

Ethical Dimensions of Ambient Assisted Living RTD

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The case – ethics in the FRR

- FP 5, Quality of Life and Management of Life Resources Programme
- Goal: to develop an „smart" toilet that automatically adjusts itself to individual needs of users
- Partners: AT, GR, HU, IT, NL, SWE
- Multiprofessional project
 - Engineering, social science, care professions, design, ethics represented
 - Interdisciplinary approach

Overview

- FRR Challenges
- Solutions
- Experiences
- Lessons learned

Relevance of ethics in FRR

- Sensitive area of research
 - Toileting, personal hygiene a taboo topic
 - Risk of embarrassment, unwillingness to disclose problems
- User group
 - On an average, more vulnerable than users of mainstream technologies
- Project design: user driven research – required early and continuous user involvement
 - Privacy issues
 - Risk of injury in the test setting – evolving prototypes
 - Involving people in research is a question of ethics per se!
- Ethical review at the request of the Commission – continuous and extensive in the FRR

AAL Relevance of FRR

- Real-life tests at Caritas Socialis in Vienna
- A toilet facility was tested and monitored for 2 months
- Sensors collected data, a computer recorded it
 - Door (opening and closing)
 - Changes of position of the toilet seat (height, tilt)
 - Use of remote control
 - ✓ Changes in the position of the toilet unit
 - ✓ Calls for help
 - ✓ Flushing
- 300 toilet uses could be identified, in some cases particular users could be identified

AT research must comply with guidelines – but which ones?

- AT in a grey area with regard to ethics
 - No widely accepted ethical guidelines in use
 - No widely adopted practice on how to deal with ethical questions (obtaining informed consent; risk assessment, privacy)
 - Increasing „push“ from financiers: ethical guidelines must be applied to ensure safety, well-being of participants and privacy of personal data
 - ✓ Recommendation from fields outside the assistive technology practice – medical research
 - ✓ Many parallels but AT researchers would be smart to make their own guidelines (Rauhala & Topo 2003)

- How many of you would have participated in the real-life test?

FRR challenge in user involvement

- How to remove the taboo effect of toileting and personal hygiene?
 - Unusual research design and setting
 - Self tests – researchers felt uneasy
 - Confident and secure users necessary for reliable results
- How to ensure that participants are sufficiently informed about the project and their own role so that a genuinely informed consent is possible?
 - What if they change their mind? How can we be sure? What would help them signalize it?
 - Exit opportunities needed to be built in

Peeling away the taboo effect – preparation of users

- Observation: engineers who constructed the unit had a different relationship to it than did others
 - The toilet as extra seating in the office

Familiarity with the toilet unit appeared to remove the taboo effect

How to make use of this observation regarding the users?

Project Worker with the early FRR prototype



Informed consent as a central factor

1) Extensive information materials

- Description of the project, project partners, purpose, role of users, data protection, tasks, pictures of the prototype, contact persons...
- Delivered by a peer active in the project prior to decision making – possibility to exit

2) Careful preparation for the test cycles

- Careful rehearsal; pilot test; revising design
- Clear roles for *all* participants

3) Test day – exit possibilities

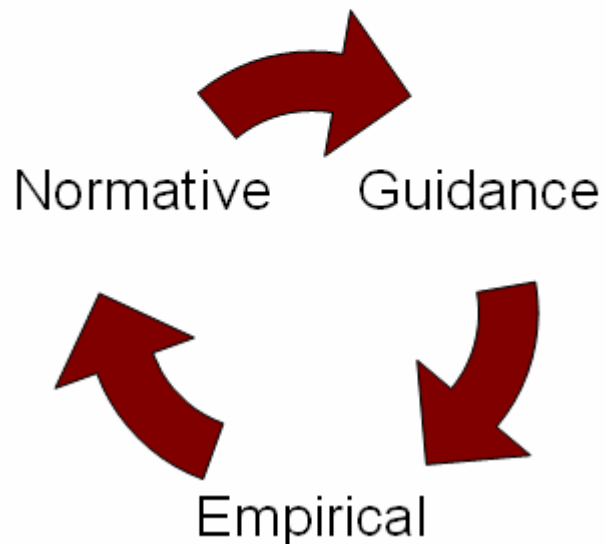
- Meeting in the Library: Video of using the prototype, showing how it is used – would you like to...?
- Moving onto the Lab: Again, a researchers shows him/herself how the prototype works – would you like to...?
- Signing of the Informed consent form – would you like to try out the prototype?

„Step-by-step“ process for informed consent in FRR

- Combination of
 - a process for informed consent,
 - user preparation, and
 - removal of a taboo effect

- Gradual increase of information (using various media) with built-in steps where consent is explicitly obtained and renewed

Ethical Review in Practice



Normative work

- Identification of ethical issues as they emerge in a research process
- Background work – review of relevant guideline documents

Guidance work

- Process for informed consent
- Support in risk identification, ethical assessment of user tests

Empirical work

- Observation of user tests
- Interviews and focus groups with users and project workers
- Analysis, feedback

Feedback - users

- "I have felt very safe here." (SWE)
- "We were always very well informed. It's like when you go to the doctor – you also want to know what is happening to you over there." (AT)
- "The information was serious. It gave a good feeling." (SWE)
- But also: "It was a lot to read. I had to read all of it twice." (AT)
- "It could have been embarrassing, but everything has been handled very delicately. No names will be published in scandalous papers." (SWE)

Feedback – project workers

- It is an „ethical „guarantee“ to have ethical review
- External view – an unintended culture of unethical practices is always possible
- Support, new point of view, improving the test situation
- Participation enhances awareness of ethical issues, highlights thoughts on ethics by putting it on the agenda
- Bringing vulnerable people to test settings is risky; external feedback on the practice useful

Feedback – project workers

- Ethical review appeared to increase awareness of ethical issues
 - "Very useful", "Helpful"
 - But also: "resource-dependent"
 - Provided new tools and perspectives for structuring one's own work; or, for dealing with new themes
- Changes in future work practice?
 - Informed consent procedure to be integrated
 - ✓ Many mentioned this: seems to indicate that the informed consent procedure was a new aspect in their work

(Rauhala & al 2007)

talk&match.it, Nov. 12 2007,

Schwechat

Lessons learned – project workers

- Organizing good user tests is time consuming
- Users consider the test situation a social event
 - Need time to chat
 - Accept it - make it a social event (e.g. refreshments)
- Risks of injury are genuine
 - Lund: insuring participants a university-wide practice
- Need to constantly renew the informed consent
 - During the test situation
 - Have the participants really understood everything?

Ethics was high on the agenda **WITHIN** the project...

- For the FRR project workers, privacy was important - guests that visited our "practice" were not bound by the same "rules"

Prototypen-Test: „Toiletten mit Hirn“!

Der Gang auf's WC stellt für viele Menschen mit physischer Behinderung ein Problem dar. Damit das „natürlichste Bedürfnis“ keine unnatürliche Anstrengung mehr kostet, forscht die TU-Wien nun an einer „intelligenten“ Toilette. Das Bezirksjournal berichtet exklusiv vom ersten „Probesitzen“!

■ von Hannes Wieser

„Bei einer 'Toilette mit Hirn' passt sich jede ihrer einzelnen Komponenten an die unterschiedlichsten Bedürfnisse körperlich beeinträchtigter Menschen an“, erklärt DI Paul Panek von der Forschungsgruppe für Rehabilitationstechnik „fortec“ an der TU-Wien.

Jedem sein „High-Tech-Klo“

Man muss sich das so vorstellen: Schon beim Betreten der Toilette stellt sich diese automatisch auf die von der jeweiligen Person als optimal erachtete Position ein. Nach

dem Verlassen sorgt ein vollautomatisches Reinigungssystem für optimale Hygiene, und die vielen nützlichen Hilfsysteme der intelligenten Toilette fahren wieder in einen unauffälligen Ruhezustand zurück.

Was die technologischen Herausforderungen betrifft, so kommen berührungslose „smart card“-Technologien mit Lese- und Schreibfähigkeit genauso zum Einsatz wie Sprachsteuerung, Bewegungssteuerung, Sensorsysteme und modernste Roboter-technik. Ob die Bedienbarkeit dieser Toilette auch verstanden wird, erforscht man



Ernst Böck testete das erste Labor-Prototypensystem der neuen „intelligenten Toilette“ sprichwörtlich auf Herz und Nieren.

gerade mit umfangreichen Anwender-Tests. Beim ersten Probesitzen im Versuchslabor gab's lediglich mit der Fernbedienung (kleinere) Probleme. Testperson Ernst Böck resümiert: „Die Symbolik der Bedienungselemente an der WC-Fernbedienung ist noch nicht ganz eindeutig. Sonst funktioniert's aber ganz gut.“ DI Panek ergänzt: „Vor allem die Sprachsteuerung kommt bei den Testpersonen sehr gut an.“ Und: „Schon im Herbst wollen wir den endgültigen Prototypen in einem Caritas Socialis Tagesheim installieren.“

Das Forschungsprojekt wird von 11 Partnern aus 7 EU-Ländern durchgeführt. Mehr Informationen zur Intelligenten Toilette: www.fortec.tuwien.ac.at/fr

Concluding thoughts

- A concept of ethical review developed in the FRR project
 - positive attitude among project workers
 - acquired new knowledge and understanding about ethical issues regarding their own work
- Empowered and well-informed users are likely to express better their opinions and to volunteer information about their needs and preferences.

Concluding thoughts

- Extensive and continuous ethical review depends on the available resources.
 - Needs to be budgeted appropriately
- However, when the user groups to be involved are potentially vulnerable and the research topic deals with a sensitive area, we find a continuous ethical review throughout the project's lifetime recommendable (and it probably pays off)

Thank you!

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