing Special Interest Group, British Society of Gerontology, 24 June 2021

The purpose of this workshop with members of the British Society of Gerontology's Technology and Ageing Special Interest Group was to understand members' current and past research and to explore the associated ethical challenges.

- **Neil Chadborn**, Research Fellow, University of Nottingham
- **Nathan D'Cunha**, Associate Lecturer, University of Canberra
- **Diane Gibson**, Distinguished Professor (Health and Ageing), University of Canberra
- **Grant Gibson**, Lecturer in Dementia Studies, University of Stirling
- **Stephen Isbel**, Associate Professor and Discipline Lead of Occupational Therapy, The University of Canberra Hospital
- **Jenni Lynch**, Senior Research Fellow, University of Hertfordshire
- **Louise McCabe**, Senior Lecturer in Dementia Studies, University of Stirling
- **Anthea Tinker**, Professor of Social Gerontology, King's College London

Roundtable on geroscience, 21 July 2021

The purpose of the geroscience roundtable was to gain insights into the current and future trends in geroscience research and explore the associated ethical issues.

- **Rhoda Au**, Professor of Anatomy and Neurobiology, Boston University (via pre-recorded video)
- **Jesus Gil**, Professor of Cell Proliferation, Imperial College London
- **Lorna Harries**, Professor of Molecular Genetics, University of Exeter
- **Sian Henson**, Professor in Immunology, Queen Mary University of London
- **Tom Kirkwood**, Emeritus Professor, Newcastle University

Roundtable on technologies, 21 July 2021

The purpose of this roundtable meeting was to gain insights on current and future trends in the development of technologies aiming to support health and wellbeing in older age and explore some of the associated ethical issues.

- **Gemma Burgess**, Director, Cambridge Centre for Housing and Planning Research
- **Malcolm Fisk**, Professor of Ageing and Digital Health, De Montfort University
- **Alex Hall**, Research Associate, School of Social Services, University of Manchester, and Manchester Institute for Collaborative Research on Ageing
- **Nic Palmarini**, Director, National Innovation Centre for Ageing
- **Shannon Vallor**, Chair, Ethics of Data and Artificial Intelligence, Edinburgh Futures Institute

Roundtable on ageing, AI, and data-driven innovation, 7 December 2021

The purpose of this roundtable meeting was to gain insights on how the developments in AI and data-driven innovation may help support people to live better in older age, and to explore some of the associated ethical issues.

- **Alastair Denniston**, Professor, Institute of Inflammation and Ageing, University of Birmingham; Consultant Ophthalmologist
- **Keith Grimes**, Clinical Digital Health and Innovation Director, Babylon Health
- **George Onisiforou**, Research Manager, NHS AI Lab
- **Elizabeth Sapey**, Professor and Director, Institute of Inflammation and Ageing; Managing Director, NIHR Clinical Research Facility, Birmingham; Consultant, Respiratory Medicine and General Internal Medicine
- **Tina Woods**, Founder and CEO, Collider Health; CEO, Business for Health; Secretariat Director, All-Party Parliamentary Group on Longevity; Healthy Longevity Champion, National Innovation Centre for Ageing

Roundtable on coproduction, 22 February 2022

The purpose of the evidence session on coproduction was to understand the key components of engagement and coproduction: how researchers and developers can work in meaningful partnership with older people, particularly in the development of health-related research and technological innovation.

- **Nick Andrews**, Research Officer, Social Work, Swansea University

- **Arlene Astell**, Director, Dementia Aging Technology Engagement lab, University of Toronto
- **Lynne Corner**, Director, VOICE
- **Bev Creagh**, Trustee of Age Concern Luton and coproducer in exploring how robots designed to be culturally competent interacted with real human beings (with Gurch Randhawa)
- **Rochelle Michaud**, coproducer on MCI@work (Canada) examining the experience of individuals who develop mild cognitive impairment of dementia while still working (with Arlene Astell)
- **Gurch Randhawa**, Professor of Diversity in Public Health; Director, Institute for Health Research, University of Bedfordshire

Roundtable with policy stakeholders, 20 June 2022

The purpose of this roundtable was to explore the emerging findings/draft recommendations from a policy perspective, with the aim of making them as well-informed and practical as possible.

- **Jessica Boname**, Head of Research on Ageing, Medical Research Council
- **Philippa Crane**, Knowledge Exchange Manager, UK SPINE
- **Shantelle Million-Lawson**, Senior Policy Manager (Care Tech and Innovation), Department of Health and Social Care
- **Sadhana Sharma**, Strategy and Policy Manager, Biotechnology and Biological Sciences Research Council
- **Elizabeth Webb**, Head of Research, Age UK
- **Glenn Wells**, Chief Partnerships Officer, Medicines and Healthcare products Regulatory Agency
- **Naho Yamazaki**, Head of Policy and Engagement, Health Research Authority

Meetings with individuals

Nuffield Council project staff and members of the working group also met (in person or remotely) with a number of individuals over the course of the inquiry (titles correct at the time of meeting). They included:

- **Yasmin Allen**, FORUM Policy Manager, The Academy of Medical Sciences
- **Samantha Benham-Hermetz**, Director of Policy and Public Affairs, Alzheimer's Research UK
- **Paula Boddington**, Associate Professor of Philosophy and Healthcare, Geller Institute of Aging and Memory, University of West London
- **Jess Boname**, Head of Research on Ageing, Medical Research Council
- **Shamma Booth**, Policy Advisor, Alzheimer's Research UK
- **Emily Boyce**, Knowledge Exchange Manager, Babraham Institute
- **Jo Brown**, Research Project Manager (Lifelong Health) at Queen Mary University of London
- **David Calder**, Knowledge Transfer Manager, Innovate UK KTN
- **Li Chan**, Senior Lecturer Paediatric Endocrinology, Queen Mary University of London
- **Jenny Collieson**, Board Member, Ageing Without Children
- **Lynne Cox**, Associate Professor in Biochemistry, Fellow of Oriel College, University of Oxford
- **Phillipa Crane**, Knowledge Exchange Manager, UK SPINE
- **Anna Dixon MBE**, Chair, Archbishops' Commission on Reimagining Care
- **Kate Dulwich**, Knowledge Exchange and Commercialisation Officer, Babraham Institute

- **Francesca Edelmann**, Technical Specialist – Software, Apps and AI, Medicines and Healthcare products Regulatory Agency
- **Catherine Foot**, Director, Phoenix Insights
- **Sharon Kaufman**, Chair, Department of Anthropology, University of California San Francisco
- **Susan Kay**, Chief Executive, The Dunhill Medical Trust
- **Ross King**, Programme Manager (Life Course and Ageing), Population and Systems Medicine Board, UK Research and Innovation
- **Anna Hands**, Policy Officer, The Academy of Medical Sciences
- **Sian Henson**, Professor in Immunology, Translational Medicine & Therapeutics, Queen Mary University of London
- **Angus Metcalfe**, Managing Director, Global Healthcare, British Standards Institution
- **Alex Mihailidis**, Scientific Director, AGE-WELL (Canada)
- **Johan Ordish**, Head of Software and AI, Medicines and Healthcare products Regulatory Agency
- **Jackie Ouchikh**, Head of Programmes, Centre for Science and Policy, Cambridge University
- **Lily Parsey**, Global Policy and Influencing Manager, International Longevity Centre UK
- **Sheuli Porkess**, Interim Medical Director, The Association of the British Pharmaceutical Industry
- **Oliver Rashbrook-Cooper**, Programme Manager, Office for Health Improvement and Disparities
- **Joanna Robinson**, Head of Population Medicine Board, UK Research and Innovation
- **James Squires**, Interim Head of Policy, The Academy of Medical Sciences
- **Sanjay Thakrar**, Head of Research Policy and Awards, The Dunhill Medical Trust
- **Graeme Tunbridge**, Senior Vice President Global Regulatory and Quality, Medical Devices, British Standards Institution
- **Elizabeth Webb**, Head of Research, Age UK
- **Glenn Wells**, Chief Partnerships Officer, Medicines and Healthcare products Regulatory Agency
- **Tom Wells**, Deputy Director, Government Office for Science
- **Tina Woods**, Founder and CEO, Collider Health; CEO, Business for Health; Secretariat Director, All-Party Parliamentary Group on Longevity; Healthy Longevity Champion, National Innovation Centre for Ageing

Practitioner survey

On 8 June 2021, the working group launched an anonymous survey aimed at practitioners who work with older adults, which received ten responses. Further details of the practitioner survey are available in **Appendix 2**.

Engagement activities

To inform its deliberations, the working group undertook a programme of engagement activities to explore the views of members of the public on biomedical science and technology and living well in later life. Further details of the engagement programme are available in **Appendix 3**.

Evidence reviews

The working group undertook four evidence reviews.

- Geroscience: a review of the current clinical trials targeting the hallmarks of ageing carried out by Molly Gray.
- An evidence review giving an overview of the technology and AI for older adults carried out by Molly Gray.
- An evidence review on health- and wellbeing-focused home technology carried out by Molly Gray and Kate Harvey.
- A rapid evidence review on older adults' own perceptions, experiences, and values of living well in old age carried out by Molly Gray.

External reviews

A draft version of the working group's report was circulated to external reviewers in August 2022. The reviewers were:

- **Jabeer Butt OBE**, Chief Executive, Race Equality Foundation
- **Neil Crowther**, Independent Social Change Consultant, Neil Crowther Consulting
- **Simon Denegri**, Executive Director, Academy of Medical Sciences
- **Michael Dunn**, Associate Professor, National University of Singapore
- **Catherine Foot**, Director, Phoenix Insights
- **Vicki Goodwin**, Professor in Ageing and Rehabilitation, NIHR ARC South West Peninsula, University of Exeter
- **Rose Anne Kenny**, Professor of Geriatric Medicine/Consultant, Trinity College Dublin
- **Tom Kirkwood**, Emeritus Professor, National Innovation Centre for Ageing, Newcastle University; Affiliate Professor, University of Copenhagen Center for Healthy Aging
- **Richard Milne**, Senior Social Scientist, Wellcome Genome Campus, University of Cambridge
- **Nic Palmarini**, Director, UK National Innovation for Centre Ageing
- **Sridhar Venkatapuram**, Deputy Director, King's Global Health Institute
- **Tina Woods**, Founder and CEO, Collider Health; Healthy Longevity Champion, National Innovation Centre for Ageing
- **Zoe Wyrko**, Well-Being Director, Riverstone

Appendix 2: Wider consultation for the report

Call for evidence

The working group's call for evidence was launched on 8 June 2021 and remained open until 2 August 2021. The aim of the call for evidence was to gather in-depth information from individuals and organisations with an existing knowledge and interest in the role that biomedical research and technological innovation can play in helping people live well in old age. We received 21 responses to the questions set out in this section: 17 from individuals; four from organisations. We had one additional response to our fictional scenarios. A summary of respondents' submissions is available on the Nuffield Council's website.

Questions posed

The call for evidence invited respondents to comment on 11 questions, which were divided into six sections.

Section 1: How we think about ageing

Question 1: Please comment on how attitudes to ageing influence research and innovation – and how more positive attitudes to ageing could be promoted within the research and innovation context.

Question 2: Please comment on the advantages and disadvantages of taking a more inclusive approach (e.g., in design, in healthcare, in wider social policy) so that the needs of older people are 'designed in' to mainstream approaches, rather than considered separately.

Section 2: The aims of research and innovation in this field - and how they are prioritised

Question 3: What priority-setting processes in ageing research / innovation are you familiar with? How do you think they should change, if at all?

Question 4: Which ageing challenges should medical and technological developments prioritise – and why?

Section 3: Design and conduct of research studies related to ageing

Question 5: Please comment on the likely benefits, and possible harms, of developments in the area of ageing research with which you are familiar.

Question 6: Please comment on the role of older people, and of intergenerational public input, in helping shape research and innovation directed towards the needs of current and future older populations.

Question 7: How can older people be better represented in clinical trials that are of potential relevance to them?

Question 8: Please comment on the ethical aspects of the regulatory challenges raised by the field of ageing research with which you are familiar.

Section 4: Understanding research and innovation in the wider policy context

Question 9: What role should biomedical and technological approaches play versus greater emphasis on, and funding of, other policy approaches that might have a similar effect on 'levelling up' the healthspans of the most disadvantaged to the least?

Section 5: Implications for who bears responsibility for healthy ageing

Question 10: Please comment on the responsibilities of the various stakeholders (older people themselves, their families, professionals, wider society, the state) with respect to a healthier old age – including with respect to intergenerational solidarity and fairness.

Section 6: Any other comments

Question 11: Please raise any other issues that you consider relevant to our terms of reference, including any comments you might wish to make on the fictional future research scenarios on our webpage.

List of respondents to the expert call for evidence

Individuals (17)

- *Anonymous (2)*
- Kjell Asplund, Chair of the Board, National Board of Health and Welfare, Sweden
- Dr Anna Bone and Professor Katherine Sleeman, Cicely Saunders Institute, King's College London
- Dr Erica Borgstrom, The Open University
- Dr Philippa Brice, PHG Foundation
- Professor Michael Dunn, Associate Professor, National University of Singapore
- Professor Leonard M. Fleck, Center for Bioethics and Social Justice, the College of Human Medicine, Michigan State University
- Professor David Gems, Institute of Healthy Ageing, University College London
- Professor Vicki Goodwin, Professor of Ageing and Rehabilitation, University of Exeter
- Professor Christine Hine, University of Surrey
- Sangeetha Neeraja Babu Manoharan, Centre for Ageing Research (C4AR), Lancaster University
- Dr Hannah R. Marston, The Open University; Dr Deborah J. Morgan, Swansea University; Dr Gemma Wilson-Menzfeld, Northumbria University; Ms Jessica R. Gates, Northumbria University; and Mr Robbie Turner, Spektrum Consulting
- Alex Ruck Keene, 39 Essex Chambers and King's College London
- Professor Andrew Steptoe
- Professor Miles Witham and Professor Avan Sayer, NIHR Newcastle Biomedical Research Centre; AGE Research Group
- Thomas Woodcock, retired NHS Consultant

Organisations (4)

- The Academy of Medical Sciences
- British Pharmacological Society
- Care England
- International Longevity Centre UK

Survey for practitioners who work with older adults

The working group launched an anonymous survey aimed at practitioners who work with older people on 8 June 2021 and remained open until 2 August 2021. The survey, titled 'Health technologies and the future of ageing' was hosted on Microsoft Forms and was publicised via the working group's professional contacts, social media, the Nuffield Council's newsletter, and personalised emails to practitioners' membership organisations. The survey received ten responses (from six doctors, one physiotherapist, a researcher, and two other practitioners who did not specify their roles).

Questions posed

The survey invited respondents to comment on 9 questions and an opportunity to share stories of experiences with technologies in the context of work.

Question 1: Please describe how you use any of these technologies to support older people.

Question 2: In your work with older people, what conditions or issues do you find are especially helped by any of these technologies?

Question 3: Do any technologies you currently use in the context of your work cause you concern? Why / why not?

Question 4: Do any technologies in development cause you concern in the context of your future work? Why / why not?

Question 5: Do you think technologies will change how your role is carried out in the future? If so, how?

Question 6: Do you think that there are any barriers to people's use of technologies as they age? If so, what are those barriers? How might they be overcome?

Question 7: Do you think these technologies will impact all older people in the same way? Please explain your answer.

Question 8: Please provide any other points you would like to make on how technologies are used in the context of your work with older people.

Question 9: Are there any resources on technologies to support older people that you think we should read and consider? Please list here if so.

Appendix 3: Engagement activities

Creative engagement workshops

To inform its deliberations, the working group undertook a programme of engagement activities to explore the views of members of the public on biomedical science and technology and living well in later life. The working group ran five engagement workshops using creative methods to illicit discussions on how biomedical science and technology can support people to have a good, or bad, older age. The workshops took place between 11 August 2021 and 8 June 2022.

Bristol Older People’s Forum drawing workshop, 11 August 2021

This workshop was held with the organisation Bristol Older People’s Forum (BOPF) and used drawing as a method to explore how science and technology can support people in later life. The workshop was held on Zoom and was facilitated by working group member, Muna Al-Jawad. The workshop consisted of nine participants; all were female. Prior to the workshop, participants were asked to create two drawings which showed, respectively, how technologies (particularly health technologies) could support a ‘good’ older age, or risk a ‘bad’ older age. Following the workshop, using the themes raised by Forum members’ drawings during the workshop, Muna drew a summary cartoon of the workshop called ‘Alice’s adventures in tech-land’, which is available on the Nuffield Council’s website.⁶⁶⁷

Open forum with members of the Greater Manchester Older People’s Network, in collaboration with Sonder Radio, 18 August 2021

This workshop took place online, via Zoom, as an open forum, with 15 members of the Greater Manchester Older People’s Network (GMOPN), and other residents living in Manchester, in collaboration with Sonder Radio. The event included performances from musician Martin Stephenson who performed ‘Old and only in the way’ and from poet Roger McGough, who read his poem ‘Love later life’, a piece commissioned by Age UK in 2014. These performances were used to open discussions with the workshop participants’ concerns around getting older, the technologies that support them in older age, and what the future of ‘living well’ in older age might ‘look like’. After the workshop, Sonder Radio created a radio broadcast bringing together the discussions held at the open forum, which is available on the Nuffield Council’s website.⁶⁶⁸

West Bromwich African Caribbean Resource Centre focus group, 23 March 2022

This focus group took place at the West Bromwich African Caribbean Resource Centre and consisted of 13 older people of African and Caribbean heritage, aged 75 years and older. Out of the 13 participants, three were male and ten were female. The focus group was facilitated by Bella Starling, Chair of the working group, and used photographs of various technologies, including care robots and personal alarms, to stimulate discussions among participants. A blog

⁶⁶⁷ Nuffield Council on Bioethics (2022) *Online workshop with members of the Bristol Older People’s Forum*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/online-workshop-with-members-of-the-bristol-older-peoples-forum-bopf>.

⁶⁶⁸ Nuffield Council on Bioethics (2022) *Open forum with members of the Greater Manchester Older People’s Network, in collaboration with Sonder Radio*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/open-forum-with-members-of-the-greater-manchester-older-peoples-network-gmopn-and-other-residents-in-manchester-organised-in-collaboration-with-sonder-radio>.

describing the key themes from the focus group is available on the Nuffield Council's website.⁶⁶⁹

Intergenerational roundtable event in Exeter, 25 April 2022

This workshop took place in Exeter and was organised in collaboration with working group member Ann Gallagher and her colleagues from Exeter University's Academy of Nursing and Chris Frankland from Exeter College. The event consisted of 41 participants on eight roundtables, predominantly college and university students (aged 16-25), with a smaller number of middle-aged and older adults (aged 50-70). The event was split into two key discussions: the role of technology in healthy ageing, and the role of biomedicine in healthy ageing. For the first session, the film 'Uninvited Guests' was used as a stimulus for discussion and for the second session, working group member, Janet Lord, gave a short presentation on geroscience to stimulate questions on ageing and biomedical research.⁶⁷⁰ A short report detailing the key themes elicited from the roundtable event is available on the Nuffield Council's website.⁶⁷¹

Greater Manchester Older Adults with Learning Disabilities workshop, 8 June 2022

The working group held a workshop in collaboration with the organisation Greater Manchester Older Adults with Learning Disabilities (GM GOLD). The workshop was held at Manchester Metropolitan University and was co-facilitated by Melanie Chapman (Research Fellow, Disability and Community, Manchester Metropolitan University) and Molly Gray (Researcher, Nuffield Council on Bioethics). The workshop consisted of 10 older adults with learning disabilities and was split into two sessions. The first session involved designing a 'dream machine' using crafting materials, that members would want in later life to improve healthy ageing. The second workshop consisted of an interview-style filming session, run by Andy Needle (Project Coordinator, Manchester People First, a self-advocacy group for adults with a learning disability). The key discussions from the 'dream machine' workshop was written up into a blog which is available on the Nuffield Council's website.⁶⁷² Manchester People First created a video from the discussions held at the filming workshop, which is also available on the Nuffield Council's website.⁶⁷³

Deliberative public dialogue

The working group commissioned insight and strategy consultancy BritainThinks, to design and deliver a deliberative public dialogue in April 2022. The aim of the dialogue was to explore people's views on our draft recommendations and provisional findings on key issues explored in this report. The dialogue involved 24 members of the public from two locations (Leeds and Kent). The participants met three times over two weeks in June 2022, once in person and twice

⁶⁶⁹ Nuffield Council on Bioethics blog (2022) *The future of ageing – learning from the West Bromwich African Caribbean Resource Centre*, available at: <https://www.nuffieldbioethics.org/blog/the-future-of-ageing-learning-from-the-west-bromwich-african-caribbean-resource-centre>.

⁶⁷⁰ YouTube (2015) *Uninvited guests*, available at: <https://www.youtube.com/watch?v=Ear8W-C96bk>.

⁶⁷¹ Nuffield Council on Bioethics (2022) *Intergenerational roundtable event in Exeter*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing>.

⁶⁷² Nuffield Council on Bioethics blog (2022) *If you could design your 'dream machine' to help you in older age, what would it be?*, available at: <https://www.nuffieldbioethics.org/blog>.

⁶⁷³ Nuffield Council on Bioethics (2022) *Workshop with Greater Manchester Growing Older with Learning Disabilities (GM GOLD)*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/greater-manchester-growing-older-with-learning-disabilities-gm-gold>.

online via Zoom. A shorter interactive report and a full report on the public dialogue is available on the Nuffield Council's website.⁶⁷⁴

⁶⁷⁴ Nuffield Council on Bioethics (2023) *Public dialogue report on the future of ageing*, available at: <https://www.nuffieldbioethics.org/publications/the-future-of-ageing/evidence-gathering/public-dialogue-on-the-future-of-ageing>.

Appendix 4: The working group

Bella Starling (Chair) is Director of Vocal and Professor of Inclusive Research at Manchester Academic Health Science Centre. She is also a Wellcome Trust Engagement Fellow and Patient and Public Involvement and Engagement lead for the NIHR Manchester Biomedical Research Centre and Clinical Research Facility. Her career has spanned basic research, science writing, biomedical ethics, public engagement, patient involvement, and science policy, as a practitioner, action researcher, strategic adviser, and funder. She is passionate about inclusion in, and democratisation of, biomedical and health research; her Fellowship explores how public engagement with research acts as a catalyst for scientific and social change.

Muna Al Jawad is a Consultant in Medicine for Older People at the Royal Sussex County Hospital in Brighton. She is a senior lecturer in medical education and lead for curriculum development at Brighton and Sussex Medical School. Muna is a practitioner-researcher. She uses qualitative methods to explore, understand, and improve healthcare practices, particularly regarding care for older people and practitioner identity. In addition, she draws comics as part of her research process – you can find some of them [here](#).

Carol Brayne CBE FMedSci is a Professor of Public Health Medicine and co-Director of Cambridge Public Health, University of Cambridge. She was previously Director of Cambridge Institute of Public Health. Her research focus has been longitudinal studies focusing on brain ageing and dementia, studies that contribute to national and international policy development. She has led research on ethical, legal, and social implications around diagnostic testing and availability. She is a member and Chair of scientific advisory boards, and Royal College Committees.

Frances Flinter is Emeritus Professor of Clinical Genetics at Guy's and St Thomas' NHS Foundation Trust, where she was also the Caldicott Guardian for 12 years. She is a member of the Nuffield Council on Bioethics, and of the Human Fertilisation and Embryology Committee. From 2019–2021 she was Scientific Adviser to the Science and Technology Committee for their investigation into Commercial Genomics. She was the elected President of the Clinical Genetics Society from 2009–2011 and previously served on the Human Genetics Commission.

Ann Gallagher is Head of Nursing and Professor of Care Education, Ethics and Research at the Academy of Nursing, University of Exeter. She is Editor-in-Chief of Nursing Ethics, a Fulbright Scholar, and served two terms as a member of the Nuffield Council. She co-led (with Michael Dunn) a Wellcome Trust funded project on the theme of Roles, Responsibilities, and the Future Care of Older Adults, bringing together perspectives from 11 countries.

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company which has developed an expert system to match people to appropriate technology. He sat on several committees and expert advisory groups, as a design judge, adviser, etc. In 2018 he was the lead author of the Compression of Functional Decline paper, which focused on the malleability of the ageing process – around which he lectures routinely across the UK and overseas.

Baroness Sally Greengross OBE (until June 2022). Until her death in June 2022, Sally was a crossbench (independent) member of the House of Lords and she co-chaired five All-Party Parliamentary Groups: Dementia, Corporate Social Responsibility, Bladder and Bowel Continence Care, Social Care, and Ageing and Older People. She was Vice Chair of the All-Party Parliamentary Groups on Choice at the End of Life and Longevity, and Treasurer of the All-Party Parliamentary Group on Equalities. Sally also chaired the cross-party Intergenerational Fairness Forum. Sally was Chief Executive of the International Longevity Centre – UK. Her work on ageing has been recognised by the UN Committee on Ageing and she received an outstanding achievement award from the British Society of Gerontology as well a British Geriatric Society Medal. Sally was UK Woman of Europe in 1990 and was an Ambassador for the Prince of Wales supporting responsible business practice.

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Janet Lord CBE FMedSci is Professor of Immune Cell Biology and director of the MRC-Versus Arthritis Centre for Musculoskeletal Ageing Research at Birmingham University. She is a theme lead in the National Institute for Health and Care Research (NIHR) and Birmingham Biomedical Research Centre in Inflammation. Her primary research focus is on the effect of ageing upon immune function and how this limits the ability of older adults to resolve inflammation and predisposes them to chronic inflammatory disease. She also researches the link between chronic systemic inflammation and physical frailty in old age and chronic disease. In this context Professor Lord has a particular interest in the role played by stress (physical and

psychological) and the altered hypothalamic-pituitary-adrenal axis in modulating immunity and frailty in old age and following an injury. In 2013 she was awarded the Lord Cohen of Birkenhead medal for her outstanding research in human ageing by the British Society for Research in to Ageing. She was elected a Fellow of the Academy of Medical Sciences in 2015 and appointed CBE in 2023.

James Nazroo FBA FaCSS is Professor of Sociology at the University of Manchester, founding and co-Director of the Manchester Institute for Collaborative Research on Ageing (MICRA) and founding and Deputy Director of the ESRC Centre of Dynamics of Ethnicity (CoDE). His research on ageing has been concerned with understanding the patterns and determinants of social and health inequalities in ageing populations. He was PI of the fRaill programme, an interdisciplinary study of inequalities in later life, and is co-PI of the English Longitudinal Study of Aging, which is a multidisciplinary panel study of those aged 50 and older. His work on ethnicity/race has focused on developing an understanding of the links between ethnicity, racism, inequality, and health.

Mark Schweda is a philosopher and bioethicist. He is Professor for Ethics in Medicine at the Department of Health Services Research of the School of Medicine and Health Sciences at the University of Oldenburg (Germany) and member of the German Ethics Council. His work focuses on ethical aspects of ageing, the life course, and human temporality, and on the role of assistive technologies and digitisation in medicine and healthcare, as well as on questions of public and stakeholder participation in bioethical debates.

Mehrunisha Suleman is a medically trained bioethicist and public health researcher who is leading the Health Foundation's COVID-19 impact inquiry. She has a range of research experience spanning from healthcare systems analysis to empirical ethics evaluation. She was previously co-editor of the NHS Atlas of Variation for Diabetes and Liver Disease at the Department of Health. More recently she has been working as a researcher at the University of Cambridge conducting an ethical analysis of the experiences and inequalities faced by patients and families trying to access effective palliative and end of life care services. She has extensive outreach and engagement experience, include working with minority groups and diverse sectors across the UK and globally. She is a member of the Nuffield Council on Bioethics.

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individuals from BAME communities who have died of COVID-19 over the last two years.

Gry Wester is a healthcare management consultant at VMLY&R Health, working on market access and business strategy in the specialty, Rx, pharmaceutical, and biotech sector. Prior to joining VMLY&R Health, Gry was a lecturer and researcher at King's College London. She has 15 years' experience in health and healthcare research, specialising in health equity, resource allocation in healthcare, and public health policy.

Glossary

Ageism: Prejudice or discrimination against someone because of their age.

Age-related macular degeneration: A condition of the eye that causes a loss of central vision and usually affects people in later life.

Alzheimer's disease: A degenerative condition of the brain associated with excessive and abnormally folded proteins accumulating in the brain.

Antiretroviral therapy: Drugs that treat viral infections, notably human immunodeficiency virus (HIV).

Assistive technology: A generic term for technological devices designed to enable independence for disabled or older people.

Biological ageing: The biological changes that take place over time in the body and increase the chance of disease and death.

Biomarker: Molecules or sets of different molecules that, when detected at a particular level in body fluids or tissues, indicate the presence of a disease.

Carer: Here: a person who spends a significant proportion of their life providing unpaid support to family or friends.

Cell: The fundamental building block of many biological systems.

Centenarian: A person who is 100 years or older.

Chronic: Referring to a health-related state lasting for a long period of time.

Chromosome: Segments of genomic DNA packaged with proteins and other accessory molecules. Most cells in human adults have 46 chromosomes that together constitute the nuclear genome of each cell.

Chronological age: Getting older in terms of years.

Clinical trial: A medical research process which allows safety and efficacy data to be collected for new drugs or medical devices.

Cohort study: A form of longitudinal study used in medicine and social science which uses a designated group of people followed or traced, usually over an extended period of time

Cognitive impairment: Reduced mental functioning.

Dementia: A group of symptoms associated with a deterioration in brain functioning, including for example the loss of memory.

Enzyme: A protein that acts as a biological catalyst in living organisms to regulate biochemical processes.

Exposome: The measure of all the (non-genetic) exposures of an individual in a lifetime and how those exposures relate to health.

Geroscience: Understanding the connection between the complex processes that underpin biological ageing and the development of age-related medical conditions.

Healthspan: The length of time that a person lives, or is expected to live, in good health.

Healthy life expectancy: An estimate of the average number of years would live in good general health.

Hypertension: A condition in which a person's blood pressure is higher than normal.

Idiopathic pulmonary fibrosis: A condition that causes scarring of the lungs making breathing difficult.

Inflammaging: A long-lasting low-level inflammation that develops with older age.

Intergenerational: Of or involving individuals of different generations.

Life expectancy: The average number of years that a person lives.

Lifespan: A measure of the actual length of an individual's life.

Metformin: A medicine that lowers blood glucose levels and is commonly used to treat type 2 diabetes.

mTOR: A protein that controls many cell functions, including cell division and survival. It is the target for Rapamycin.

Multiple long-term conditions: Living with two or more long-term conditions in a single individual.

Neurodegenerative diseases: A collection of diseases resulting in or characterised by degeneration of the nervous system, especially of neurones in the brain.

Neurological: Relating to nerve systems.

Paradigm: A representative example.

Parkinson's disease: A chronic, progressive neurological disorder characterised by tremor, muscle rigidity, and difficulty in initiating movement.

Pharmacological: Relating to the branch of medicine that deals with the uses, effects, and modes of action of medicines.

Prevalence: Total number of cases (for example, of a disease) in a population at a given time.

Psychological: Relating to the branch of science related to the mind and emotional state of a person.

Rapamycin: A drug that is used to suppress the immune system and to prevent the body from rejecting organ and bone marrow transplants.

Senescence: The cellular process in which cells stop dividing and growing.

Senolytics: A class of drugs that target senescent cells with the aim of eliminating them.

Stem cells: Undifferentiated or partially differentiated cells that can develop into various types of cells and can multiply indefinitely to produce more of the same cell.

Telehealth: Uses communication and digital technologies to allow a person to access to healthcare services remotely and manage their health.

Telecare: Uses remote technology to monitor the health of the person and alert an appropriate person where necessary.

Telomeres: The tips of chromosomes.

Telomerase: An enzyme that repairs and lengthens telomeres.

List of abbreviations

AFAR	American Federation for Aging Research
AI	Artificial intelligence
AMS	The Academy of Medical Sciences
APPG	All-Party Parliamentary Group
AWOC	Ageing Well Without Children
B4H	Business for Health
BBSRC	Biotechnology and Biological Sciences Research Council
BOPF	Bristol Older People's Forum
BSI	British Standards Institution
CBI	Confederation of British Industry
CBT	Cognitive behavioural therapy
CQC	Care Quality Commission
DAIs	Deficit accumulation indices
DEEP	Dementia Engagement and Empowerment Project
DHSC	Department of Health and Social Care
DMT	The Dunhill Medical Trust
EDoN	Early Detection of Neurodegeneration
ELSA	English Longitudinal Study of Ageing
ESG	'Environmental, social, and governance'
EU	European Union
FDA	US Food and Drug Administration
GM GOLD	Greater Manchester Growing Older with Learning Disabilities
GMOPN	Greater Manchester Older People's Network
GP	General practitioner
HIV	Human immunodeficiency virus

HRA	Health Research Authority
ICD	International Classification of Diseases
ICS	Integrated care systems
ILAP	Innovative Licensing and Access Pathway
LGBT	Lesbian, gay, bisexual, and transgender
LGBTQ+	Lesbian, gay, bisexual, transgender, queer/questioning, and many other terms
LIN	The Housing Learning and Improvement Network
LTC	Long-term care
MHRA	Medicines and Healthcare products Regulatory Agency
MLTCs	Multiple long-term conditions
MRC	Medical Research Council
MRI	Magnetic resonance imaging
NHS	National Health Service
NICA	National Innovation Centre for Ageing
NICE	The National Institute for Health and Care Excellence
NIA	National Institute of Aging
NIH	National Institutes of Health
NIHR	National Institute for Health and Care Research
NSC	UK National Screening Committee
OLDF	Open Life Data Framework
PIPs	Paediatric investigation plans
PPIE	Patient and public involvement and engagement
PROMs	Patient reported outcome measures
SMEs	Small and medium-sized enterprises
TAME	Targeting Aging with Metformin
TAPPI	Technology for our Ageing Population: Panel for Innovation

The future of ageing

UK	United Kingdom
UKRI	UK Research and Innovation
US	United States
WBACRC	West Bromwich African Caribbean Resource Centre
WHO	World Health Organization

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