Elderly Carers, Technologies, Privacy and Data Protection: Challenges in Matching User Needs and Ethics Issues

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Interactive Session - Workshop 10
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Executive Summary

Technological developments for informal care are a very important and timely topic. Many and various research projects have been devised to address the design and development of technological aids for the elderly and their close relatives caring for them (their informal carers) and, not surprisingly, pervasive technologies have emerged as strong allies to the task of providing carers with informational, emotional and tangible support, which may help them cope with their inner burden [1]. Despite the benefits that pervasive technologies can provide, current and past research has raised several important ethical considerations about their use, as reported by Zwijsen, Niemeijer [2] and Niemeijer, Frederiks [3]. In addition to that, our experience in the AAL TOPIC project shows that user-centred design approaches should also be confronted with ethics, e.g., when users ask for technologies that can in fact conflict with ethical issues. At this workshop we addressed the ethical issues that may arise from the use of user-centred design approaches for the elaboration of pervasive health technologies, with the objective of identifying elements of an ethics roadmap regarding technologies for informal care.

The main output of the workshop was the identification of elements of an ethics roadmap concerning the design, development and deployment of pervasive health technologies to allow future research on the matter to deepen their understanding on such issues. The workshop was seeking answers for questions such as:

- Which types of ethical concerns does pervasive health technology raise?
- Which types of policies do we need to regulate their use and what are the variables associated to their definition?
- Who should be in charge of deciding whether and how such technologies can be offered in particular settings?
- Is it ethical at all to decide for the users?
- How is UCD (user centred design) supposed to work?
- Should the users not be autonomous in deciding what is good or bad for them?
- How about when what they want affect the others?
- What should be the position of researchers and practitioners who intervene in projects, which are designing and offering pervasive technologies to elderly people?
- How to end the projects without “abandoning” the participants?
- How to ensure a sustainability of the provided technologies after the end of a project?

Six speakers were invited to this workshop. They introduced their opinion based on their current work by including three most relevant papers, showing challenges in matching user needs and ethics issues when designing technologies for informal care. The workshop was started with the initial presentations of the following speakers:

- Nitesh Chawla, Frank M. Freimann Professor of Computer Science and Engineering, Director, iCeNSA
- Martin Kampel, TU Wien / CogVis
- Katja Neureiter, Center for Human-Computer Interaction, University of Salzburg
- Miroslav Sill, AIT Austrian Institute of Technology
- Hilda Telioğlu, TU Wien, Institute of Design and Assessment of Technology, Multidisciplinary Design Group
- Anton Zahneisen, SOPHIA Franken GmbH & Co. KG
The initial talks, which are included in this report, were followed by the discussion and interactive group work that was organised in two groups, to discuss the following subjects:

- **How can ethical issues be adequately addressed within technology-driven research or commercial projects?**
  - Participatory design framework, user-centred design processes (user needs, protection and appreciation conditions; acceptance criteria for users)
  - Engineered software development \(\Rightarrow\) risk of discrepancies
  - Solution?
    - Discussion between stakeholders, considering two approaches: consequentialist, deontological
    - Design fiction for ethical computing...

- **What are the contradictory approaches and conflicting interests to the AAL research and development? How can these be addressed?**
  - High speed developments driven by AAL funding and research policy
  - Business-cases
  - Smart home technologies (pervasive, adaptable, connecting, easy-to-configure, ...)
  - Ethical principles
  - Solutions for better social practice?

The results of the group discussions were presented in the last part of the workshop. Some of the discussion points are listed in the following:

- It needs to be distinguished between ethical issues in terms of “how do we conduct studies” and ethical issues that refer more to “ethical consequences” (e.g., the result if we use a certain product). One participant indicated that their organisation particularly invites experts, who provide advice; however including an “ethical board” often causes delays for studies. In this context we also talked about distinguishing between research ethics and ethics in daily practice. Research ethics might be sometimes even stricter than research ethics in daily practice.
- One suggestion was to ask users in terms of ethical issues. However, it needs to be considered that products become more and more complex (Internet of Things) that make it difficult for users to understand the consequences. Hence in this particular context we need new methods and approaches to better understand ethics (see also the example from the talk – design fiction as approach to explore ethics).
- What is ethical “ok” or “not ok” might change throughout the course of a project. This needs to be addressed somehow.
- Needs (and corresponding ethical issues) do not only depend on the user alone but on other stakeholders such as family members or care givers as well.
- Problems might occur when users do not understand the informed consent.

We closed our discussion by asking everyone to either indicate an answer to one of the points we discussed or to raise a final question. Most of the participants raised a question, which are listed below:

- 10 years ago we had testers of a certain system. Now we rather deal with customers. How to deal with this fact?
- We need to identify underlying values/incentives/motivations in order to provide added value for participants. How do we actually assess these underlying needs?
- Added value versus privacy – How can we gain that much user data so that we can run our data interpretation models to detect security issues and provide added value for older adults?
- Who decides what is ethical (if ethics change): end users, experts, ethical boards, the consortium, the scientific community?
- Are we allowed to involve people who are hardly able to give their consent? If yes, how? If no, what about all the dementia projects?
- How do we balance care needs addressed by stakeholders such as family members or caregivers with the privacy needs of the person being cared for?
References


Nitesh Chawla, PhD
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- Health information technology can help facilitate out-of-home caregiving experience.
- In the study, privacy rules were identified as the most significant impediment.
- Access, privacy and trust in health information systems can help resolve bottlenecks.


- Smart home technologies can prove to be of an asset to dementia patients, helping them with independence and helping reduce the burden placed on the informal caregivers.
- Participatory design framework to involve informal caregivers in the needs analysis and design of smart home user interfaces.
- User centered design processes to involve different stake-holders for the development of multi-disciplinary approaches to user interfaces designs.


Dasgupta, D., Greeves, K., Chaudhry, B., and Chawla, N. V., “eSeniorCare: Technology for Promoting Well-Being of Older Adults in Independent Living Facilities, IEEE International Conference on Health Informatics, 2016"
Acceptance criteria for Vision based Fall detection

Martin Kampel

Vienna University of Technology

16 papers in total studied as a basis to excerpt acceptance criteria

- Two studies interviewed elderly people about their theoretical views and opinions of AAL technologies [Roelands et al., Tinker et al.]
- Four papers where technologies were presented, followed by interviews or open-ended discussions [Wild et al., Phang et al., Londei et al., Beringer et al.]

Example: Londei et al. - ‘An intelligent videomonitoring system for fall detection at home: perceptions of elderly people.’, 2009

- Developed an intelligent video monitoring system to automatically and immediately detect falls.
- evaluate the perception and receptivity of elderly people of a video monitoring system
- 31 elderly, 65 or over, were selected
- Video with fall scenarios and images that were sent in case of an emergency were shown
- Interviews asked about sociodemographic data as well as perception and receptivity about the system
Usability versus privacy protection

11 acceptance criteria selected

- Perceived usefulness
  
  how much a person imagines that a particular AAL system or technology would increase his or her independence, safety and quality of life

- Perceived ease-of-use
  
  if potential users feel that using a technology is free of effort, they are more likely to accept and use it

- Control & security
  
  users wish to still have the control over their personal data and over the system
Criteria

- **Financial ability & willingness**
  AAL technologies that are affordable for everyone and to provide financial solutions

- **Privacy versus independence/safety**
  The less privacy intrusive the system is and the more independence and safety the user gets, the higher the acceptance

- **User involvement**
  High importance to include the end user in all phases of development to increase the acceptance

- **Human replacement**
  Acceptance decreases if AAL technologies are developed with the aim of replacing human care

Criteria

- **Awareness**
  Many elderly are not aware of the existence of AAL technologies, more awareness would increase acceptance

- **Reputation/ alignment to current lifestyle**
  Needing help is often seen as a stigma, a higher reputation would help the image of AAL technologies

- **Government/ politics/ legal aspects**
  Plays an important role as they can support AAL technologies financially or increase awareness

- **Experience**
  Elderly with more technological experience are more accepting of a new technology
From Research to Products ...

- No AAL technology without end user integration
- Identify your major acceptance criteria
- Think about your buyers, installers, and user with respect to acceptance
- Integrate in existing technologies
- Take care about privacy protection

Thank you for your attention!

Contact

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References:


Elderly Carers, Technologies, Privacy and Data Protection: Challenges in Matching User Needs and Ethics Issues.

Selected Papers


Rationale

Turkka Keinonen. 2008
Satisfy users’ fundamental needs through UCD?
→ Discuss/consider the „nature“ of user needs – “design for need - protect users from harm”
→ Relationship between human and artefacts – “component user versus lead user”

Zarla Ludin. 2011
Encourage a discussion among practitioners on ethical problem solving that goes beyond the usage of ethical codes that guide behavior
→ User research dynamically changes – new methodological opportunities require a forward-thinking discussion on ethics

Joseph Lindley and Dhruv Sharma. 2016
Understanding ethics needs to be bound to the future
→ Design fiction as approach to explore ethics
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Elderly Carers, Technologies, Privacy and Data Protection

Challenges in Matching User Needs and Ethics Issues

AAL Forum 2016

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YouDo

An easy-to-understand and easy-to-use information and training platform for informal caregivers

- Provides helpful information on different device types
- Able to take personal user needs and preferences into account
- Adapts the presented content
- Fosters the social interaction and interchange with other people

A lightweight information and communication system for older adults, their relatives and formal caregivers

- Connects different target groups
- Implements various information sources
- Supports different input / output modalities
RelaxedCare

Connecting People in care situations

- Connects IC & AP
- Helps to feel socially connected
- Nicely designed pervasive UI
- Developed to be brought to market as “AAL system in a box”

Thank you!

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The Online Platform for Informal Caregivers

www.topic-aal.eu

OUR GOAL
is to understand informal caregivers’ needs and design ICT solutions to support them in their daily needs
Independence – How?

INDEPENDENCE of Informal Carer

Care Receiver

Professional Carer

Action

Finance

Peers

Emotion

Decision

INDEPENDENCE of Care Receiver

Professional Carer

Action

Finance

Peers

Emotion

Decision

INDEPENDENCE of Informal Carer

Coordinated (Health)Care

Resources

Artefacts

Protocols

Planning

Execution

Decision Making

Safety

Availability

Flexibility

Friends

Neighbors

Professional Carer

Execution

Decision Making

Safety

Availability

Flexibility

Friends

Neighbors

Persons

Coordinated (Health)Care

Resources

Artefacts

Protocols

Planning

Execution

Decision Making

Safety

Availability

Flexibility

Friends

Neighbors

Persons

Coordinated (Health)Care
Independence – How?

Further considerations …

• Ethical core dimensions:
  Care, autonomy, safety, justice, privacy, participation, self-conception (Marzeschke & Diehl)
  Safety, security, reliability, liability, promoting autonomy and independence, justice, integrity, dignity (Rauhala)
  Informed consent, solidarity, right of access to ICT (Salvi)

• Ethics is not only about regulatory compliance
  Ethics needs integration and internalisation in the R&D process
  "Science with and for society" (H2020)
  RRI: Responsible Research and Innovation

• Questions to ask:
  – 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 way of providing care?
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Lessons learnt in TOPIC and other European and national AAL projects

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My Home – my living lab – my background

http://panorama.webdesign-bamberg.net/ 
or
http://www.sophia.com.de
Lesson 1

User-centred design and software-development are not automatically good partners.
There is a high risk, that both parties write a different story!

Lesson 2

A strictly business-case orientation risks to deny ethical principles

There is no real and well-accepted use-case for a video-monitoring-system!

- Acceptance?
- Legal?
- Ethical issues?
- Real benefit?
- Cost?
- Abuse?
The AAL funding and research policy („with high speed to the market“) evades public responsibility for a better social practice!

Thank you for your attention

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