



# Ethics of AAL for People with Dementia

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## Ambient Assisted Living for People with Dementia

Ambient assisted living (AAL) technologies can provide assistance and support to vulnerable persons, including those who suffer from dementia. They might allow these persons the possibility of living at home for longer whilst still maintaining their comfort, safety and security. However, the development, introduction and use of AAL technologies also trigger serious ethical issues. This presentation will provide an overview of the ongoing scholarly debate about these issues. We address the question of what ethical issues are involved in the various stages of research and development, clinical experimentation, and clinical application of AAL technologies for people with dementia (PwD) and other related stakeholders? The presentation will focus specifically on the value of the goals of AAL for persons with dementia.

## Why do we need AAL for PwD?

Due to increased life expectancy and falling birth rates, the age distribution in developed countries is gradually shifting towards older populations. This evidence points to an unavoidable, worldwide, increase in the age profile for humankind and therefore, an increase in the prevalence of age-related diseases, including dementia. The ageing population necessitates better and more effective healthcare systems and technologies. AAL technologies show promise in contributing to a solution to this challenge.

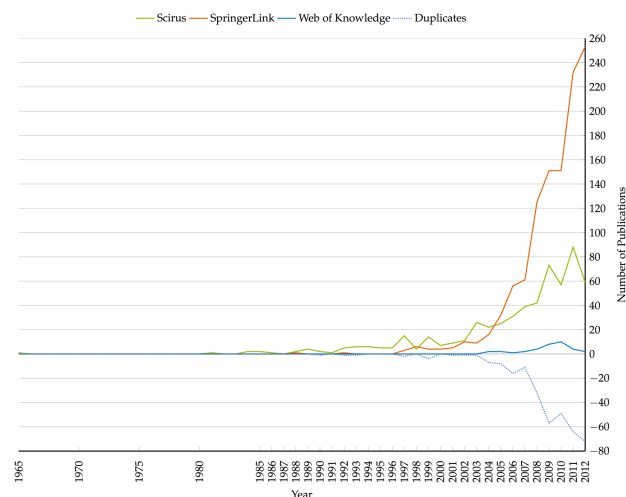
## Why do we need ethical analysis?

### Clinical trials

The responsible development of AAL technologies demands substantial analysis of the ethical issues that might arise during R&D, clinical trials or clinical practice. During these stages of development, various claims and interests emerge from different stakeholders.

### Literature review

Only a few literature reviews are available on this topic. We conducted an extensive systematic literature review on the ethics of AAL technologies for PwD.



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## Results

The ethical challenges and opportunities in the scientific literature have been categorised according to the stakeholders involved during the various stages of development (R&D, clinical trials, clinical application):

- PwD
- Formal and informal caregivers (nurses, family proxies, etc.)
- Researchers and clinicians
- Software/hardware engineers
- Designers
- Technicians

Various challenges and opportunities were found in the following areas of AAL technologies for PwD: independent living, socialisation, empowerment, safety and security, care and cost burdens.

## The ethical challenges and opportunities

An extensive list has been identified of ethical challenges and opportunities throughout the literature review (for a complete list, see Novitzky et al., 2014). Three main topics of the development of AAL for PwD have been specified that need further attention and ethical analysis.

### The value of the goals of AAL

The value of the goals of AAL technologies has to be carefully assessed in the light of issues, such as:

- AAL technologies provide only non-therapeutic treatment with all its ethical implications
- Lax regulation of testing standards for AAL has been reported (Hofmann, 2012)
- The overlapping stakeholders' motivations for R&D are often conflicting.

Many articles accept the benefits of AAL without critically questioning this presumption. The justification of AAL for PwD is weaker if it provides benefits only for the caregivers or third parties instead of primarily the persons in need of care. This would violate the ethical principle of proportionality between the burdens/harms and benefits of AAL.

### Special vulnerability of PwD

The special vulnerability of PwD pose challenges for AAL technologies used in home environments, where there is a lack of 'safety nets' present in healthcare institutions. Errors, malfunctions, and usability require very high standards for safety, security and reliability of AAL technologies.

### Informed consent

We propose defining a concept of rolling informed consent during the R&D of AAL technologies for PwD. Such an adaptation of the ethical requirement of informed consent should consider the special needs of PwD, while actively engaging them in the R&D of AAL technologies.

