Some ethical issues in research on the housing of older people

Anthea Tinker PhD[a]

[a]Institute of Gerontology, Department of Social Science, Health and Medicine, King's College London, UK, E: anthea.tinker@kcl.ac.uk

A.Tinker. Some ethical issues in research on the housing of older people. Gerontechnology 2016;15(4):192-197; doi:10.4017/gt.2016.15.4.002.00 In this article some ethical issues that arise in research on older people and their housing are discussed. It starts by underlining the importance of defining older people, the dangers of generalising, and the effect of excluding them from research. Ethical issues over the involvement of older people in research are then discussed. It looks at their living arrangements including the role of home and whether there are special issues for certain groups. The challenges over the use of assistive technology, including practical ones, are considered. There are particular issues connected with longitudinal studies and these are addressed. Finally, guidance over ethical issues and research on older people including housing and technology are discussed. It is also concluded that the use of measures that are generally agreed to enable comparisons across the world would be helpful.

Keywords: housing for older people, ethics, assistive technology, home

Although housing is of key importance to older people there is little attention paid to the ethical issues involved. This article attempts to address some of these issues.

Defining older people

For the provision of most services, chronological age that is measured by a person's birthday is considered the least controversial way of defining an older person. This will vary. In some cases it is the age at which a person receives a pension. For example in the United Kingdom it was 60 for a woman and 65 for a man, but this will become 67 for both sexes in the next few years. But in other cases it is a different one. Again taking the United Kingdom as an example, an 'older worker' is defined by the Department for Work and Pensions as 50 and over. Using a chronological age, it is argued, is 'fairer' as it is less open to opinions or views. If, for example, a retirement community sets a particular age for entry, there is less room for argument than if it was left to discretion. This is particularly the case for social housing where treating people equally is important as public funds are involved. Where there are variations in age in relation to access to services, there are ethical issues about unequal treatment[1].

However, people are sometimes considered 'older' when they retire from their profession. This could be at a relatively early age such as 40 for some athletes although there are elite sports where older people continue to perform at the highest level. It used to be the case that only young people would be pop stars but the success of many groups who continue into their 60s and 70 contradicts this.

Some housing schemes have been set up to cater for people from a particular job, cultural background or profession, which may or may not have an age criterion for admission. For example in England, there are schemes for owners of pubs and those who work in them. The Licenced Victuallers Association has a scheme called Denham Garden Village managed by a housing association (Anchor Trust). There are also schemes for people in the retail trade or from a particular store/shop. In some cases some of the larger stores have welfare teams and operate 'purchased' nomination rights with housing associations[2]. There are also schemes for other particular groups. In the Netherlands there are schemes which cater for people from specific backgrounds such as 'de Hogeweyk' village for people with dementia. Although this is a nursing home with several smaller groups, each one is planned so as to reflect different life styles. 'Het Gooi', for example, is for well off residents attaching importance to etiquette and appearance and cultural for those with interests in art and culture[1]. These could be a model for a retirement community. Differences according to ethnic background have also to be taken into account. Are these forms of 'discrimination' ethical?

It has also been argued that biological age is an alternate marker of age. There are tests which can calculate the age of particular organs or parts of the body so that, for example a person's bones may be those of a very old person but their brain that of a person who is much younger. It is difficult to see how such a definition of age would work when housing policies or allocations are made.

Another way in which attempts are made to define age is by vulnerability. Defined as 'exposed to harm' this is surely something which everyone can experience. People can be vulnerable physically, mentally and socially. However, there may be a particular combination of circumstance which makes a person more vulnerable, for example, a female living alone in a deprived area. She may be vulnerable because she is a woman, without another person in the household and without access to facilities such as help.

The dangers of generalising

There are dangers in generalising about older people in relation to their housing needs. For example Ebrahim argues about older people (however defined): 'There is greater variation in biological characteristics, such as blood pressure, lung function and muscle strength and in health status than at younger ages'[3]. There will also clearly be differences between people with different levels of cognition. Those with cognitive impairment, and this has a wide spectrum, may need different housing designs or technology than people who are not cognitively impaired.

Cultural differences may also impact on housing design. For example, sheltered housing for older people from particular ethnic groups may be different from that required by the indigenous population. In a number of towns in England, for example Leicester and parts of London, there are schemes specifically for older people of South East Asian origin.

Involvement of older people in research

Much research now is predicated on a high involvement of those being researched from the design to the dissemination. Disabled people were among the first to argue that 'no research about us but with us'. Many ideas for research will, of course, come from the constituent field but it is unrealistic to think that this is the only source. However, it is increasingly being held that the groups being researched for both ethical and practical reasons need to be involved in the various stages. There can, however, be problems. In one research programme in the United Kingdom, the New Dynamics of Ageing, a reference group of older people wanted to change the methodology of the research despite the grant having been given on the basis of what was being planned. In this case when the methodology was not changed they resigned. A more positive experience was a group of older people who were trained to be the interviewers on a research project. An evaluation of this project was an account of learning by doing – of finding out what research is and how to do it by learning both from theory and from experienced researchers[4]. The older people were so successful that they subsequently set up their own company to undertake such work.

It is normally the case that the group being researched will be represented on any advisory group. Practically and ethically it would be ideal to have a representative group from which to choose but all too often it can become the 'usual suspects'. It is not always easy to recruit new members. Some research bodies keep a list of potential participants on whom they can draw. But ways to find the 'hard to reach groups', is always a problem in design of appropriate housing, as well as in research.

More fundamental is the involvement of older people in co-designing their homes and environment. An example of this is a large UK research council project 'Mobility, Mood and Place'[5]. Older people in Manchester and the London Borough of Hackney have been involved in suggestions about housing and neighbourhood in association with architects in training. Not only does this involve the older people but it can help train the next generation of architects about the need to adopt a bottom up approach.

Exclusion of older people

In general, older people may not be included in research or there may be an upper age limit. This occurs particularly in health care and research on drugs[6]. An age bias has been shown. The effect of the exclusion of older people from research is particularly dramatic where drugs are tested in younger people and then prescribed for an older age group. This can lead to uncertainty re risks and benefits of new treatment, under treatment, delays in bringing treatment to older people, and possible adverse reactions[6]. The same is true for children who may be not be subjected to trials and yet are later prescribed this medication.

In housing it has been shown that some groups of older people are 'invisible' both for research and in the provision of housing. These include those who are homeless (with so called 'rough sleepers' being particularly challenging to find), very old, from minority groups, hard to reach, people with learning disabilities and older non-heterosexual men and women[7]. This latter group have been described as invisible in terms of policy despite improvements in social attitudes in the past decade (Brown, 1997, quoted in [7]). It can be argued that it is unethical for housing to be designed for people whose needs have not been established. Further, where older people are excluded from research the results may be flawed.

It is also difficult to provide appropriate services for those who are 'invisible'. More research is

required to address the needs of very old people. While some attempts have been made, such as two major studies of those aged 85 and over in England[8,9], this is a rapidly growing cohort whose needs must be taken into account.

There are serious ethical issues if some older people are not considered in both housing provision and in research. Ethics committees should question applications for research which have an upper age limit without clear justification. It is argued here that there should be no automatic presumption that older people are vulnerable and therefore cannot take part in research. In England the Department of Health (DH) has stated 'It should *never* be assumed that people are not capable of making their own decisions, simply because of their age or frailty (p.1) and 'age or frailty alone is not a reason for doubting a person's capacity' (p.4)[10].

The reverse of older people being excluded is retirement communities where provision is solely for older people. While this may be their choice if they are given favourable treatment such as tax incentives, there may be concern about younger people who do not have this advantage.

Living arrangements

This article is concerned with older people living in a home of their own which is the normal situation for older people. There are different issues for the relatively small percentage of older people living in institutions. Scandinavia has the highest rates of institutionalisation (Sweden 7.9%, Norway 6%) and the Netherlands (2.4%) and Japan (3.2%) the lowest[11]. For those older people who live at home there will be different issues depending on whether they live alone or with a family. A significant proportion, especially women, do live alone, (*Table 1*).

However, there may be even more complex housing issues where older people live with their extended families but this is not discussed here.

The role of home

There is extensive research on the role of the home. Home can provide a sense of identity, a place of privacy, a focus of security, a site of key relationships and a point of orientation in relation to what may be a chaotic world outside. Bowes et al maintain that 'The front door is a barrier beyond which we normally expect not to be observed'[13]. Loss of home can result in significant changes in wellbeing and have pathological consequences and lead to increases in rates of morbidity and mortality[14].

Table 1. Older people (60+) living alone in percentages as reported in 2009[12]

Region	Living alone %	
	Men	Women
World	9	19
Africa	6	11
Asia	6	11
Europe	14	34
Latin America	9	12
Northern America	15	34

For older people home can be mainstream housing (i.e. either ordinary undated or adapted), especially designed/provided housing such as sheltered/assisted living or other kinds such as co-housing. For any form of shared housing there are both practical and ethical issues. For researchers looking at older people living in their own home there are issues over finding a representative group, how to access a sample and what to do if something, such as signs of mistreatment, need attention.

Special issues for certain groups?

It could be argued that for people in certain situations, not only is special provision needed, but that they should be excluded from research. People at the end of life are one such example. However, what is the justification for their exclusion from research? If issues to do with inclusion, sensitivity, ongoing consent and attrition are taken into account, this group can be included in research.

Technology challenges and issues

Developments in technology that can be used in housing for older people raise particular dilemma for researchers. Some of these dilemmas are discussed below.

Defining technology

Until recently assistive technology was the most used description for technology enabling older people to remain at home. The definition used in this paper is that of the World Health Organisation (WHO) for assistive technology: 'An umbrella term for any device or system that allows an individual to perform a task they would otherwise be unable to do and increases the ease and safety with which the task can be performed'[15]. It can cover a range of services and products including aids, adaptations and computers. The first generation was relatively simple including alarm systems where a button would be pressed. The second moved on to monitoring from a distance such as the use of sensors to detect falls. The third is more proactive and intelligent and involves tracking, for example, to detect changes in health and activities. The terminologies increasingly being adopted across the world for these proactive assistive technologies are the terms

'telecare' and 'telemedicine' but in the academic world the term used is 'gerontechnology'.

The role of technology

Assistive technology can be used for health, contact, help with various problems and for surveillance. Consent must of course be given for the installation of such technology.

Health includes diagnosis, treatment, and rehabilitation. Contact includes the provision of information, reassurance, medication, social reasons and practical help. Many older people use technology such as SKYPE for contacting relatives and friends. It is a myth that all older people are not able to use technology[16].

Help with various problems includes personal (such as washing, bathing, feeding), domestic tasks (such as cleaning the home), and mobility (such as walking and reaching). These problems may be related to sensory and motor such as trembling restrictions. Surveillance/sensor based technology for monitoring includes seeing if the person has fallen, to check on who is at the door and who is in the property, to check on carers and to monitor movements and patterns of behaviour. This issue is explored in detail by Bowes et al[13] who argue that lifestyle monitoring devices (LMD) provide an obvious reminder of reduced privacy, e.g. cameras and microphones. They may cause discomfort to the individual and subsequent rejection of the system[17]. Recognising the link between obtrusiveness and user acceptability, systems for capturing LMD have been designed to be unobtrusive[18] allowing people to go about their lives without being conscious of data being collected. However, in a research context, particularly with older participants experiencing cognitive impairment, this could lead to a situation in which continued monitoring becomes, in essence 'covert observation'[13].

Ethical issues

There are many ethical issues with this use of technology. Does it, for example, encourage the independence or isolation of older people? Marshall argues that there is potential for isolation in the use of technology drawing on the experience of the ASTRID (A Social and Technological Response to meeting the needs of Individuals with Dementia and their carers) project[19]. There are major issues to do with consent and the balance between benefit and harm. There are issues to do with records – access, storage and the sharing of data. But the major one is that of replacing humans with technology. Could they diminish human contact? In what circumstances is this both feasible and ethical?

One area of surveillance where there has recently been advice in England is 'Thinking about using a hidden camera or other equipment to monitor someone's care' is by the Care Quality Commission[20]. It gives detailed guidance but starts with words of warning 'Installing a camera or other recoding equipment is a big step and a decision for people and families to make. On the one hand, it might set your mind at ease about any concerns you may have. Or it might help you to identify poor care or abuse. However, you should think carefully about how it may intrude on other people's privacy, including other people who use the service, staff, families and visiting professionals.'(ibid, p. 5). The advice also stresses the need for 'the permission (consent) of the person whose care you are concerned about, and only in their private room;' (ibid, p. 5). There is also advice about the legal risks and effect on people's privacy (ibid, p. 10).

Ethical issues and longitudinal studies

Longitudinal studies, where people are followed over a period of years by researchers are increasingly being recognised as essential in gaining an understanding of the ageing process in older people, particularly as life expectancy and the proportion of older people in the population continues to increase. They are crucially important when considering the changing circumstances of older people's housing. The case for more investment in such studies was put forcefully in the House of Lords report 'Ageing: Scientific Aspects'[21]. However, participation rates in such studies have been decreasing[22,23] and research has shown that dropout is greater among older participants[24.]. It is particularly important that they remains as representative of the population as possible[25]. However, although it is important to retain participants in longitudinal research studies there are ethical issues over how far they should be encouraged/persuaded to remain in the study and not drop out. Should they, for example, be given incentives to remain in?

A major study involving a literature review, questionnaires to other researchers worldwide, secondary analysis of data and collection of new data from the Whitehall 11 study involving focus groups and telephone interviews revealed that there was a major issue of drop out but that other studies were anxious to find ways to avoid this[25]. Researchers in these longitudinal studies had devised a variety of ways, such as follow up correspondence and telephone calls to reduce drop out. It would not, of course, be ethical for this process to be coercive.

Some conclusions

Where there is positive discrimination as in many of the examples given there are ethical issues over those who receive a service such as special provision or treatment and those who do not.

An even wider issue for policy makers is that of tenure. The current generation of older people, especially in the UK, have become owner occupiers. Many of whom have been helped in some way by favourable tax treatment for mortgages. They have also benefitted from free higher education and many other benefits which are increasingly not available to the current generation of older people. The new generations of older people will face years, if not a lifetime, of renting and it could be argued that this is unethical. There are issues of intergenerational justice here.

Some of the major ethical issues in housing for older people relate to the use of assistive technology. This is of particular concern for people with cognitive impairment. Consent from them or a nominated person is essential.

There are wider issues in research that have not been explored here. These include whether funding should be accepted from providers of housing and in what circumstances, for example from a provider of private sheltered housing. If it is, then it must be clear that the results, both positive and negative, must be shown.

Another issue is that would bear further exploration is that of comparisons. For some of the topics discussed here, such as indicators of the well-being of older people, it would be useful to be able to make comparisons between countries. Such an index has been suggested in the Global AgeWatch index[26].

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