

***Ethical dimensions in involving  
older end users in technology R&D  
projects***

**AAL Forum  
Vienna 1/10/2009**

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## ***Outline for the next 15 minutes***

1. Significance of ethics in the context of AAL
2. Lessons and questions in ethics in project contexts
3. What kind of issues have been labelled „ethical“ in the context of ICT R&D and ageing?
  - Findings of the ICT and Ageing project
  - Ethical issues identified by researchers

# 1) Significance of ethics in AAL

## ***Significance of ethics – some more obvious reasons***

- Involvement of potentially – but not necessarily - vulnerable user groups
- Target of intervention: well-being, independent living of older people (= lives of older people);
- Invasive character of technologies
- Context of use – the private home
- Issues or transparency
- Allocation of responsibilities, burdens and benefits
- Not forgetting: safety, security, reliability, protection of integrity and dignity, promoting autonomy and independence...

## ***Significance of ethics in AAL – some less obvious reasons***

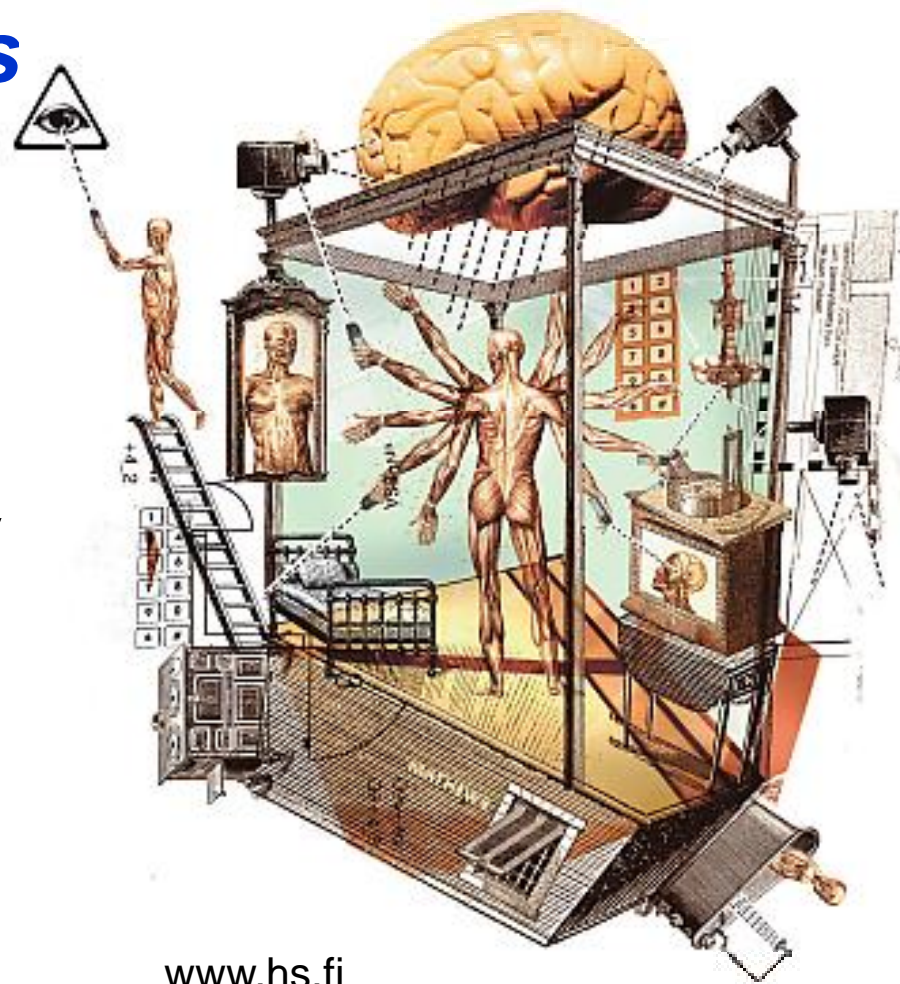
- Inscribed in the emerging technologies are
  - images of users and their abilities, skills, preferences
  - idea(l)s about the good life in old age
    - ✓ As perceived by those who are participating in the project
- Technologies are „actants“; they can prescribe actions to people, limit our range of actions and choices (Actor-network theory)

## ***Intersection: technology - ageing - ethics***

- AAL technologies participate in shaping the discourse on some basic questions in ethics:
  - What is the good life?
  - What kind of society do we want to live in?
  - How do we treat others who are in weaker positions?
  - What is the good or the right way of providing care?
- Awareness of the power technologies can have in shaping the lives of users is desirable

## *Significance of ethics: Concerns of users*

- Fear of reduced human contact and increased isolation
- 24-7 surveillance
- Threats to privacy and dignity
- Non-reversibility once adopted...
- Inequalities in care



[www.hs.fi](http://www.hs.fi)

2) Lessons learned and questions raised regarding ethics in project contexts

## *Technologies for older people*

- From simple to very complex
- Individual devices low- and hi tech
- Entire service systems: telecare
  - involving networks of heterogenous materials and people (often with diverse professional backgrounds);
  - sensors, alarms, data, ICT infrastucture, call centers, care and service providers, family members etc...
- Ethical dimensions present as soon as we involve potentially vulnerable people in research

## *Technology, Ethics & Dementia Project*

- FP 4, BIOMED II Program
- Evaluation of a simple-to-use telephone with persons with dementia
- Who should pay for the costs incurred from the use of telephone by the persons with dementia during the 2-month trial?
- What happens to the phones after the trial?



## ***Some parallels: participation in clinical research and technology R&D trials***

- Trial participation does not equal benefit
- Problematic informed consent
- Risks in participation
  - Burdens of trial participation; risk of injury
- Participation may cause costs
- Post-trial management of drug/technology
- Vulnerable user groups needed in research
- Raising unfounded expectations

(M. Rauhala & P. Topo 2003)

# *Friendly Rest Room – intelligent & self-adjusting toilet*



Note: Persons in these pictures have explicitly agreed to publication of this material

## ***Friendly Rest Room – intelligent & self-adjusting toilet***

- Potentially vulnerable user group
- Sensitive area of research personal hygiene, taboo topic
- Trial setting – laboratory conditions, cameras, tape recorders, research staff
- Risk of injury



Note: Persons in the picture have explicitly agreed to publication of this material

## *ENABLE (2) Project*

- Wearable wrist unit (fall, movement, temperature, humidity sensors etc.)
- Assistive technology or medical device?
- Validity of informed consent (example: retirement home)
- Problems in research design: studying „naturally occurring falls“ not possible



## *ICT and Ageing Project*

- Focus on market barriers that hinder the uptake of new ICT-based solutions in supporting independent living of older people in their homes
- e-Inclusion Unit of the European Commission
  - Data collection through national correspondents and workshops
  - What ethical issues have come to the fore in the area of independent living and ICT based home care services?
  - What agencies are in charge of dealing with ethical issues in the ICT and ageing domain?

## ***ICTA – Research clearance***

- Practices across EU Member States with regard to research activities and ICT and ageing vary greatly
  - For example: in the UK ethical clearance required for all project proposals from a research ethics committee, no such clearance possible in some other countries where there is uncertainty about what body would be in charge (Austria, Poland)
- Different practices tend to complicate international cooperation

## ***ICTA - Identified ethical issues***

- Privacy
- Protection of personal data
- Informed consent
- Security (of data transfer)
- Access to information by unauthorized persons
- Recruitment practices
- Private home as a location for research

## ***Ethical issues for researchers (lit.review)***

- Informed consent procedure
- Privacy, confidentiality, sensitivity of data
- Method/technique of user needs elicitation
- Work culture clash/disruption of routines
- Ethical approval/clearance
- Timing of user involvement
- Power issues
- Inclusion/exclusion
- Costs of participation (Rauhala 2007)

## 4. Possible next steps in AAL and ethics

## *AAL and ethics*

- The field of ethics in AAL, telecare and telehealth R&D is evolving and immature;
  - Multidisciplinary area; heterogeneous actors:
    - Different kinds of ethical guidance could be applied; many relevant sources (but which is the most appropriate approach?)
  - Many good practices and approaches can already be identified – no need to start from scratch
    - Medical research, social care, social science research
    - How to learn from them and transfer their experience to other contexts?
-

## *AAL and ethics – next steps?*

- Collect and identify ethical issues from the perspective of different actors and stakeholders
- Learn from those countries where ethical clearance is practiced; evaluate:
  - Does clearance contribute to improved the user involvement, or, increased safety and well-being of users?
  - Or do they unnecessarily complicate research and development?
  - What could be a good solution regarding ethics for AAL?

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## ***AAL – Next steps in ethics?***

- Consider the need to establish a practice for the ethical clearance of research and development projects in AAL that involve potentially vulnerable persons in the research process
- In the light of increased international cooperation, consider the need for some common – general – guidelines for a good R&D practice
- Collection of experience-based guidance in ethics from the AAL field for discussion

***Thank you for your attention!***

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## ENABLE

- wearable approach (Wrist Unit) including fall sensor, movement sensors, humidity sensor, temp, sensor, interfaces to ECG etc....., many additional services integrated: speech input, easy access to mobile phone...)
- Assistive technology or medical device?
- Validity of informed consent in living lab conditions (example: retirement home)
- Activity monitoring of enable to increase safety and health / versus privacy (a balance which need to be identified according to the individual preferences which might change over time as experiences gathered from daily usage might show personal benefits)
- Problems in research design: studying „naturally occurring falls“ in lab not possible as test persons need to be informed about falls might happen (additionally other problems: younger people might fall differently than older people)

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