

# Older Adults' Perspectives, Experiences, and Expectations of Ageing in England: A Grounded Theory Study Protocol

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## ABSTRACT

**Background:** Pessimism about ageing can have negative impacts on older people's health and wellbeing and foster negative societal views of ageing and older people. These negative views can impact how people age, with more negative views producing more negative outcomes. To reduce ageism in society, concepts such as ageing well have been developed. However, our understanding of what ageing and ageing well means to older adults is limited. In this study, we will explore the perceptions, experiences, and expectations of ageing of older adults in England and develop a theory of ageing and ageing well.

**Methods/Design:** A constructivist grounded theory approach will be used to interview 30-60 older adults from diverse backgrounds and locations in England. We will include healthy adults, adults with physical illnesses, people with dementia, and carers of people with dementia.

**Discussion:** The findings will help to provide much needed information about whether people can age well, and what is needed to achieve this for people from diverse backgrounds. This could help to develop and highlight interventions and services needed to effectively meet the needs of the diverse ageing population. This could highlight action points for providing adequate targeted services and care and support for people as they age.

*Keywords: ageing, ageing well, qualitative, grounded theory*

## 1. Background

As people age, the body can slow down, become frailer, and be more susceptible to illness or disease (World Health Organisation, 2021). Adults over the age of 65 are more likely to live with more than one long-term health condition (Banerjee, 2015). Older adults therefore are more likely to experience ill health and need more healthcare interventions. Some of the conditions common in older age include arthritis, heart disease, diabetes, depression, and dementia (Centre for Ageing Better, 2022; World Health Organisation, 2021). The risk of developing symptoms of dementia increases with age. Dementia is one of the biggest causes of mortality for older adults in the UK (Office for National Statistics, 2021). Currently second only to Covid-19, dementia was the most prevalent cause of death for older adults from 2015 to 2020. However, despite being superseded by Covid, overall, dementia is still a bigger cause of death compared to other conditions and illnesses such as cancer and heart disease (Office for National Statistics, 2021). Importantly, in 2020 and 2021 the leading cause of death for men was Covid-19 and ischaemic heart disease, respectively, whereas for women, the foremost

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cause of death was still dementia, despite the prevalence of Covid-19 (Office for National Statistics, 2020, 2021). Therefore, dementia and its impacts are an important aspect of ageing and the lives of older adults that needs consideration.

These aspects of illness and frailty in older age described above are often seen as inevitable consequences of ageing. This stereotypical view of ageing as a time of loss and decline has led to the belief that being old means being ill (Stewart et al., 2012), or that older people are a burden on society (Centre for Ageing Better, 2020a). Although older age can indeed include increases in physical illnesses and frailty, and although age is the biggest risk factor for dementia, it is not inevitable that these will occur as we age; they are only loosely associated with age (World Health Organisation, 2021). This resultant pessimism from ageist stereotypes is widespread in different parts of society. Sectors such as politics, media, social media, advertising, and even ageing focussed charities use negative age discourses and draw on negative stereotypes (Centre for Ageing Better, 2020a, 2020b). Such pervasive pessimism about ageing can determine the perceived worth and value of human beings as they age (Gullette, 2004) and can have real-world impacts such as influencing political agendas and determining funding strategies for older adult care and support services (Kendig et al., 2019; World Health Organization, 2021).

Ageism is a significant problem in many societies which can have considerable impacts on older people in terms of healthcare provision, treatment in the workplace, and emotional wellbeing (Giasson & Chopik, 2020; World Health Organization, 2021). Self-directed ageism can also have an impact on older adults' health and wellbeing outcomes. Older adults who hold more negative views about their own ageing are less likely to engage in preventative health behaviours such as exercising, healthy eating, and smoking cessation, thus potentially resulting in worse mobility and physical functioning, and an increased risk of cardiovascular events (Levy et al., 2009; Levy & Myers, 2004). People who hold ageist views from a younger age are also subject to the physical ill-effects of ageism, with people experiencing worse health and wellbeing outcomes because of the biases they hold about age and older people (Ackerman & Chopik, 2021). This can also lead to higher incidences of cardiovascular events compared to people who have more positive views of ageing (Levy et al., 2009).

In order to move away from concepts of ageing as decline and loss, and to reduce ageism, there has been a development and promotion of more positive concepts of ageing. First promoted from the 1950s onwards (Katz & Calasanti, 2015), terms such as healthy ageing (Havighurst, 1961), and active ageing (World Health Organization, 2002) have tried to reframe ageing in a more positive light, whereas other terms such as harmonious ageing (Liang & Luo, 2012) have tried to provide a more balanced view of ageing by including both the challenges and opportunities related to older age. However, although these positive aspects of ageing are meant to provide an alternative and better narrative to that of ageing as decline, they are still overly focused on function, activity, and productivity in older age as markers of positive/healthy/successful ageing (Sandberg, 2013). As Sandberg posits, concepts such as successful ageing "*retain[s] youth and the characteristics of youth as desirable*" (Sandberg, 2013, p. 13). These concepts and ideals could be seen as an unattainable goal to reach for many people, particularly those who are ageing with physical or cognitive impairments. Indeed, it has been shown that these positive concepts of ageing actually led people to blame themselves, or others, for failing to age in a specific way, or for failing to achieve the goals set out by these approaches (Calasanti, 2016). Thus, it has been argued that these concepts and terms could increase ageism instead of decreasing it (Angus & Reeve, 2006; Calasanti, 2016).

A broader lay term being used in the UK to denote positive ageing is ageing well (Fernández-Ballesteros et al., 2008). The use of this term has grown in the UK and has been used predominantly outside of academia, in discussions and documentation related to the health and social care sector and their policies and directives. For example, it is used by various

councils as part of their strategies and campaigns to improve the lives of older people, and it is included in ageing charity organisation mission statements as a way to help people live better in the community. Ageing well is also a central part of the NHS England long term plan (<https://www.longtermplan.nhs.uk/areas-of-work/ageing-well/>). However, we do not know what the term ageing well means to people, how useful this term is and whether it is as negatively impactful as other concepts of positive ageing. From our work with the Pam Britton Trust for Dementia, one of the partners of this research, and from discussions with people involved in dementia and ageing research, we understand that terms such as ageing well and living well with dementia are contested. Some people advocate for their use as an honourable goal to achieve, whilst others argue that it makes too many assumptions about, for example, quality of life, and is an unattainable goal for all and should not be used. Such arguments highlight the need to investigate further the value of terms such as ageing well and to understand what people mean by ageing and ageing well. Similarly, the usefulness of such terms to older adults is unknown, and how older adults perceive these terms and concepts in relation to their own ageing is unclear.

The ageing population have diverse backgrounds and life experiences, such as cultural and ethnic background, which will lead to different experiences and expectations of ageing. These diverse backgrounds will impact on an individual's ideas of what ageing means, and on what ageing well means. People from different cultural and ethnic backgrounds may have different experiences and expectations of growing older because of their differential backgrounds (Wray, 2003). Different expectations and experiences of ageing could be because of differences in when important life events occur. For example, Wray (2003) found that British Pakistani and Bangladeshi women felt older at an earlier age compared to other women because they had children at a younger age. Further, the very notion of ageing well or successful ageing is a western cultural concept (Wray, 2003). What constitutes successful ageing or ageing well will differ from culture to culture and may not translate to any meaningful concept from one culture to another. In addition to culture and ethnicity, the location where people live can have an impact on ageing. There are differences in life expectancy and wellbeing in rural locations compared to urban locations, and people living in urban areas have different opportunities for care and support intervention compared to people living in rural areas (Centre for Ageing Better, 2021). All these differences in opportunity and experience will impact on perceptions of ageing and ageing well. Adults do not age physically or cognitively in a homogenous way either. They will have differing levels of conditions, illnesses, and impairments which will impact on ageing. Experiencing physical ill health, cognitive decline, or caring for someone with cognitive decline is likely to have significant impacts on how people age and whether ageing well is a useful term or goal to aim for. Similarly, fearing physical or cognitive ill health may also have an impact on how people age, their views of ageing, and their expectations of their life as they age.

This study therefore wants to learn about ageing from a diverse section of the ageing population. We will explore what ageing means to older adults, how pessimism about ageing or ageism has impacted them and explore the impact that characteristics such as cultural context, ethnicity, location, and health status has on these views. We will explore perceptions of concepts such as ageing well, and probe how views of this are influenced by diverse experiences and fears about ageing. We will also investigate how anticipations of potential physical or cognitive ill health might impact how people think about ageing.

This study is a part of a wider research programme 'The Sciences of Ageing and the Culture of Youth' (SAACY) that reaches across disciplines and sectors to understand and improve experiences and perceptions of ageing (<https://www.kcl.ac.uk/research/saacy>). The study will develop a conceptual framework to overcome cultural pessimism about ageing and influence policy.

## 1.1 Aim

The aim of this study is to understand the perceptions, experiences, and expectations of ageing of older adults in England.

The study objectives are to:

1. Carry out a small pilot study to test interview topics and questions
2. Examine what ageing means to people, using an appreciative inquiry approach
3. Explore what ageing well might mean: explore its core components and understand what prevents older people from ageing well
4. Explore views of ageing: what aspects and experiences lead people to perceive of their ageing as positive or negative
5. Understand anticipations and fears about ageing
6. Examine differences in the experiences and expectations of ageing between people from diverse groups or with distinct characteristics such as sex, ethnicity, geographic location (urban, rural, suburban), and socioeconomic status
7. Examine how views of ageing may change over time, and what influences this, by following-up a sub-set of participants longitudinally throughout the study

## 2. Methods/Design

### 2.1 Study design

A constructivist grounded theory design will be used to collect data from older adults in three geographic locations in England using semi-structured interviews.

While there are a number of approaches to grounded theory (McCall & Edwards, 2021), in this study we adhere to constructivist grounded theory (Charmaz, 2006, 2014). Constructivist grounded theory is a systematic and flexible approach to collecting and analysing data about a phenomenon that is used to generate a new theory from the data; this is to say, the theory is 'grounded' in the data (Charmaz, 2014). Constructivist grounded theory design proposes that knowledge is constructed from experiences and is co-created through the relationship that is developed between the researcher and the research participant, as they work together to explore and understand the participant's experiences and meanings of the phenomenon of interest (McCall & Edwards, 2021).

### 2.2 Patient and public involvement

We have convened a Lived-Experience Advisory Panel (LEAP) of older adults who will support and guide the research objectives, progress and dissemination. The study has been created with input from the LEAP group members. They provided insight and amendments to the ethics application, interview topic guide, and participant facing documents. LEAP members are older adults aged over 50 years. They were recruited through the charity partners, both local and national, of the wider SAACY research programme (see below). LEAP members have diverse backgrounds and life experiences and live in London, Sussex, Warwickshire, and Yorkshire.

### 2.3 Charity and organisation partnerships

We will work with our charity and organisation partners throughout the study. The charities and organisations we are working with are The Pam Britton Trust for Dementia in Warwickshire, Age UK, The Centre for Ageing Better, Ageing Well Brighton and Hove, and Hackney Council. The partnerships will focus on collaboration in recruitment, dissemination, and impact activities to ensure that the research is successful, meaningful, and impactful. Charities and organisations are a mix of regionally and nationally based organisations which

will help to provide targeted regional impact that is meaningful to local members of the population, as well as providing wider impact and reach of the research findings. As the study progresses, we will engage with local councils in each location with a view to broadening the study's reach and ensuring our sample is as diverse and representative as possible.

## **2.4 Setting and participants**

We will use purposive and theoretical sampling to recruit participants from three locations in England. Participants will be recruited from a variety of geographic areas; these include inner-city London and the surrounding boroughs; Warwickshire; and Sussex and its surrounding regions. These geographic areas offer the opportunity to recruit people from diverse locations such as urban, rural, sub-urban, and coastal areas, and to recruit people with diverse backgrounds and experiences such as people with a variety of ethnic backgrounds and with different socioeconomic statuses. This also reflects a pragmatic decision to recruit within the regions covered by our study charity partners as well, which will enhance the impact of our collaborative work for local communities. For example, we will be able to work with the charity partners and participants in each location to understand local service needs and work collaboratively to make local impactful changes. The charity and organisation partners will aid in recruitment by advertising the study to their service users through their networks and connections. We will use social media posts and flyers to advertise the study more widely. To ensure we are inclusive in our recruitment and that we can include isolated adults with limited or no online connectivity, we will contact organisations that offer befriending services and phone calls to lonely older adults to help with recruitment of this population.

We will recruit 6-8 older adults aged 50-80 years old to carry out a small pilot of the interview topic guide to ensure that the questions are appropriate and understandable. We will then recruit 30-60 adults aged 50-80 years old to take part in interviews. We will recruit four groups of participants, these are: healthy adults; adults with a physical condition or ailment that causes pain or problems with mobility; adults with a diagnosis of dementia; and adults who care for someone with a diagnosis of dementia.

## **2.5 Inclusion/exclusion criteria**

The inclusion and exclusion criteria for the study include the following:

- Aged 50-80 years old;
- Healthy adults: have no diagnosed/self-diagnosed physical or cognitive impairments or conditions commonly associated with ageing (e.g. dementia, stroke, arthritis);
- Adults with a physical condition: have a diagnosed/self-diagnosed condition or ailment that causes pain or affects mobility;
- Adults who care for someone with dementia: provide care for a relative with a diagnosis of dementia. Diagnosis will not be checked;
- Adults with cognitive impairment: have a diagnosis of dementia or cognitive impairment and have a carer who knows them well and either lives with them or would be available on the day of research visits. Diagnosis will not be checked.

## **2.6 Data collection procedure**

The timeframe of data collection will be approximately 24 months.

A small pilot study will be carried out to test interview questions to ensure that they are appropriate and understandable to participants and that they elicit meaningful responses. We will ask participants for their feedback and amend questions as needed prior to the main study.

For the main study, each participant will be invited to: 1) complete a questionnaire which will ask about their demographics such as age, sex, ethnicity, and education level; 2) complete

the short-form Attitudes to Ageing Questionnaire (AAQ) (Laidlaw et al., 2018), which asks questions about attitudes towards ageing from the perspective of older adults; and 3), take part in an interview with a researcher who will ask questions about their perceptions and experiences of ageing. Interviews will last for approximately 60 minutes.

An interview topic guide has been developed and includes questions such as ‘what does ageing mean to you?’, ‘what do you think ageing well means?’, and ‘could you describe your feelings about growing older?’

Questions will be refined and adapted as the interviews progress and as new questions and topics emerge throughout analysis. With permission, participants will be contacted throughout the study to answer further questions as they arise. Participants may also be re-contacted to take part in focus groups, should the need become apparent throughout data collection and analysis. Focus groups will provide an opportunity for group interaction, discussion, and collaboration about important aspects of ageing in a group setting. This is argued to be a more natural form of discussion than individual interviews (Litosseliti, 2003). All interviews and focus groups will be audio recorded using a digital voice recorder to ensure accuracy. Field notes will be used to record relevant researcher observations and perceptions and a reflective diary will be kept by the researcher to document the impact of the research process.

We will follow-up a sample of 10-15 participants throughout the course of the study for two purposes. The first is to see how perceptions of ageing change over time, the second is to understand whether taking part in the research and talking about ageing has had any impact on participants’ views on their own ageing. Follow-up participants will be asked to complete the AAQ and take part in an interview every 6-12 months over the duration of the study. Specifically, we will follow-up participants who score within the first and fourth quartiles of the psychosocial loss scale of the AAQ; higher scores on this scale in particular are indicative of more negative attitudes.

## **2.7 Data analysis**

Demographic and AAQ data will be entered onto SPSS. We will calculate the means, standard deviations, and frequencies of demographic data and scores of the subscales of the AAQ according to instrument guidelines.

Qualitative data analysis will be conducted alongside data collection as far as possible. As soon as data has been collected, audio recordings will be transcribed and analysed. This is to ensure that the emerging findings inform subsequent data collection. Each interview will be checked for accuracy and read through in detail so that the researcher becomes familiar with its content. We will use open, axial, and selective coding, with constant comparative analysis to ensure the voice of the participant is maintained (Charmaz, 2006; Strauss & Corbin, 1998). Qualitative data analysis will be supported by the use of NVivo software.

## **3. Ethics**

Ethical approval was provided by King’s College London Social Science & Public Policy, Humanities and Law Research Ethics Subcommittee on 3<sup>rd</sup> May 2022. Each participant will be provided with a participant information sheet that clearly describes the aim and purpose of the study. Each participant will be asked to sign a consent form or provide verbal consent to take part, depending on whether interviews are conducted face-to-face or virtually. Interviews will be audio recorded and will last approximately one hour. To reduce burden, participants can take breaks whenever they need, and data collection can be spread over more than one session. Some of the topics discussed during interviews could be sensitive and emotional. The research team will be mindful of providing appropriate support to those affected by the discussions. The

nature of the topics to be discussed will be highlighted before participants consent and before the interviews begin.

#### **4. Discussion**

Pessimism about ageing can have significant impacts on the way that people view older people and the way that older people view themselves. These can have important impacts on an individual's health and wellbeing as they age, regardless of age. This pessimism can also have far-reaching impacts such as affecting the value that people attribute to older adults in society, colouring their view of their own ageing, and impacting policies for ageing and older adults by perpetuating negative discourses of ageing.

The study presented here will increase our understanding of the experiences of ageing of older adults in England and provide more nuanced information about what influences the way that people age and how they perceive their own ageing, in relation to wider negative societal views of ageing. The theoretical framework developed from this study will highlight the experiences of ageing from the perspective of older adults and provide insights into the needs of people as they age whilst considering the diversity of older people and the diversity of experiences and expectations.

One of the strengths of the study is its engagement with the third sector. We will collaborate with our charity partners to enhance ageing and ageing well in the local community. Together with them, we will be able to provide recommendations for each organisation that are specific to the cultural, ethnic and location needs of the users of the services provided by the charities. With more tailored support, advice, and services, people could be supported in a more appropriate way to age within their community and to age or live well, within the parameters that older people place on ageing well. For example, the findings could provide insights into the types of services adults want as they age, or understandings about fears of ageing could be used by organisations to develop and provide specific interventions or information to their service users to allay those fears. That said, in focusing on people living in England, this study is not able to capture nuanced differences in ageing that are experienced by people living in the other devolved administrations in the UK, which have differing health and social care support systems and strategies.

More broadly, the related work in the different projects of the SAACY research programme will develop policy recommendations and work with policy makers, relevant stakeholders, and our charity partners to develop outputs and outcomes that will have direct benefits to older adults and ageing outcomes.

#### **Declarations**

**Conflict of interest:** The authors declare no competing interests.

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