

# Balancing Ethics in Research with Older Adults and Persons with Dementia

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## ABSTRACT

This paper will discuss ethical considerations for research on technology-based solutions to support memory in healthy older adults and persons with dementia (PwD). The authors have reviewed past research proposing innovative ways to help memory, well-being and independence for healthy older adults and PwD, as well as literature on ethics relating to the use of assistive and ambient technologies for PwD. This review has surfaced issues for discussion in a workshop setting. The key finding from this review is that fundamental practices in HCI (e.g. user-centred research and participatory design) are well-suited to address ethical issues that arise when project goals and benefits across stakeholders are not aligned. HCI research can contribute to the ongoing discourse on ethics of working with vulnerable older adults by providing a space to explore practices such as rolling informed consent and resulting impacts on levels of engagement of healthy older individuals, PwD, families and carers.

## Author Keywords

Interaction design, Human-computer interaction, Human memory, Everyday remembering, Older persons, Dementia, Ethics

## ACM Classification Keywords

K.4.1 Public policy issues (e.g. Ethics); H.m Information interfaces and presentation (e.g. HCI): Miscellaneous.

## INTRODUCTION

This position paper covers ethical issues in the design of studies that aim to understand the needs of older adults and persons with dementia (PwD) - particularly in relation to everyday memory and forgetting - and in the evaluation of possible solutions to help cope with age-related loss of memory function. The PhD research which

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prompted this position paper relates to the development of technology-based solutions to support memory in older adults and PwD.

By way of background, the researchers took into consideration the demographic shift towards an ageing population, growing numbers of PwD, the lack of effective treatment options for dementia, and significant costs to individuals, communities and government of providing care for individuals who choose to remain at home. In addition, one of the authors has a parent with dementia, prompting an interest in exploring possible solutions to help other PwD remain at home and autonomous for as long as possible. The social and personal relevance of the project are key motivators to explore innovative solutions to support everyday memory function.

This paper has been developed in the process of preparing a submission to the university human research ethics committee to conduct a study to work with PwD (as well as other individuals with an acquired neurological conditions that would affect memory function), and their families and carers. The proposed study will focus on identifying user needs and will be followed by iterations of solution development (possibly through participatory design) and prototyping (based on identified needs) and subsequent testing with users (including PwD, family members, friends, and carers). An initial study with healthy older adults has already been conducted.

## RELEVANT RESEARCH

A review of the literature in HCI and other fields (including psychology, gerontechnology, and computer engineering) has provided a useful foundation on previous approaches and has also identified a range of issues with possible ethical implications. The challenge of catering to the complex needs of ageing populations is explored briefly as one of the issues that design research can untangle (Zimmerman et al. 2007). A range of projects has explored how various technologies can be applied to support independent living among older adults. (Alm et al. 2004; Cahill et al. 2007).

Factors that stimulate and inhibit interest in technology among older users (regardless of cognitive ability) are well-documented (Cahill et al. 2007; Charness et al 2012; Melenhorst et al. 2006; Mynatt et al. 2004; Rialle et al.

2009; Robinson et al. 2009; Wallace et al. 2010) and are summarised in Table 1 below.

Factors that stimulate interest:	Factors that inhibit interest:
<ul style="list-style-type: none"> <li>• Promote and enable independence</li> <li>• Assist by compensating for weakening abilities (e.g. memory)</li> <li>• Integrate with and take part in familiar activities in the individual's normal life</li> <li>• Ensure that carers support and encourage use</li> <li>• Allow the individual to contribute positively within established contexts and relationships</li> </ul>	<ul style="list-style-type: none"> <li>• Restrict the individual's autonomy</li> <li>• Encroach on the individual's privacy in unwelcome ways</li> <li>• Create anxiety about the individual's ability to use the technology</li> <li>• Remind the user of a disability or failing abilities</li> <li>• Create a stigma by making an individual's disability or failing abilities more visible to others</li> <li>• Place increased burden on family or carers</li> </ul>

**Table 1. Factors that stimulate and inhibit interest in technology-based solutions for older adults**

However, designing for older individuals also requires balancing conflicting forces, such as independence vs privacy, assistance vs autonomy (Mynatt et al. 2004), comfort vs passivity, and convenience vs complacency (leading to loss of ability and erosion of independence) (Melenhorst et al. 2006). Furthermore, user needs vary tremendously, not only between individuals but also over time (Gregor et al. 2002). As an example, independence may be a key consideration for healthy individuals, but regular social contact could be a critical factor as cognitive faculties decline. These challenges highlight a range of ethical issues that arise when working with older adults.

In research involving healthy older adults, ethical considerations relate to the extent to which individual perceptions, needs and abilities vary from the general population. As many adults remain active and independent well past retirement age, some of them might find the notion of belonging to a 'vulnerable group' objectionable. Past research has also found that healthy older adults can inadvertently understate their own abilities when asked to participate in memory tests, effectively replaying stereotypes of age and memory (Kit et al. 2008). Nevertheless, they do not have any cognitive impairment which could inhibit their ability to give full informed consent and participate in research that evolves over time.

Ethics in research involving assistive technologies for PwD has had limited coverage (Zwijnsen et al. 2011), with the focus being on specific research outcomes rather than how the research could impact users more broadly. For

example, a review of memory stimulation programs for persons with Alzheimer's Disease provides detailed evaluations of the efficacy of various approaches, but no mention of ethical considerations (Grandmaison and Simiard 2003).

A more recent review (Novitzky et al. 2014) of 186 papers on ambient assistive technologies for PwD provides an extensive listing of ethical issues relating to multiple stakeholders (including PwD, carers, family, software engineers, nursing and medical practitioners) involved in the development, operations and use of these technologies. In addition to issues relating to safety, privacy and security, Novitzky et al. highlight two ethical concerns that have not been sufficiently addressed in past research. First, the values and goals of research may be problematic when the benefits to policy-makers, organisations and caregivers (such as increased efficiency through the introduction of technology-based solutions) are not aligned with the needs of PwD (who may experience decreased personal contact as a result of the introduction of new technologies in the home). In this way, outcomes that may be valued by the research can have unintended consequences for the PwD. Second, obtaining informed consent directly from the individual may not be possible as individuals might forget being briefed about the research. In these instances, rolling informed consent has been suggested as a means of giving PwD the means to exercise their own decisions (with the support of their families and caregivers).

#### **ETHICAL CONSIDERATIONS FOR THIS RESEARCH**

So, the tensions and the ethical considerations identified in past research lead to multiple questions on how to apply a robust ethical framework across the different stages of the proposed PhD research on designing to support memory for older adults and PwD.

- How have other projects developed ethical frameworks for designing with vulnerable groups (people who require highly personalised solutions, but whose needs could evolve rapidly)?
- In the current stage (exploring user needs and context):
  - If informed consent is not possible with PwD, is a rolling informed consent model a practical alternative? What examples exist?
  - How could other ways of obtaining informed consent, e.g. through a proxy, work alongside rolling informed consent?
  - What approaches work best to ensure that the individual goals and values of PwD are captured (in addition to goals and values of family members and carers)?
- In what ways have past research projects engaged PwD to ensure that their day-to-day needs are acknowledged from project inception to evaluation (and even to ongoing use)?
- In the next stage (prototype solution development and testing iterations):

- How to continue involving participants (who may begin showing a decline in cognitive faculties during the life of the project) with appropriate consent?
- Given the nature of the users (whose needs could be changing as the project progresses), should the solution development phase be broken down into co-design and testing?

Additional insights from further literature review will be presented during the discussion to respond to these questions, and feedback from other workshop participants will be welcomed.

## CONCLUSIONS

Through its focus on user-centricity, the field of HCI is well-positioned to support ethical practices for research with older adults and PwD. User-centred research is intended to acknowledge and explore different ways of meeting human needs and interactions in real-world contexts. Participatory design is meant to ensure that users play an active role in solution development, so that their perspectives are represented fairly in the solutions that emerge.

Although dementia erodes the individual's ability to retain and process information presented during the design process, the authors believe that PwD can still contribute actively to solution development through moment-to-moment awareness and engagement. Even if momentary, the inputs of PwD are both valid and relevant, and can be captured fairly with participation of support persons (e.g. family members and carers) through the use of rolling informed consent.

In this way, HCI research can align with the core values of respect for the individual and justice outlined in the Australian National Statement on Ethical Conduct in Human Research (2007). In this way, ethical practices provide explicit signs of respect for the individual, thereby strengthening engagement with PwD, family members and caregivers in the research process.

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