

OVERVIEW OF REPORT

The future of ageing: ethical considerations for research and innovation

Published April 2023

The Nuffield Council on Bioethics has published the findings of an in-depth inquiry exploring the ethical issues that arise in relation to the role of biomedical research and technological innovation in helping people to live well in old age.

This inquiry was overseen by a multidisciplinary working group and was informed by a range of engagement and evidence gathering. Contributors to the inquiry include older adults, intergenerational discussion groups, practitioners and academics from many different disciplines.

The report identifies the values, principles, and factors that are ethically significant in relation to research that seeks to influence people's experience of ageing, across these three broad areas:

- Research into biological ageing
- Assistive, monitoring, and communications technologies such as health apps and smart home technologies
- Innovative predictive and diagnostic technologies.

We propose an ethical framework (see overleaf) to help everyone involved in research and innovation related to ageing think through the ethical implications of their work and to suggest practical and actionable steps for change. An interactive version of the ethical framework can be found on our website at www.nuffieldbioethics.org/publications/future-of-ageing.

Recognising the influence of the wider research ecosystem on the scope for researchers and others 'on the ground' to adopt these approaches, we make 15 recommendations to those with influence on the conduct and publication of research, including the UK Government, research funders, regulators and practitioners.

Our recommendations will help embed an approach that puts the diversity, agency, and value of older adults firmly at the heart of all research concerned with ageing.

See opposite for our ethical framework for research and innovation linked to ageing.

See the next page to read our recommendations.



What does it mean to age well?

How do we know we can trust new tech?

Who decides research priorities?

What is the impact of ageism on science?

How do we support a healthy old age for everyone?

How do we involve older adults in research?

Recommendations

1

We recommend that everyone with influence over how research and innovation concerned with ageing - from individual researchers and practitioners to governments and funders - takes account of the ethical framework and toolkit presented in our report to guide their thinking. A more detailed interactive version of this framework is available on our website.

Public input into policymaking

Many organisations - including the House of Lords Science and Technology Committee - have raised the need for a cross-strategy to support the UK Government's aim of using science and technology to help people live longer, healthier lives. We echo this call and believe that members of the public of all ages, and from a wide range of backgrounds, should have a voice in how it is implemented.

2

We recommend that a cross-governmental strategy on ageing should be supported by a public intergenerational advisory forum including people of a range of ages including older adults.

Inclusion: influencing the research agenda

Action is needed within many parts of the research system to make sure that the experiences of diverse older adults help to shape decisions about research. This should be a core part of wider commitments to include diverse public representation in how research is conducted in the UK.

3

We recommend that research funders, regulators, research ethics committees, and journals should all require meaningful collaboration with older adults to inform decisions about research that is related to ageing.

4

We recommend that public research funders who support research in ageing should collaborate to support partnerships between research teams and public contributors.

Inclusion: taking part in research

Older adults with significant care needs are unlikely to be included in research. This needs to change. Research on ageing must include more older participants - with a particular focus on ensuring diverse experiences of ageing.

5

We recommend that funders of research on ageing should require (and fund) researchers to collect a minimum demographic dataset about their research participants. This should include, as a minimum - age, sex/gender, ethnicity, socioeconomic status, and nature of access to family or other support.

6

We recommend that the Medicines and Healthcare products Regulatory Agency (MHRA) should consider mandating the inclusion of data from 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.

7

We recommend that the Health Research Authority (HRA) working with funders such as the National Institute for Health and Care Research (NIHR), should identify and share examples of good practice in the inclusion of older adults, especially those with impaired mental capacity, in research. These should be shared with ethics committees to support them when scrutinising research proposals.

8

We recommend that research funders should provide dedicated funding to support researchers and engagement practitioners in developing relationships with older adults in their communities and with the care sector, to enable older adults with care and mobility needs to participate in research.

9

We recommend that researchers and research funders responsible for large-scale volunteer databases and cohort studies should ensure that the studies capture both the breadth of diversity in the ageing process, and the scope to intervene positively in the ageing process.

Supporting interdisciplinary research

Recent initiatives to improve the coordination of research in ageing and bring together different disciplines include the creation of 11 UK Ageing Networks, established by the Biotechnology and Biological Sciences Research Council and the Medical Research Council. Such networks can play a crucial role in supporting collaboration on research.

10

Provided the initial funding of the UK Ageing Networks demonstrates its success, we recommend that all relevant funding councils within UK Research and Innovation (UKRI) should commit to long-term joint funding of these networks.

11

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

- **Recognise the importance of interventions and support across the life course to enable people to live as healthily as possible, with a particular focus on preventative approaches at all ages**
- **Prioritise the needs of those who are currently most disadvantaged, with particular emphasis on addressing structural barriers to ageing well**
- **See scientific and technological innovation as an important complement to, but not substitute for, wider social policies that are fundamental in supporting people to age well.**

Regulation and accreditation

Many technologies that promote healthy lifestyles at all ages or provide support for people to live well in later life are marketed as general consumer products; they are not regulated in the category of 'medical devices'. Given the growing commercial interest in these technologies, it is particularly important for developers to demonstrate ethical processes in their research and innovation.

12

We recommend that the British Standards Institution (BSI), the MHRA and Innovate UK, should collaborate to develop accredited standards for promoting ethical research practices for technologies designed to support people to live well in older age. We suggest our ethical framework is used as a starting point for these standards.

Better links between research and implementation

Research and innovation can only make a real difference in people's lives if the resulting treatments and products are made available to those who will benefit from them. This requires close working between researchers, older adults, and service providers, to ensure that the aims of research are relevant and achievable. It also requires commitment and flexibility from those who fund services used by older people.

13

We recommend that research funders should take active steps to promote closer working between researchers, and those directly involved in providing services for older people. Possible approaches include creating grant opportunities directly aimed at partnerships between researchers and practitioners.

The value of early detection or screening depends on the availability of effective support or treatment for the conditions that are being screened for.

14

We recommend that any new screening or testing programmes associated with age-related conditions should only be rolled out if accompanied by services and support for people who receive diagnoses and their families and those who provide care and support.

Promoting interdisciplinary approaches

Professional education has a particularly important role to play in increasing awareness of: a life course approach to ageing, the benefits of interdisciplinary approaches to supporting older adults, and making the best use of research and innovation.

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, supported by our ethical framework and toolkit.