

NUFFIELD COUNCIL ON BIOETHICS

Expert call for written evidence: summary of responses

September 2021

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Introduction

On 8 June 2021, the Nuffield Council on Bioethics' [working group](#) on the future of ageing launched a [call for written evidence](#). The call was designed for academics and policymakers with an interest in ageing.

Targeted emails were sent to over 400 individuals and organisations, in addition to promotion via social media channels and the Nuffield Council's newsletter. In total, 21 responses were received.

This document summarises the responses we received, taking each of the 11 questions we asked in turn. It excludes two responses which were submitted by respondents who did not wish their responses to be published or quoted.

Some respondents chose to answer a selection of these questions; others responded to each. Some also chose to provide responses which did not address the questions directly but instead offered overarching views on the call's themes. Where possible, these responses feature in the analysis of relevant questions; where this has not been possible, they are captured in the 'other points' section at the end of this document.

Respondents also helpfully provided reference to external sources to support their submissions. Where appropriate, hyperlinks to these references have been added to this analysis.

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.

There are two parts to this question – analysis of which will be taken in turn.

Attitudes to ageing and their influence on research and innovation

Ageist attitudes were highlighted in several responses to this question. One anonymous respondent, for example, notes:

“Although age is typically a proxy for disability and mortality, it does not mean that age correlates with either disability or mortality. This notion however has manifested itself within societal structures and often results in ageism.”

In a comment with a similar focus, Michael Dunn notes:

“There is occasionally an assumption that older people will lack capacity – despite the fact that there are important legal and ethical reasons to presume the opposite. Many voices are excluded on these grounds, in my experience sitting on a research ethics committee.”

Drawing on the findings from a workshop the PHG Foundation ran in 2018, Dr Philippa Brice summarises its conclusions that:

“the development of technologies specifically to assist older people to stay healthy runs the risk of stigmatising this population group, and that this effect could be magnified by technologies ‘using inaccessible language, setting unrealistic standards or becoming a controlling force’.”

However, in a response which highlights ageing in the context of the US, Professor Leonard M. Fleck suggests that **ageism could “cut two ways”**:

“The term could just as easily be used to call attention to all the ways in which the elderly have managed to accrue for themselves all sorts of political and economic advantages at the expense of the non-elderly. This point is likely less true in the UK and the EU. In the US, however, the health care needs of the elderly are largely adequately met by the Medicare program, sometimes described as national health insurance for the elderly. That latter phrase is intended to call attention to the fact that non-elderly Americans have no assured access to needed health care”.

Later in his response, Professor Fleck continues:

“No doubt it is true that the elderly, as a class, have many more health needs than the non-elderly. However, no conception of health care justice would

warrant the elderly having all their health needs addressed while many of the non-elderly would be forced by economic circumstances to endure the consequences of not having their equally serious health care needs met. Taking seriously this argument does not represent ageism.”

Drawing from his experience as director of the English Longitudinal Study of Ageing, Professor Andrew Steptoe highlights two areas where attitudes to ageing influence research. The first concerns how **the range of research topics may be circumscribed by attitudes to ageing**. He states:

“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. There has been some neglect of older populations in studying socioeconomic inequalities in health. Much of the emphasis of inequalities research is placed on early life and people of working age, but socioeconomic gradients persist at older ages and affect multiple health outcomes. There are also specific topics that tend to be ignored (such as the sexual attitudes and behaviour of older people).”

Professor Steptoe also emphasises the effect that attitudes to ageing might have on **how research is conducted**:

“Older aged people may miss out on involvement in research because of the perception that they may not be able to cope with digital technologies and methods of data collection. In fact, our experience in ELSA is that high proportions of people at older ages are able to participate, although there are socioeconomic gradients in access to digital technology.”

A further respondent also draws on their experiences as part of ethics committee processes to highlight **exclusionary approaches to older people’s participation in research**.

“I’ve had experience with ethics committees indicating that those with some cognitive impairment should not be recruited into our study of rehab for older people living with frailty even though findings regarding adherence and other aspect of intervention fidelity would be hugely valuable in terms of implementing findings into practice.”

A related point was made by a further anonymous respondent:

“Another example is where older people and those with health problems or multiple long-term conditions are automatically excluded from studies even though they may make up the majority of people with the condition of interest. This is particularly seen in pharma and surgical trials. This means that the evidence produced may not be generalizable to those excluded.”

In the context of **palliative care research**, Dr Anna Bone and Professor Katherine Sleeman also observe:

“... older people have not historically been the primary subject of research in palliative or end of life care. It is likely that ageism has played a part in this.”

Protective attitudes towards older people were also highlighted as having an influence on research and innovation.

“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). For example not wanting to burden them or feel that just because they are older that they cannot make decisions for themselves even though they have capacity and eligible to take part.”

Dr Hannah R. Marston similarly noted:

“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. This leads to the othering of older people which can reinforce paternalistic and patronising services, innovations that do not meet the needs of older people as well as the use of language and behaviours that are disempowering and demeaning.”

Thomas Woodcock also highlighted similar concerns around the infantilisation of people as they age. He notes that there is a *“presumption that it is OK to go to first name terms – this initiative should come from the client, not the carer. ‘Hello Mrs Jones, can I call you Lottie?’ is not good enough.”*

The exclusion of older people based on their age was highlighted further in a response from Michael Dunn:

“Much research seems to be formulated around highly structured and limited [assumptions] about [old] age, and the definitional boundaries concerning what counts as an ‘older person’. Thus, inclusion criteria in research studies might be limited to those over the age of 60, 65 etc. This often looks often to be arbitrary, and difficult to defend, even in light of the study’s specific aims or objectives.”

One anonymous respondent, who indicated that they *“do not speak as an academic or a policymaker, just someone who is getting old”* stated, however, that attitudes to ageing research and innovation *“are becoming more flexible.”*

Promoting more positive attitudes to ageing in research and innovation

In the light of the PHG Foundation’s 2018 workshop on healthy ageing, Dr Philippa Brice notes its conclusion that *“changing the social perceptions of ageing to reduce the fatalism sometimes associated with the ageing process would be important, as would adopting a holistic approach to lifetime planning including for older age from much earlier in the life-course, and considering possible interventions in the context of all the needs of an individual rather than focusing on isolated elements.”*

An anonymous respondent suggests that reconceptualising the ageing process might challenge *“archaic concepts of ageing”*. They offer the example of *“emphasising the chance for older persons to remain in the world of work.”* They further note:

“To consider one example, the hegemonic discourse prevalent within society denotes that the ageing population presents a growing burden for younger generations. However, this discourse does not take account of the growing potential of the ageing population owing to transitions in both demography and epidemiology. Contrary to this overriding narrative, contemporary research indicates that the older population holds enormous value in providing intergenerational transfers over a life course.”

Michael Dunn suggested that many research studies are ‘deficit’ orientated and address health problems or functional limitations associated with the ageing process. He suggests: *“It would be good to see a stronger focus (from research funders and individual researchers) on what it means to age well, what the good life in late life consists in, etc.”*

Sangeetha Neeraja Babu Manoharan from the Centre for Ageing Research at Lancaster University highlighted that when *“coming up with research design and formulating research questions, it is important not to treat older adults as a homogenous group viewed through the stereotypical lens of ageism. 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 positive, innovative, active ageing and have an innate need to be included in the digital world and not left behind.”*

An anonymous respondent similarly highlights the importance of promoting *“positive images of older people taking part in research and not just those who are healthy.”* The same respondent states that some groundwork is needed to achieve this:

“We should educate those who work with older people but are not older people specialists how to be more inclusive and provide the resources to be able to include the population of interest and not just those that are easy to access eg white educated people with access to transport / resources who live in urban areas.”

Dr Hannah R. Marston suggests that to promote more positive attitudes, researchers and innovators should work with older people, *“and not ‘do to’ older people.”* She notes further that older people *“are more than the wrinkly hands portrayed media stories, they are not the homogenous group implied by the term - they are a diverse group of people aged 50+ with skills, and knowledge that can be shared, they are active citizens and should be included in innovation and research from the outset.”*

A further suggestion for how more positive attitudes for ageing could be promoted concerns the role that funders might play in developing innovation and research in particular contexts. An anonymous respondent suggests:

“One could also consider how the funding environment in adult social care could be improved to develop innovation and research. There is a lot of research within our sector, however, the difficulty is actually replicating it in all parts of the system given the lack of parity within different parts of it. For example, the funding context of privately funded care homes is very different to publicly funded. Arguably, this funding context is a manifestation of ageism.”

Another anonymous respondent places the promotion of positive attitudes to ageing in research and innovation as something which everyone could contribute to *“by all groups accepting that this is what’s going to happen to most of us.”*

Criticisms of the question

A response from David Gems suggests that this question was a loaded one “geared to obtain the answer that it wants”. He suggests that ‘normal ageing’ is a myth: rather, ageing “is a largely deteriorative process, leading to degeneration, illness and death.” From his perspective as a scientist, Professor Gems states that “talking of promoting positive attitudes to ageing in the context of research makes about as much sense as promoting positive attitudes to cancer.”

He notes further:

“Treatments for ageing are a possibility; to maintain the lie that ageing is not even a disease state is to deny the existence of a cause of incalculable suffering. To do this at the time when we are beginning to understand ageing, and when possibilities for treatment of ageing are emerging, in a way that obstructs that approach risks committing a crime against human well being. It is about as unethical as one could imagine: like denying that smoking causes cancer, thereby discouraging research on the topic.”

The International Longevity Centre also comment on the tensions indicated by the question’s wording.

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

Research is often presented, even if just by the media, around one of these extremes.

Your own question “How more positive attitudes to ageing could be promoted” highlights the problem we face.

From science and research, we don’t need positive attitudes to ageing. We need an honest approach which presents evidence in a balanced way. Group think is unhelpful and we must rely on science telling the truth to power.”

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.

Responses to this question leaned heavily towards those which commented on the advantages of inclusivity, although several respondents also highlighted the challenges inherent in such an approach.

Advantages of taking a more inclusive approach

The rationale for taking a more inclusive approach is highlighted by the Academy of Medical Sciences, which observes that *“ageing is a process that affects the entire population, so ageing policies should take an inclusive life course approach to promote healthy ageing.”* The Academy suggests that one advantage of adopting this approach is that it offers an opportunity *“to predict and possibly prevent future illness.”*

Michael Dunn suggests that researchers, health and social care providers, and policymakers *“would better attenuate their concerns to the real-world experiences and concerns that an older person would identify as relevant to them, in light of their person and social positioning”*. This, he suggests, would be instead of *“being led by presumed issues/big’ problems associated with technological solutions to preventing the ‘negative aspects’ of late life in ways that do not resonate with older people’s experiences.”*

Professor Andrew Steptoe similarly indicates that an inclusive approach *“recognises that people [vary] substantially in their rate of ageing, so age thresholds are somewhat arbitrary. There are wide variations in changes in physical capability, cognitive function, social participation, economic activity, biology and health with age, so research benefits from including individuals across a wide age span.”* A similar point is raised by Professor Leonard M. Fleck, who notes that life circumstances can make healthy ageing a practical impossibility for some people across the socioeconomic spectrum:

“One might have one’s health status significantly compromised from early on in life as a result of a number of factors collectively referred to as the social determinants of health. These factors would include poverty, racial or ethnic discrimination, a poor educational environment, an unhealthy environment in terms of pollutants, poor housing, health risks associated with low-paying jobs (farm workers exposed to the sun and carcinogenic chemicals), minimal access to health care resources, food insecurity, abusive family life, a stressful work or social environment (threats from street gangs) and so on. Finally, individuals who are socially and economically secure may make poor choices that adversely affect their health and leave them vulnerable to chronic degenerative conditions as they grow older, such as poor diets, lack of exercise, smoking, careless sun exposure, inattentiveness to health needs, inappropriate substance use, and so on.”

The Academy of Medical Sciences suggests that a further advantage of an inclusive approach is that it supports the prioritisation, tackling, and minimisation of health inequalities. The Academy highlights that the context of this advantage is the fact that *“health inequalities are observed between many groups across society, often exerting significant effects on the likelihood of developing age-related conditions.”*

The Academy of Medical Sciences also suggests that *“providing an inclusive and holistic approach to both clinical and research settings would improve care provision for patients with MLTC [multiple long-term conditions], many of whom are older people, ‘designing in’ their needs to the system.”*

Some respondents also offered suggestions for **how more inclusive approaches might be achieved**. The Academy of Medical Sciences, for example, indicates that it

would require interdisciplinary working *“between different hospital departments, between healthcare practitioners from different specialties, and between clinicians, researchers and local authorities to fully ‘design in’ the needs of older patients with MLTC to health and social care services and extend healthy lifespan.”*

Disadvantages of taking a more inclusive approach

Very few respondents directly addressed the disadvantages of inclusion. However, Michael Dunn states:

“[Inclusivity] will inevitably mean that concerns that are not directly experienced by e.g. an older person or a family caregiver will fall off the radar when there might be good arguments for ‘big picture’ perspectives.”

Adopting a slightly different approach, one anonymous respondent states:

“My ideal would be that we didn’t need specific human rights/guidance etc for older people (or any other group) in that we were all equal in society and services/research would meet our needs. But that isn’t the case and without fundamental change we will be continually having to put a sticking plaster over major trauma.”

An anonymous respondent observes that *“one would expect most of the needs of older people to be designed into mainstream approaches rather than considered separately.”* However, the respondent suggests that there may be some exceptions:

“For example, whilst the force and torque requirements to open products and the visual capabilities required to operate systems are known and can be used to design many interfaces, there is the possibility that older people might injure or poison themselves, so these need to be carefully weighed against usability benefits.”

While not focusing on disadvantages, **other respondents did highlight the challenges which might affect an inclusive approach.**

Sangeetha Neeraja Babu Manoharan, for example, notes:

“While it is important to keep inclusivity at the heart of technology interventions for older adults, at the same time, it is critical to remember the unique challenges faced by the older adults as a group in terms of sensory, motor, and cognitive impairments, which designing the technology hardware and software.”

In the context of end-of-life care, Dr Anna Bone and Professor Katherine Sleeman state:

“A challenge of including older people in the design of services in this field is that the direct population of interest is vulnerable given their proximity to end of life. Finding innovative ways to support inclusion in research is important, as well as finding alternative ways to include this voice, e.g., via advocates or family members.”

In the context of human rights, Alex Ruck Keene also indicates a further challenge:

“Whilst the potential for a Convention on the Rights of Older Persons is identified, there is an important issue here in relation to the Convention on the Rights of Persons with Disabilities, which is already in force, and sits in potential tension with the Convention on the Rights of Older Persons. It seems to me that this is an issue which needs to be addressed in this area.”

How inclusion might be achieved

An anonymous respondent felt that integration should be judged by the experiences of people who use services. They note: *“We must shift our focus from organisations and processes to people and outcomes.”*

Sangeetha Neeraja Babu Manoharan suggests that one option for achieving inclusion could be to involve older adults in research to understand their attitudes, needs, and capabilities. She highlights the work of the Centre for Ageing Research at Lancaster University, which has a panel of older adults who have signed up to be involved to participate in research. She suggests that there might also be a ‘next level of inclusion’:

“The next level of inclusion would be to do, co-choice, co-design and co-develop, technology interventions (VR-Content/ experience) along with the older adults.”

The same respondent notes, however, that mainstream technology may be limited in the extent to which it can be inclusive. But technology, she suggests, *“could be made more accessible to the older adults by establishing [tech] support networks, which could guide the older adults to newer technology and be there when glitches happen to help them navigate as they find their way around technology.”*

Dr Hannah R. Marston offers an example of an inclusive approach to design from her own experience.

“In the ‘Adapt Tech, Accessible Technology’ (ATAT) project, end users recruited via Digital VOICE for communities (based in Gateshead) and Digital Communities Wales has facilitated the research team to engage with older people from the beginning of the project.

Taking an inclusive approach within the ATAT project has enabled an interdisciplinary research team comprising of social scientists, computer scientists and gerontologists / gerotechnologists the opportunity to collaboratively understand the needs, barriers and challenges experienced by older adults who are proactively engaging with various digital technologies and practices.”

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?

Priority-setting processes respondents are familiar with

An anonymous respondent highlights the work of the **James Lind Alliance (JLA)**, observing that there is *“nothing specific to older people in the UK except for when they have another issue eg lower limb fractures, dementia, Parkinson’s.”* Professor Miles Witham and Professor Avan Sayer note a different perspective on the JLA, indicating that its priority setting partnership has *“delivered sets of priorities in several areas related to ageing research. For example, a PSP for research in multiple long-term conditions in later life [reported in 2019](#); this PSP was led from Newcastle and delivered a set of 10 broad areas where research needed to focus. The James Lind alliance priority setting methodology is now well established and has successfully brought the patient in public voice into the priority setting process.”* The British Pharmacological Society also highlight the JLA’S work as a good example of using engagement to inform research priorities with the lived experiences and needs of patients.

Michael Dunn highlights his experience of research studies which made use of ‘community conversations’ and other patient and public involvement (PPI) mechanisms throughout the research process. These methods have, he indicates, been used to guide research questions and methods. He adds:

“These are important, but need to be carefully managed and directed in order to stay on focus. In my experience, the general issue here is that the vast majority of people outside research have a very limited understanding of what research consists in (and that, critically, it is not about the delivery of services/support).”

One anonymous respondent states: *“I’m not familiar with these [priority-setting processes]. If there are any, they are not very obvious.”*

In a US context, Professor Leonard M. Fleck suggests that priority-setting is not achievable in the context of care provided through Medicare:

“... priority-setting is a practical impossibility in Medicare as it is now because Medicare has no fixed budget which, in effect, creates hard limits that require priority-setting.”

How priority-setting processes should change

Some respondents focus on **who should be involved in priority-setting processes**. For example, Dr Anna Bone and Professor Katherine Sleeman highlight that *“the palliative and end of life care sector of health and social care are paradoxically often missed in the healthy ageing agenda.”* They suggest that priority-setting processes for this sector should be informed by the inclusion of professionals who deliver palliative and end of life care, family members with experience of caring for relatives towards the end of life, and older people themselves.

Sangeetha Neeraja Babu Manoharan also highlights that “multiple stakeholders (older adults, carers, family members, social workers, academic researchers, policy makers, politicians, technology providers, and investors) should be involved.” Dr Hannah R. Marston also states: “Future priorities should include end users from across different age cohorts and socioeconomic status (SES), utilising grass root networks and stakeholders. This would provide a greater overall perspective of views and opinions.” Dr Marston continues:

“Future priorities should directly include the voices of people (including SES) to inform future research priorities because it is they who will be directly impacted, and they who have the first-hand knowledge and experience(s). For example, adults who are ageing without children (AWOC), future directions surrounding this sub-population in society should be invited to discussions to inform research directives, policies, strategies, and route plans.”

Professor Miles Witham and Professor Avan Sayer indicate that “Challenges remain in ensuring that the voices of particular groups (for instance people living with frailty, people living in care homes, people with sensory impairment, cognitive impairment or disabilities) are heard.”

Professor Leonard M. Fleck takes a different stance, and suggests:

“It might be the case that we need to start the [priority-setting] process of public engagement and democratic deliberation regarding priority setting among the non-elderly. It is the non-elderly who are paying into the Medicare program in the hope that they would enjoy the benefits of that program.”

An anonymous respondent highlights that changes to **priority-setting might focus on including older people who are particularly underrepresented in research**, including the over-80s, those with multiple long-term conditions, people with cognitive impairment, carers, and those who live in rural or coastal communities. Thomas Woodcock also notes:

“I sense that patient or public participation is sometimes only given lip service. Continue to encourage participation and especially engaging with older participants.”

Michael Dunn also comments on the **importance of inclusivity**, noting “[there] is a lot of work to be done to better contextualise research activities and the fundamental[s] of conducting research, to ensure these can be genuinely inclusive and useful for all participants.”

A response from David Gems focuses on changes to realise “greater integration between research on the basic biology of ageing, and the study of ageing-related diseases. This is really aimed at the biogerontologists, rather than the clinical researchers. Also, among the biogerontologists, more emphasis on developing the conceptual foundations of the field, which are currently in disarray.”

Focusing on **organisations integral to priority-setting processes**, Professor Andrew Steptoe states:

“I am familiar with some of the priority-setting by UKRI, NIHR, and government departments such as DHSC, DWP and DfT. The priorities in ageing cut across

different areas, so priorities in one area (e.g. transport) will impact on others (health, environment). Oversight across organisations would be beneficial.”

Question 4: Which ageing challenges should medical and technological developments prioritise – and why?

Respondents offer a range of suggestions for the ageing challenges which should be prioritised by medicine and technology.

David Gems indicates that one challenge to prioritise is “*to **understand ageing in terms of its underlying causes**, and use this knowledge to understand the causes of ageing-related disease. This is one of the greatest unsolved problems in medicine.*” Professor Gems adds:

“Ageing is currently the main cause of chronic disease and death worldwide, and we do not understand its causes. Ethically, it behoves us to do better at solving this biological mystery.”

Also commenting on the **biology of ageing**, Professor Miles Witham and Professor Avan Sayer state:

“[Investment] in translational science is critical in ensuring that the advances made in recent years in the biology of ageing can be evaluated in human experimental medicine studies and clinical trials, in order to ensure [that] these benefits reached the clinic”.

The Academy of Medical Sciences highlights the important role that **social care** will play in addressing the ageing challenges faced by society. It notes the effect of the COVID-19 pandemic on social care provision, coupled with the fact that “*our ageing population are spending longer periods of time in ill health towards the end of life compared to 2010*”. These factors, suggest the Academy, mean that “*ensuring social care is appropriately resourced to care for an ageing population and support innovations in care will be vital.*” Professor Andrew Steptoe also notes the importance of supporting independent living at older ages, in addition to other key issues which should be addressed in order to “*enhance the quality if not the quantity of life*”:

“Supporting independent living at older ages; cognitive decline and dementia; digital inclusion; better understanding of intergenerational processes; multimorbidity; fundamental ageing processes; enhancing social connectivity; research involving minority ethnic groups; assistive technologies.”

Professor Miles Witham and Professor Avan Sayer also state that “*the underlying aim of medical and technological developments for ageing challenges should be to improve healthspan rather than life span.*” They highlight [a recent modelling paper](#) which supports the concept of interventions to tackle the biology of ageing as the most effective way to improve health span, not just lifespan.

A specific group who might require separate consideration in the context of social care is those **adults who age without children**. This group is noted in a response from Dr Hannah R. Marston, who suggests that “*at present, society, Government, and organisations do not acknowledge this sub-population*”. Dr Marston indicates that

“greater work is needed surrounding this proposed priority, and digital technology and practices may have a role to play.”

Addressing **multiple long-term conditions** (MLTCs) and their association with **increased polypharmacy** was highlighted by the Academy of Medical Sciences. The Academy notes that *“as the number of long-term conditions experienced by the patient increases, so does the prevalence of further age-related conditions such as frailty.”* The cumulative detrimental effects of MLTCs, suggests the Academy, *“stresses the importance of diagnostic tools and biomarkers, or indeed preventative measures, to either facilitate the detection of one condition so that it can be treated before it has the opportunity to influence the emergence of another, or reduce the likelihood of a condition occurring in the first place.”*

The British Pharmacological Society also highlights polypharmacy as a key challenge. It suggests:

“It will be crucial to ensure that pharmacists are trained and made to feel confident – if they are not already – with consultation skills to facilitate patients to make shared decisions about their medicines. Unlike single organ-based conditions, there is no established referral pathway for specialist review of patients with complex polypharmacy. A more joined up service to manage patients with polypharmacy and help to upskill the workforce is needed.”

Late in its response, the Society states that there is *“a need to target investment towards supporting delivery of care against known challenges in elderly populations (such as polypharmacy).”*

The Academy of Medical Sciences highlights a further challenge for medicine and technology to address: **the design and development of tools that facilitate disease diagnosis**. It adds: *“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.”* To realise the development of such tools, the Academy suggests 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.”*

The **development and use of medical devices in social care settings** was an area highlighted by an anonymous respondent, but caution was urged on their application in these settings:

“It needs to be realised that the use of medical devices across social care settings requires training and extra resources, at least in the initial stages, before the benefits are realised. 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.”

Professor Miles Witham and Professor Avan Sayer note the role of **assistive technologies**. They observe that they are *“likely to be essential in mitigating the impact of functional limitations that have already developed, but interventions to prevent, slow or reverse biological processes associated with ageing will be essential to prevent the loss of physical and cognitive function over the lifecourse.”*

To meet the Healthy Ageing Grand Challenge, the Academy of Medical Sciences also notes the importance of **prevention research**. It suggests that a “*shift to proactive, preventative measures would have the added benefit of curbing the increasing demand for care and improve the sustainability of the healthcare system.*” On the ethical importance of preventative research, the Academy also states that “*making use of preventative rather than responsive interventions could also be seen as representing a more ethical choice as preventative measures should reduce the likelihood of patients developing ill health.*” Dr Anna Bone and Professor Katherine Sleeman similarly highlight the Grand Challenge and its aims “*to enable services and business models to be developed and adopted at scale which support people as they age to allow people to remain active, productive, independent and socially connected across generations as long as possible.*” However, Dr Bone and Professor Sleeman suggest that there is something missing from this vision:

“What is missing from this vision is supporting people age right up until death, when older people may no longer be able to be active, productive and may struggle to remain socially connected. We require a positive vision for how services and communities can support people towards the end of life.”

Supporting healthier life was a priority highlighted in response from Dr Philippa Brice at the PHG Foundation. Dr Brice suggests that “*efforts to extend overall life expectancy should not be prioritised above those to extend healthy and high-quality life, including to address the current socio-economic imbalances on both these measures.*”

The International Longevity Centre suggests that **tackling inequalities** should be a priority for research with respect to life expectancy, healthy life expectancy, and opportunities to age well. It adds: “*And in doing so we need to recognise that innovations that increase life expectancy for some might also increase life expectancy inequalities.*”

The **focus of this question** was, however, subject to some **criticism** from Michael Dunn:

“The very fact that this question presupposes a focus on ‘medical and technological developments’ seems to limit the exploration of challenges in ways that are not true to the open, inclusive process of priority setting outlined above. Why should we presuppose that older people, caregivers, and members of the public would agree that the ‘medical and technological’ lens is the correct lens to think about prioritisation of this kind? Does the framing of the question in this way not involve an implicit prioritisation in focus that could, at best, be disputed by those involved in receiving or providing care? I recall many occasions when I have been involved in research where an older person has said something along the lines of ‘stop seeing me as a patient’, ‘my age does not define me as being in need of medical help’ etc.”

An anonymous respondent also reflected on the thrust of the question, stating:

“Whilst there is a place for basic ageing research, I would say that we shouldn’t just focus on technological developments and interventions. There is a lack of investment in research on eg rehabilitation and although technology has a place, it shouldn’t be the answer to everything for older people. The tendency to prioritise commercial research does not sit well with me as I’m not

always convinced the solution to a specific problem is at the heart of it – more about the commercial benefit. I also have issue with wanting to increase the lifespan rather than trying to reduce life with disability or improve poor health and health inequalities. Physical activity and good nutrition have a huge part to play but are often relegated in favour of a magic pill.”

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.

Likely benefits

Respondents highlight several likely benefits in the context of research they are familiar with.

In the context of **end-of-life care research**, Dr Anna Bone and Professor Katherine Sleeman state that *“improving access to services in and out of hours for older people in community settings, including care homes, would be beneficial to this population.”* They also highlight [evidence](#) of inequalities in end-of-life care according to people’s socioeconomic position, and suggest that *“research that seeks to address these inequalities are likely to benefit older people”*.

An anonymous respondent indicated that *“a greater level of research has the capability of creating a greater level of public and political awareness in relation to the issue prevalent within the sector.”* However, they note that the success of such endeavours is dependent on the proactiveness of policymakers:

“[If] the recommendations presented by the research are not acted upon by policymakers, the value of research is lessened and the sector’s perception of future research projects may be undermined.”

A further anonymous respondent suggest that **the use of routine data and AI** alongside healthcare professionals’ clinical judgment and shared decision-making *“would be a valuable thing and give added value to clinical decision making that may not be as good with each approach individually.”*

David Gems highlights further benefits: *“preventing illness and suffering and increasing years of healthy life.”*

The Academy of Medical Sciences focus on the benefits that might be realised through an increase in the **identification of novel therapeutics**. However, it highlights a note of caution on such research outcomes:

“[To] promote healthy ageing and to avoid increasing health inequalities... it is important to ensure equity of access to novel therapeutics, non-medical interventions and health and social care services in general. Furthermore, older people commonly take several drugs for multiple conditions, and the harmful effects of inappropriate polypharmacy in the older community may increase further with the advent of novel treatments. Care is needed to minimise the possibility of adverse drug reactions associated with polypharmacy. Considering the emerging evidence about the benefits of non-medical interventions... striking a balance between medical and non-medical interventions will be vital.”

The Academy also highlights a range of other **technological advances** that have the potential to improve people’s quality of life as they age, and to reduce burdens on healthcare systems. They include:

- *“Research to assess the results of introducing home sensors that can collect data which are subsequently analysed by artificial intelligence (AI), to track and predict health outcomes.”*
- *“Advances in wearable technologies or mobile applications can monitor and remind patients to take medications at appropriate and timely intervals, potentially resulting in a reduction to such costs [from prescription drug wastage in the NHS] and better health outcomes.”*

In the context of such advances, however, the Academy notes that *“inclusivity is imperative when attempting to maximise societal gain. To ensure these technologies are used effectively and consistently by older patients, they should possess suitable interfaces for the older community to guarantee and simplify usability, and be equitably accessible to individuals from different socioeconomic or ethnic backgrounds.”* A similar point is raised in a response from the British Pharmacological Society.

“... older, more frail or disabled people are less likely to have access to smart phones or the internet so could miss out on technological innovation, leading to digital exclusion. Unless support is put in place, younger, wealthier, tech savvy patients stand to benefit the most.”

The benefits of taking a multidisciplinary approach to ageing research were noted by Professor Andrew Steptoe. He explains:

“The reason is that as people age, there is pronounced interaction between areas of human experience. For example, economic choices are dependent on cognitive functioning, social engagement is limited by physical capability, mental health is related to biological processes such as inflammation, socioeconomic circumstances affect loneliness and quality of life, and so on. Without a cross-disciplinary approach, we will be unable to understand ageing and enhance the experience for the population in general.”

Professor Miles Witham and Professor Avan Sayer suggest that potential benefits will depend on different time frames.

“The likely time frame for benefit will... differ depending on whether an intervention targets prevention or reversal of age-related conditions, and at what point in the life course the intervention is applied. For example, interventions to prevent the onset of disability in later life which are applied during midlife are likely to take decades to show an effect. Conversely interventions applied to older people with existing multiple chronic conditions which seek to reverse age related pathophysiology may deliver benefits within a few years.”

The same respondents also suggest that effect of timeframes on benefits realised in research contexts also has an impact on possible harms (see below).

Possible harms

Drawing on the findings of the PHG Foundation’s [workshop on healthy ageing](#) – specifically its conclusions that using new technologies to improve health outcomes and quality of life for older people relies in many instances on the collection and amalgamation of information from multiple sources such as sensors and digitally enabled support systems – Dr Philippa Brice highlighted the following concerns:

“Loss of privacy – individuals might feel that they are ‘being watched’ ostensibly for the provision of support

Data sharing – essential to maximise utility, but also highly dependent on public trust and acceptability

Liability – who is liable for errors made by technologies?

Person-centred care – will the increasing use of technologies effectively depersonalise healthcare and decrease the scope for flexible and responsive clinical judgement and shared decision-making?”

An anonymous respondent raised a possible harm that there might be an **overreliance on devices** rather than using other methods such a rehabilitation “to empower older people to utilise their assets rather than just compensate for deficits.”

Professor Miles Witham and Professor Avan Sayer highlight that testing treatments on “carefully selected and relatively fit groups of older people may be seen as a way to minimise the harms that participants are exposed to in clinical trials”. However, they observe that such mitigation of “harm risks exposing much larger groups of older people to harms if such treatments are not tested with those who will eventually be taking the treatment. There is also a degree of paternalism in such an approach; 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.”

Noting their comments on the effect of research timeframes, Professor Witham and Professor Sayer highlight **harms might take some time to become clear**:

“[Ageing] is a lifelong process and 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 shorter term therapies. In particular, the very long lead times required for preventive interventions in mid-life make gathering trial evidence of harms very difficult. Late effects, for instance an increased cancer risk, are possible and would not become evident until a therapy had been used for many decades.”

A response from Michael Dunn suggests that **research should not be the point of focus for a discussion on potential risks and harms** (see further ‘[criticism of the question](#)’ below).

“All research on new technologies imposes inequities simply because of the deep economic and social unfairnesses that are intrinsic to our care system in the UK. It is a mistake to think that research itself is the cause of the harm here; the harms lie elsewhere and they need to be addressed first and as a matter of priority. It would be a missed opportunity if this report mis-places these harms and frames injustice in this setting as solely a matter of research ethics. There is, of course, an important question about how researchers ought to proceed when conducting research that could give rise to developments that will inevitably accentuate injustices when introduced in practice. Here, I think there is much that could be learned from the literature on ancillary benefits, social obligations and ‘layered vulnerabilities’ in global health research ethics.”

Criticism of the question

In the preamble to this question in the Nuffield Council's call for evidence document, three examples of research and innovation were highlighted: geroscience, communication and assistive technologies, and developments in diagnostics.

A response from Michael Dunn commented critically on these areas of focus.

"I find the list of the three areas of research outlined on the website and that pre-empt this question to be problematic at face value. These look like technological fixes that could potentially (or implicitly) be accounting for what counts as benefit in a pre-emptive and narrow way. They also look like they have been picked out of nowhere, again presuming the prioritisation of research in ageing contexts without adopting an inclusive strategy. I would have thought that terms like 'geroscience' would generally be best avoided, unless an older person herself would accept such terminology."

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.

Role of older people

Respondents' submissions to this question highlight the important and positive role that older people might play in helping to shape research and innovation.

Dr Philippa Brice from the PHG Foundation, for example, notes that *"it is essential that older people (and the carers and families of older patients) should be involved in research and innovation to meet the needs of older population."*

Drawing on their experiences, Dr Anna Bone and Professor Katherine Sleeman indicate that *"older people and members of the public are passionate about improving services for people with serious illness and/or people who are towards the end of life."*

However, one anonymous respondent indicates that the voice of older people are not *"heard as loudly"* as might be expected. The respondent states that *"the voice of the service user is paramount in guiding how health and social care services develop person-centred, quality care. Older people do sometimes experience a reality that is different to other cohorts of the population, therefore their particular needs must be taken account of."*

Drawing on their experiences at the NIHR Newcastle Biomedical Research Centre, and with VOICE (Valuing Our Intellectual Capital and Experience), a global patient involvement organisation, Professor Miles Witham and Professor Avan Sayer note a specific challenge in ensuring representative voices:

"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 events or processes. This is not easy, and further work is required to find the best ways to reach those with cognitive impairment, those who are housebound, those living in care homes, and those with sensory impairment or disabilities."

These challenges intersect with challenges in ensuring that PPIE contributors are drawn from a representative cross-section of people with particular reference to ethnicity, education and socioeconomic position – a common criticism of PPIE contribution is that contributors are not representative of the population that research is intended to serve.”

Noting these challenges, Professor Witham and Professor Sayer highlight an example of their own work in establishing a representative patient, public, involvement and engagement (PPIE) group:

“We have delivered a diverse, active and engaged PPIE group as part of this project by deliberately seeking and recruiting PPIE contributors living with multiple long-term conditions. We have ensured geographical diversity by recruiting from three areas (Newcastle, Birmingham and London), we have included carers as well as patients on the panel, and we have succeeded in ensuring ethnic diversity in the panel. The use of remote meetings, with technical support from a professional PPIE team, has made it possible for participants with significant levels of disability to play an active part in the PPIE panel. Whilst this approach is not perfect (issues remain around including those who lack digital literacy or connectivity, and including participants with cognitive impairment), our example shows what can be achieved in this domain.”

The Academy of Medical Sciences similarly note that *“care must be taken to ensure engagement with a wide range of older people belonging to diverse groups (e.g. across different gender, ethnicity, socioeconomic groups, etc.) to fully comprehend and incorporate the specific needs of different groups of older people during policy development”*. Dr Philippa Brice from the PHG Foundation suggests that there may be a requirement for *“dedicated effort to achieve appropriate levels of diversity and inclusion, such as developing a broader range of mechanisms and opportunities for involvement in early adoption and ongoing development of health technologies and other interventions. This should be a priority alongside efforts to address other underrepresented groups.”*

Michael Dunn suggests that the first step to involving older people and members of the public more broadly rests *“in the underpinning conceptual questions concerning the good life in late life, and the varied forms of global, social, economic and intergenerational injustice that manifest in our society. We must not proceed with research on ageing technologies, for example, without a parallel and strong focus on involving older people, broader stakeholders and other members of society in addressing key questions of justice and well-being, as they pertain to the ageing process.”*

David Gems, however, queries the question’s focus on ‘older people’ and ‘intergenerational publics’. He notes: *“it is worth bearing in mind that older people means effectively all of us; we’re not dealing with a separate minority group here. This is about all of our interests.”*

Input of intergenerational public

The Academy of Medical Sciences suggests that *“whilst intergenerational public input can provide many benefits in research settings, the lived experience of older people*

and carers provides them with unique insights into the challenges surrounding ageing that should play a substantial role in the future development of ageing research.”

Sangeetha Neeraja Babu Manoharan from the Centre for Ageing Research at Lancaster University suggests:

“It is important to establish a constant feedback loop with the older adults in varying age cohorts (older adults in their 90s, 80s, 70s, 60s) and those in their 50s and 40s. This inter-generational spread, will give insights on how attitudes and exposure to technology, could influence the way technology devices could be accepted by the older adults.”

Professor Andrew Steptoe states that *“the input of the current and future generations of older people are crucial to set priorities and identify implications that will need to be addressed. Much of the promise of technological developments will have limited effects on the current older population and are much more relevant to young and middle-aged groups, so they should have a say in priority setting.”* The Academy of Medical Sciences raise a similar point, noting that *“[since] the young generation of today is the older generation of tomorrow, there is value in encouraging voices from all age groups to contribute to the ageing discussion.”*

Question 7: How can older people be better represented in clinical trials that are of potential relevance to them?

Respondents offered several suggestions for stronger representation of older people in clinical trials. However, before examining these proposals, a submission from Professor Miles Witham and Professor Avan Sayer prompts a prior question: **why older people might be under-served by clinical trials.**

They suggest that clinical trials have “*often explicitly excluded older people on the grounds of advanced age, and although this is less common now, older people are often still excluded from participating due to narrow inclusion and exclusion criteria*”. They note that there may be two reasons why these criteria are imposed:

- 1) To reduce the risk of adverse events due to treatments
- 2) To ensure a homogenous study population

They observe that “*homogeneity has advantages in reducing variation within the sample and thus enables a smaller sample size to be used, but this comes at the cost of generalisability.*”

They note further **practical barriers to older people’s inclusion in clinical trials**, including travelling to research centres, a point British Pharmacological Society also highlights:

“It is also important to consider whether older and elderly patients feel able to engage with research or whether there are barriers stopping them, that need to be addressed. This includes an assessment of all aspects of research including issues in trial design which are often overlooked. For example, the number of follow up visits can be particularly difficult for the elderly because of transport difficulties, and so ensuring that there are alternative arrangements may help participation.”

Respondents also address a further prior question: **why it is of concern that older people might not be well-represented in clinical trials.**

Professor Miles Witham and Professor Avan Sayer suggest that it is because:

“older people who are recruited into trials are often not at all typical for people of their age, or of people who are likely to receive a treatment in clinical practice... Evidence of benefits and harms derived from trials with unrepresentative populations is unlikely to reflect the balance of benefit and harms in the real world; such evidence is therefore potentially misleading or even dangerous.”

Professor Leonard M. Fleck highlights a similar issue, but notes that addressing the limitation he identifies may be difficult:

“As I think all clinical researchers understand, the more variation that exists in trial subjects, the more likely the results will be skewed in ways that yield misleading or otherwise unreliable results. Someone might suggest that as a corrective, participation in these trials should be limited to very healthy older individuals with no serious co-morbid conditions. That, no doubt, will yield

more reliable results for that very healthy trial population. Unfortunately, those results may not have much reliability when they have to be applied to an older population with many co-morbid conditions who are taking many drugs to manage those conditions, not to mention all the different ways in which bodies might age. It may be unfortunate that this is the way that the world is, but it does not appear to be any way in which we can address this limitation. Most of the time older patients will have to rely upon clinicians who have practices with many older patients, which may have increased the diagnostic skills and acuity of the clinical judgment of these physicians.”

The International Longevity Centre also notes:

“It is of course necessary to find ways of engaging older people better in clinical trials. The risks of not doing this are highlighted bluntly by the relatively small numbers of 65+ included in one of the trials of the AstraZeneca Covid-19 vaccine. This failure played a part in creating negative public perceptions around the vaccine with significant negative global health impact.”

Professor Miles Witham and Professor Avan Sayer suggest that clinicians who care for older people *“are naturally sceptical about evidence derived from such unrepresentative trials and may often disregard such evidence or not recommend treatments for older people even where trial evidence exists. In some cases, this is the correct choice of action and protects older people from harm, but in other cases, this mismatch between evidence and the real world has led to low uptake of treatments that have subsequently been shown to be of great benefit older people.”*

The British Pharmacological Society raises a further concern on older people’s underrepresentation in clinical trials.

“Inclusion in clinical trials would also help inform polypharmacy management in the future – at present there is very little evidence of the effectiveness and safety of drugs in the oldest old or those with multiple long-term conditions. 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 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, dose protocol and reduce risks for older patients.”

To address the question of **how older people can be better represented in clinical trials**, suggestions include that offered by one anonymous respondent who indicates there should be more **engagement with service user groups**. Another anonymous respondent suggests that highlighting the potential direct benefits of clinical research might also support better representation of older people in clinical trials:

“Older people need to feel that there is some likelihood that the treatment in clinical trials will be of direct benefit to themselves rather than providing yet another data-point.”

A further anonymous respondent urged that participants **should not be excluded based purely on their age**:

“Don’t exclude people purely based on age. I recently saw an outline application for a trial of a surgical procedure that is mainly conducted with older people and they were planning to exclude everyone over 70. Older people (and those with multiple long-term conditions) should be part of the PPIE group and be representative of those seen in clinical practice for a particular condition and the selection criteria should represent them in terms of age as well as other diverse demographics. The safety concerns of the study team may well be through ignorance or just lazy in that working with older people (and other underrepresented groups) requires a bit more thinking in terms of planning and delivery. Funders and ethics committees should be more cognizant of this and challenge otherwise this poor practice will continue.”

The same respondent states that the corollary of such exclusions is that *“trial findings are not truly representative... and then older people may not get access to treatments that may benefit them.”*

Michael Dunn suggests that there is *“a lot of important work to do on capacity assessment in research, as well as tailoring consent and information provision to the precise needs of older persons.”* He notes further that while work with [‘Dementia Enquirers’](#) and [‘Innovations in Dementia’](#) has led to improvements on paper, *“the translation and connection of these insights to those who lead clinical trials is, however, the big stumbling block. Researchers need education here; currently this is very limited in my experience.”*

Professor Dunn also highlights specifically the involvement of **older people who have limited capacity**:

“A stronger focus on what it means to meaningfully engage with older people who are judged to lack capacity to consent to participate in research but are still capable of meaningful engagement in research is needed. Here, in particular, we need to stop thinking about this in terms of ‘assent’ or ‘dissent’ – unhelpful terms that can be misunderstood and misapplied.”

Professor Miles Witham and Professor Avan Sayer similarly observe, *“Many trials exclude older people with even mild degrees of cognitive impairment, further limiting the opportunities for participation and restricting the generalisability of results.”*

Respondents also indicate that people who have **multiple long-term conditions should be better represented in clinical trials**. The Academy of Medical Sciences, for example, states:

“... steps should be taken to enable clinical trials that are safe and inclusive of MLTC patients, and consist of diverse and representative populations. Such steps would involve increasing awareness of MLTC patients in research and healthcare settings, and ensuring MLTC-related research is not disadvantaged due to complexity or breadth of study. By safely including MLTC/older patients in clinical trials, we stand to gain more information about how medications interact with, and benefit, a more representative slice of society.”

Professor Miles Witham and Professor Avan Sayer note that living with MLTCs *“is the norm at advanced age, indeed the accumulation of diseases and physiological limitations is a hallmark of the ageing process. Any attempt to research age related*

disease therefore needs to take this into account and embrace the complexity that comes with multiple long-term conditions.”

However, the same respondents note that the *“current paradigm for conducting clinical trials is based around the study of a single condition at a time.”* They suggest that a focus on one or more treatment for each single condition *“leads to an evidence base that is very narrow in terms of improving overall health, and importantly neglects harms in overall health and in conditions other than the target condition.”* They note further that polypharmacy is driven *“in large part by the current treatment paradigm whereby multiple treatments are given for each condition rather than finding single treatments that target multiple underlying conditions.”*

To address the challenge of MLTCs, Professor Witham and Professor Sayer suggest that *“a new approach to therapeutics is required, focusing on underlying fundamental biological mechanisms common to multiple conditions.”* To focus on these mechanisms, they suggest that *“clinical trials and other clinical research needs to take a much broader view, enrolling older people with multiple conditions, selecting therapies that target multiple conditions at once, and measuring outcomes that reflect the overall balance of benefits and harms rather than focusing on individual diseases.”*

Professor Witham and Professor Sayer also highlight the role of funders, ethics committees, and regulators in improving older people’s inclusion in clinical research. On **funders’ role**, they state:

“For non-commercial research, funders need to mandate the inclusion of older people, both by ensuring that upper age limits are avoided, but also by ensuring that funded research is designed in such a way as to remove barriers (such as inclusion and exclusion criteria), and to facilitate delivery of the research for older people (by reducing participant burden and supporting delivery of trials in environments other than hospitals).”

They also highlight the precedent set by the mandatory involvement of patients in the public in developing research grant applications, which *“shows that where funders mandate, researchers quickly follow.”* Also on funders’ obligations, they suggest that funding bodies need to ensure that they *“provide adequate funds to facilitate recruitment of older people to clinical trials. Older people require more time to participate in research, and the heterogeneity and higher dropout inherent in studies for older people means that sample sizes may need to be larger. Money is required to facilitate participation, whether this is through home visits or by provision of taxi transport.”*

Professor Witham and Professor Sayer also highlight that **research ethics committees have a role to play in supporting better representation in clinical trials**. They suggest that they can hold researchers to account and provide advice to researchers on these issues. They note, however, that directives on older people’s inclusion from ethics committees or from regulators (for example, the Health Research Authority for NHS research; or the Medicines and Healthcare products Regulatory Authority for commercially-led research which requires marketing authorisation decisions) *“need careful framing... it is not sufficient to mandate inclusion based on the basis of age alone”*.

An alternative perspective was offered by Thomas Woodcock:

“Curiously, research ethics committees can easily be overloaded with older people! I sometime think that, in medicines research, it is younger people’s values that are not adequately addressed.”

Question 8: Please comment on the ethical aspects of the regulatory challenges raised by the field of ageing research with which you are familiar.

Few substantive submissions were received in response to this question.

The Academy of Medical Sciences suggests that one challenge is that *“the vast majority of regulatory processes are planned around developing interventions that target specific conditions.”* It notes that *“designing interventions or clinical trials to generally target ‘ageing’ could pose a challenge in terms of identifying a specific endpoint for regulatory purposes.”*

An anonymous respondent indicates that *“the ethical considerations given to older person research must centre around the issue of consent and transparency so as to not breach basic human rights.”* A response from Alex Ruck Keene similarly focused on consent.

“The area that I am most familiar with here is the question of capacity and consent in relation to research, and it seems to me that addressing these issues very important – especially in the context of a challenge from the Committee on the Rights of Persons with Disabilities interpreting the CRPD as only ever permitting research on the basis of capacitous informed consent. How does that pan out in the context of those with conditions such as Alzheimer’s which may mean that there may come a time that they cannot give such consent?”

David Gems highlights that one challenge are *“well-meaning concerns about not discriminating against older people [which] leads to nonsensical ideas about ageing being a good thing, and so not an appropriate target for medical treatment.”*

Thomas Woodcock urges *“greater emphasis on individualised risk assessment allowing the research participant to make his/her own informed judgment on acceptable risk, rather than trust this judgment to researchers and their ethics committees.”*

Michael Dunn emphasises the support that RECs might need in the context of ageing research:

“RECs need to be assisted in applying their ethical review criteria to the specific issues as they present in ageing contexts: how should we think about harms and benefits in the conduct of research in people’s lives; the risk of missing ethical concerns relating to privacy and dignity that can often present in care research involving older people in care homes or in their own homes; stating and clarifying the methodological value of engaging in qualitative social science research (particularly interviews) that seek to involve older adults lacking capacity.”

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?

Some respondents indicated there was **a balance to be struck between biomedical and technological approaches and other policies that might ‘level up’**.

Professor Andrew Steptoe, for example, notes *“both are surely important. Biomedicine and technology cannot solve all the problems of ageing, but policy that does not take advantage of technological innovation will also have limited impact.”*

In the context of balancing the two approaches, an anonymous respondent indicates that *“the betting is that both approaches would be beneficial, but it seems likely that biomedical and technological approaches would, pound for pound, have a more cost-effective impact than ‘levelling up’ of healthspans.”*

Dr Philippa Brice notes that **striking the right balance is critical:**

“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.”

Some respondents, however, suggest that the balance might be tipped in favour of one of the two approaches. David Gems, for example, suggests that **social interventions should be prioritised.**

“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.”

Thomas Woodcock also **rejects the proposition that the two factors emphasised by the question should be balanced.**

“I don’t see this as a balancing; having a shorter expected healthspan IS a disadvantage, unhelpful to presume disadvantage CAUSES rather than ASSOCIATED WITH shorter health span.”

The key **role of biomedical and technological approaches** is highlighted by both the Academy of Medical Sciences and Dr Philippa Brice (PHG Foundation):

“novel biomedical and technological approaches could have an important role to play in equalising health spans of the most disadvantaged to the least.”

“In the past, some technologies have proven to have the power to change health outcomes with significant social determinants (for example, vaccination against infectious diseases). It would therefore be unwise to exclude science-

based approaches of this kind from consideration for public funding and policy; indeed, limiting the development and provision of innovations proven to be cost-effective and beneficial solely to the commercial sector would be even more likely to result in widening health inequalities.”

However, the Academy observes that *“great care should be taken to ensure novel health-related technologies are deployed in an equitable and appropriate manner. 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 socioeconomic spectrum.”* Dr Brice also notes that *“whilst it can be tempting to look to science and technology for relatively quick fixes, they can only ever be part of the solution to complex issues such as the maintenance of good health and prevention of disease. 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.”*

The inequalities which underpin the focus of this question were also highlighted further in the Academy’s response, with the observation that *“people living in the most affluent areas of England can expect to live 18-20 more years in good health compared to those living in the least affluent regions”*. It therefore suggests that, while biomedical and technological advances *“display promise, they must be considered as part of a suite of interventions put in place to tackle the health inequalities present across society.”*

Sangeetha Neeraja Babu Manoharan from the Centre for Ageing Research at Lancaster University suggests:

“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. The focus here is to support the older adults, if technology could pave a way, it should be considered as a useful alternative and to supplement the existing support infrastructure.”

An anonymous respondent called for technologies to have **“a more equitable focus”** when compared with other approaches such as public health, rehabilitation, and care. The respondent also calls for *“greater funding and support for translation of effective interventions into policy and practice”*, noting *“It isn’t just a case of ‘this works, just do it!’ (I wish it were)”*.

Equity was also a concern for a further anonymous respondent who suggests that *“inequalities are modifiable through the modification of the social structure and environment. Identifying individuals who might have been subject to inequality when they enter the health and social care system, and providing meaningful aid to these individuals, is imperative.”*

In the context of technologies, Dr Philippa Brice (PHG Foundation) suggests that *“maximising equity of health benefits is likely to require active measures to maximise accessibility and utility for all groups – for example, directly addressing disparities in health and digital literacy and social infrastructure.”*

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.

This open question generated a broad spectrum of submissions from respondents.

On the responsibilities of **family members**, Thomas Woodcock suggest that *“the extent to which family are / should be engaged is vary variable with strong cultural influences.”* An anonymous respondent also comments on the role of family members and suggests that *“families clearly have some responsibility, but, by no means, in every case.”*

In the context of **professional responsibilities**, an anonymous respondent indicates that *“professionals are, by definition, expected to act responsibility, regardless of any prejudice they might have at a personal level.”* Thomas Woodcock suggests that they professionals are *“generally still too patronising / judgmental”*.

Governmental responsibilities were also highlighted by respondents, including the Academy of Medical Sciences:

“Government also has an important role to play with respect to fostering and encouraging healthy behaviours across society. Higher level policy or government interventions may reduce health inequalities to a greater extent than educational campaigns; for example, stricter regulatory interventions such as alcohol and tobacco taxation have often yielded the greatest behavioural changes.”

On the issue of choice and **personal responsibility**, Dr Philippa Brice (PHG Foundation) observes:

“With increasing options for innovations to support older people’s health, it will be important to ensuring personal choice by focusing on the desires, concerns and circumstances of individuals. At the same time, the link often made between personal choices and personal responsibilities has limitations that should be acknowledged. Some have the knowledge, resources and capabilities to take responsibility for their health, but this expectation may be unreasonable when applied to those who lack such capacity. This applies to all adults, but no less to older adults.”

An anonymous respondent also highlights personal responsibility from their own perspective, noting that *“as a 52-year-old, it is really up to me to take care of myself.”* A further anonymous respondent suggests *“older people have considerable responsibility to behave in a prudent fashion. Most of them know what is beneficial and what is detrimental to their healthspan and they make (and have made) conscious decisions based on this knowledge.”* On the role of personal responsibility, Sangeetha Neeraja Babu Manoharan from the Centre for Ageing Research at Lancaster University observes:

“The first onus lies with older adults, to take care of their health by adopting healthy lifestyle choices such as exercising, eating healthy with a focus on wellbeing and mental health and work to create a network of support through friends, family, neighbourhood groups and hobby / interest groups. More awareness needs to be created about the existence of support networks like charities meant for older adults.”

One anonymous respondent suggests that **wider society** “would benefit from better education re the needs of older people”. David Gems also comments on the role of societies:

“... modern societies need to radically adjust to the higher proportion of older people, in many respects. This includes devolving responsibility for healthcare to some extent from the NHS to local communities, with a greater contribution of older people themselves in mutual aid organizations, using devices such as time banking. This would also guard against alienation and loneliness among older people. 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. All this would need some funding from the state, and other sources, but it should also relieve pressure on the NHS which threatens to become overwhelming, without major change.”

The failings of **state responsibilities** in this context are highlighted by Michael Dunn:

“There are clear failing 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. Currently the playing field upon which a clear, defensible account of social responsibilities in ageing could be articulated and applied is so imbalanced in terms of the meeting of basic needs of older people that it is difficult to make any substantive progress (or to even open up a conversation about wider social and interpersonal responsibilities).”

Some responses emphasise **shared responsibilities** of various stakeholders. For example, the Academy of Medical Sciences indicates that “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.” Michael Dunn also comments on the shared nature of responsibilities in this context:

“... late 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. For me, this is not just a matter of intergenerational justice; it is part of what we owe to developing an understanding of, and then realising, the good life for people as they get older – something that we all stand in relation to within families, neighbourhoods, communities and across the nation as a whole (and that, in my view, is best understood in terms of enabling a rich, socially embedded, capability-founded notion of personal agency, rather than by recourse to more amorphous ethical values such as solidarity). I am wary of attempts to try to allocate specific responsibilities prior to, or in ways that might blur, this understanding of what social justice demands in an ageing society (or at least potentially risk being misunderstood as implying that any particular response is ‘someone else’s duty’)”

On the prompted values raised by the question – i.e., **intergenerational solidarity and fairness** – Thomas Woodcock suggests that *“intergenerational solidarity is desirable, but perceptions of fairness will be difficult to reconcile.”* An anonymous respondent also indicates that *“it’s difficult to know quite how much intergenerational solidarity there is, at present. It is apparent that there is some unfairness, but what can be done about this at a practical level is difficult to define or articulate.”*

On fairness, David Gems observes:

“In terms of fairness, it is well established that without major state intervention, inequality progressively increases with time, as it is now and will continue to do so until reintroduction of appropriate social policies.”

Any other comments

Our call for evidence invited respondents to provide any other comments in response to the themes and issues raised by our consultation.

Two substantive points include a note from Dr Anna Bone and Professor Katherine Sleeman on the importance of **including end of life care** in the healthy ageing agenda.

“The focus of healthy ageing with increased years in good health, delaying the onset of ageing etc, without acknowledging what this means when people inevitably reach the end of life, misses an opportunity to improve care and support for older people at this important time of life. The Healthy Ageing agenda should encompass old age until the end of life.”

Professor Andrew Steptoe emphasises the importance of **evidence**:

“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 inter-generational processes directly. My view is that without a sound evidence base of this kind, it will not be possible to evaluate futures such as the fictional scenarios with any confidence.”

Conclusion

The outcomes of this expert call for evidence will be considered by the Nuffield Council’s working group on the future of ageing and will inform its project report which will be published at the end of 2022.