

# Disability and Information Technology: ethical aspects in AT design

EU workshop  
“Workshop on ethics and e-Inclusion”

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Prof. ir. Jan Engelen  
Kath. Univ. Leuven (Belgium)

# Overview

- Introduction
- Three important contributions at AAATE 2007
- Ethical issues in FP7
- A few open questions: food for thought



- is the Association for the Advancement of Assistive Technology in Europe
- is the major organisation for persons working in this field
- Mission statement:  
*"to stimulate the advancement of assistive technology for the benefit of people with disabilities, including elderly people"*
- was created in 1995, a few years after the EU's start of the TIDE research programme (1991)
- AAATE's two-yearly conferences are highly valued in Europe en elsewhere

# AAATE conference 2007

- Who determines the Ethics of AT research?  
[P. Cudd, B. Boyle, M. Hawley; UK & IRL]
- Ethics and Assistive Technology Development  
– Project Workers' experiences with Continuous Ethical review  
[M. Rauhala, G. Edelmayer, P. Topo, W. Zagler; AT & FIN]
- Privacy Matters and Functionality in Ambient Supportive Technologies: Mobile Phone Tased activity monitoring systems  
[M. Soede, F. Vlaskamp, H. Knops, R. Childs; NL]

# Cudd et al. (1)

- Formal Ethical procedures tend to be very slow and may hinder AT research
- 62 researchers in 4 countries have been consulted
- An introductory course on ethics was created to elicit views of the participants
- Behaviour of researchers changed during the course; several ones became more attentive to ethical issues but not as much as ethicists had hoped for.

## Cudd et al. (2): Problems

- To avoid time consuming ethical reviews, researchers sometimes choose testing methods that made ethics easier...
- Sometimes getting ethical approval caused such delays that AT innovation had to be stopped
- For clinical situations, ethics specialists do exist; for AT research the situation is often unclear

# Cudd et al. (3): Questionnaire

- Four short stories (fictional but realistic except for nr 4 – flying wheelchair) were presented to non-specialists within the Artemis project (FP5)
- Their opinion about *good* and *bad* was compared with a specialist view
- In most cases researchers opted for reducing ethical measures...
- This happened independently from the fact that several participants might have chosen “what they were supposed to choose” (in their opinion)

# Rauhala et al. (1)

- Describes a continuous ethical peer review process for the FRR (Friendly Restroom) project
- Ethical reviewers were involved in research and management meetings
- Reference is made to former TIDE/eInclusion projects: USERFIT and FORTUNE
- But in general not much information, e.g. on how to obtain informed consent, seemed to be available

## Rauhala et al. (2)

- Procedure: ethical reviewers joined meetings, were involved in designing user tests, observed user tests and interviewed users
- Their work was: normative, guiding and empirical (“empirical ethics”)
- At the end of the FRR project a special ethics workshop was organised: overall remarks were very positive; empowered users can provide high quality feedback to the researchers
- However, the organisation of a continuous ethical research often will be dependent on available project funding.

# Soede et al.

- Contribution focussed on Ami (Ambient Intelligence)
- Is potentially very important for disabled users, especially in relation to autonomous living & telemonitoring of health conditions
- Ami systems rely on user profiling, but this type of information can be misused easily
- Focus on the Adams and Sasse model for trust where a user can decide on a trade off between the wanted benefits and a lower privacy level

# IST/eInclusion application form



	YES	PAGE
Informed Consent		
Does the proposal involve children?		
Does the proposal involve patients or persons not able to give consent?		
Does the proposal involve adult healthy volunteers?		
Does the proposal involve Human Genetic Material?		
Does the proposal involve Human biological samples?		
Does the proposal involve Human data collection?		
Research on Human embryo/foetus		
Does the proposal involve Human Embryos?		
Does the proposal involve Human Foetal Tissue / Cells?		
Does the proposal involve Human Embryonic Stem Cells?		
Privacy		
Does the proposal involve processing of genetic information or personal data (eg. health, sexual lifestyle, ethnicity, political opinion, religious or philosophical conviction)		
Does the proposal involve tracking the location or observation of people?		
Research on Animals		
Does the proposal involve research on animals?		
Are those animals transgenic small laboratory animals?		
Are those animals transgenic farm animals?		
Are those animals cloned farm animals?		
Are those animals non-human primates?		
Research Involving Developing Countries		
Use of local resources (genetic, animal, plant etc)		
Benefit to local community (capacity building i.e. access to healthcare, education etc)		
Dual Use		
Research having direct military application		
Research having the potential for terrorist abuse		
ICT Implants		
Does the proposal involve clinical trials of ICT implants?		
I CONFIRM THAT NONE OF THE ABOVE ISSUES APPLY TO MY PROPOSAL		

# Example: GPS tracking and ethics



# A real world dilemma...

Project for monitoring of elderly people at home by judging their functioning (fall detection, oven switched on/off, heater use etc...)

- Question to researcher:  
“do elderly people agree with this monitoring”
- Answer:  
“Yes, *but...*”  
they *had* to agree as otherwise they would not be allowed to stay in their own homes...

# Thanks

Address:

Prof. Ir. Jan Engelen

Kath. Univ. Leuven (Belgium)

[jan.engelen@esat.kuleuven.be](mailto:jan.engelen@esat.kuleuven.be)



KATHOLIEKE UNIVERSITEIT  
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