MULTIDISCIPLINARY DESIGN GROUP

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

AAL-Forum 2016
Interactive Session - Workshop 10
(27. 09. 2016)

Organiser:
Hilda Tellioğlu

Speakers:
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Martin Kampel
Katja Neureiter
Miroslav Sili
Hilda Tellioğlu
Anton Zahneisen

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Faculty of Informatics

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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 heath 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 Sili, AIT Austrian Institute of Technology
- Hilda Tellioğlu, 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 → 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

[1] Plaza, I., et al., Mobile applications in an aging society: Status and trends. Journal of Systems and Software, 2011. 84(11): p. 1977-1988.

[2] Zwijsen, S.A., A.R. Niemeijer, and C.M.P.M. Hertogh, Ethics of using assistive technology in the care for community-dwelling elderly people: An overview of the literature. Aging & Mental Health, 2011. 15(4): p. 419-427.

[3] Niemeijer, A.R., et al., Ethical and practical concerns of surveillance technologies in residential care for people with dementia or intellectual disabilities: an overview of the literature. International Psychogeriatrics, 2010. 22 (Special Issue 07): p. 1129-1142.

Nitesh Chawla, PhD

Frank M. Freimann Professor of Computer Science and Engineering
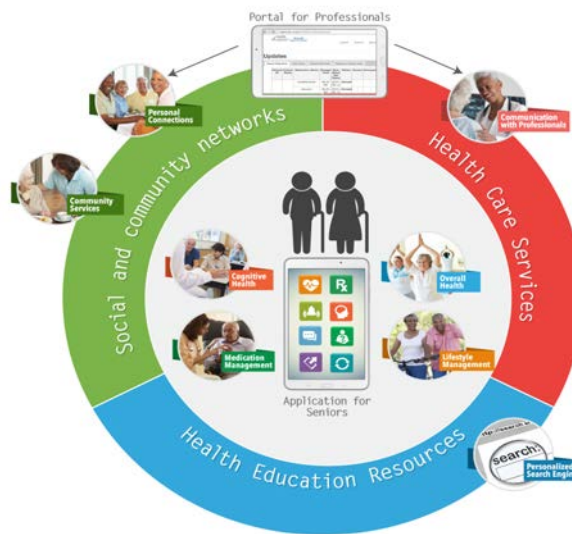Director, iCeNSA
@nvchawla

Zulman, D. M., Peitte, J. D., Jenchura, E. C., Asch, S. M., Rosland, A. M., "Facilitating Out-of-Home Caregiving Through Health Information Technology: Survey of Informal Caregivers' Current Practices, Interests, and Perceived Barriers," J Med Internet Res. 2013 Jul 10;15(7):e123. doi: 10.2196/jmir.2472.

- 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.

iCeNSA
Interdisciplinary Center for
Network Science & Applications
UNIVERSITY OF
NOTRE DAME

Nitesh Chawla, PhD (c)

Hwang, A.S., Truong, K., Mihailidis, A., "Using participatory design to determine the needs of informal caregivers for smart home user interfaces," *International Conference on Pervasive Computing Technologies for Healthcare*, 2012
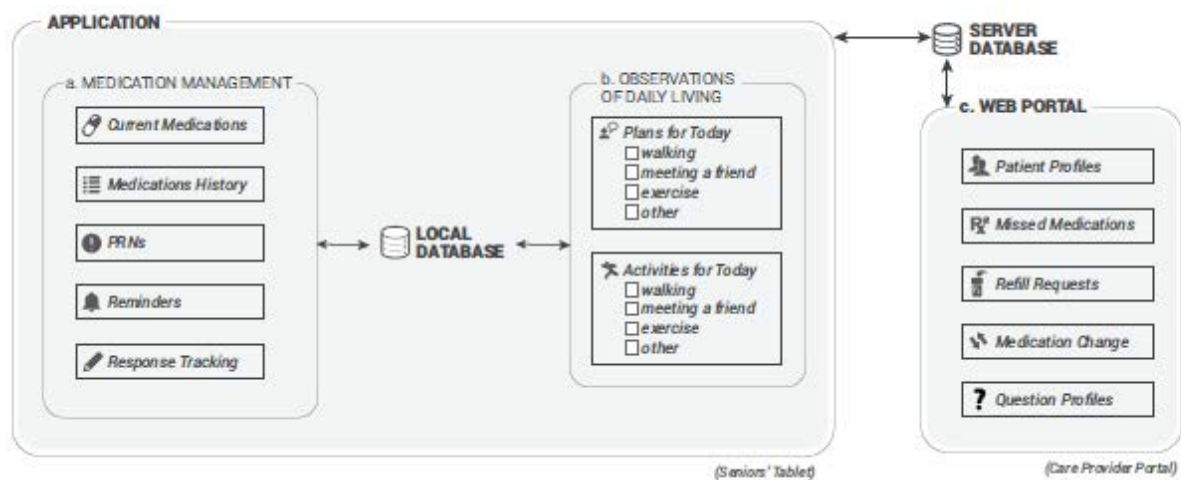
- Smart home technologies can prove to be of an asset to dementia patients, helping them with independence and helping reduce the burden placed on the informal caregivers.
- Participatory design framework to involve nvolve informal caregivers in the needs analysis and design of smart home user interfaces.
- User centered design processes to involve different stake-holders for the development of multi-disciplinary approaches to user interfaces designs.

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Nitesh Chawla, PhD (c)
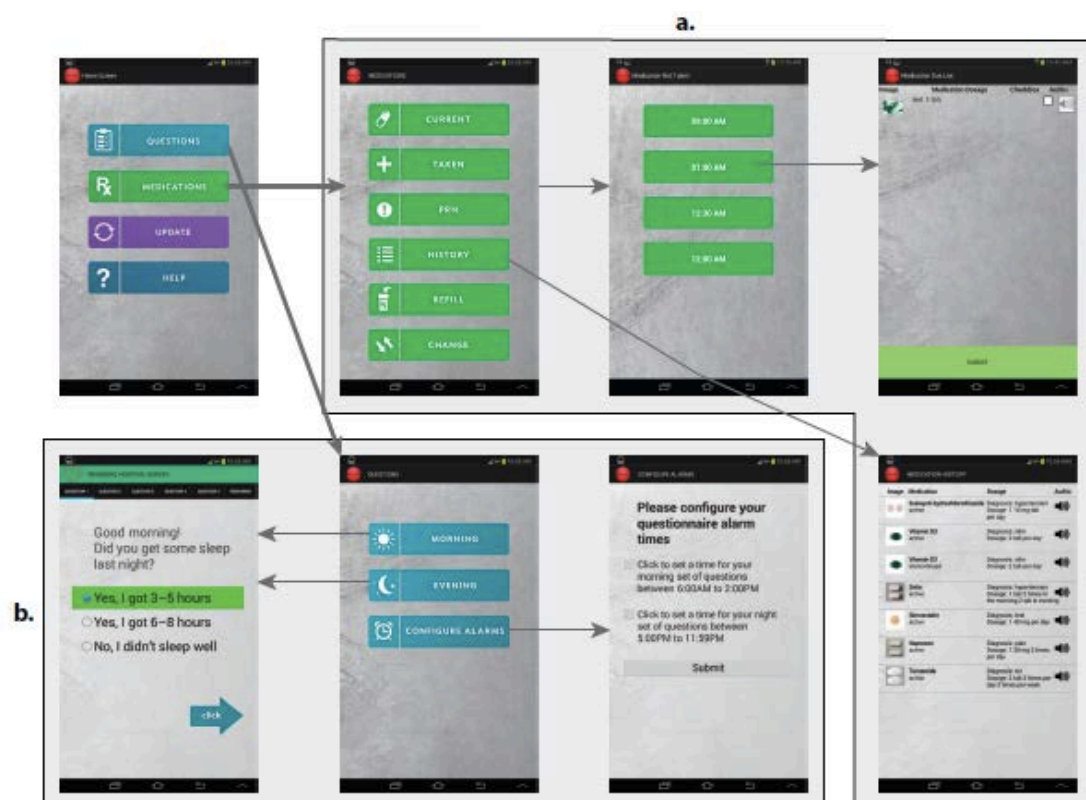
Modified Socio-ecological model of EseniorCare

Dasgupta, D. and Chawla, N. V., "Design and Evaluation of a Medication Adherence Application with Communication for Seniors in Independent Living Communities", AMIA 2016

Chaudhry, B., Greeves, K., and Chawla, N. V., "Successful Aging for Low-Income Older Adults: Towards Design Principles," *10th EAI International Conference on Pervasive Computing Technologies for Healthcare*, 2016.

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

APPLICATION

a. MEDICATION MANAGEMENT
- Current Medications
- Medications History
- PRNs
- Reminders
- Response Tracking

b. OBSERVATIONS OF DAILY LIVING

Plans for Today
- [ ] walking
- [ ] meeting a friend
- [ ] exercise
- [ ] other

Activities for Today
- [ ] walking
- [ ] meeting a friend
- [ ] exercise
- [ ] other

LOCAL DATABASE

SERVER DATABASE

c. WEB PORTAL
- Patient Profiles
- Missed Medications
- Refill Requests
- Medication Change
- Question Profiles

(Seniors' Tablet)

(Care Provider Portal)

Nitesh Chawla, PhD (c)

a.

b.

Good morning!
Did you get some sleep last night?
- Yes, I got 3–5 hours
- Yes, I got 6–8 hours
- No, I didn't sleep well

Please configure your questionnaire alarm times

Click to set a time for your morning set of questions between 6:00AM to 2:00PM

Click to set a time for your night set of questions between 5:00PM to 11:59PM

Submit

Martin Kampel

Acceptance criteria for Vision based Fall detection

Vienna University of Technology

Literature survey acceptance criteria

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
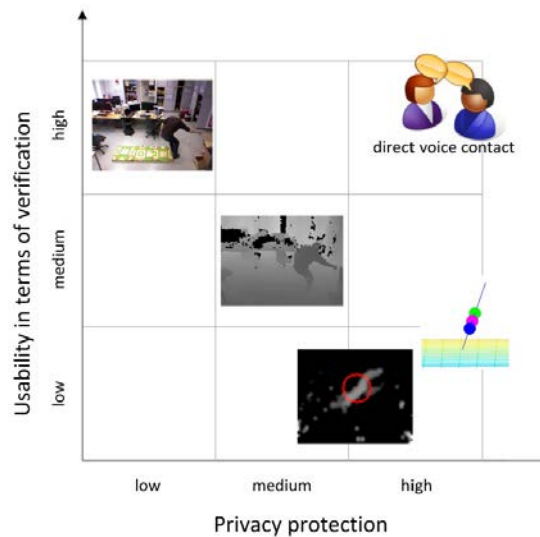
11 acceptance criteria selected

- **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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www.fearless-system.com

1) S. T. Londei, J. Rousseau, F. Ducharme, A. St-Arnaud, J. Meunier, J. Saint-Arnaud, and F. Giroux, — An intelligent videomonitoring system for fall detection at home: perceptions of elderly people., *Journal of Telemedicine and Telecare,* vol. 15, no. 8, pp. 383-390, 2009.

2) Planinc R., Ortlieb S., Carbon C.-C., Kampel M. "User-Centered Design and Evaluation of an Ambient Event Detector Based on a Balanced Scorecard Approach", International Journal On Advances in Life Sciences, 5(3-4), pp. 237-249, December 2013.

3) Weegh, H; Kampel, M. "Acceptance criteria for vision based fall detection", Proc. of Advancing Assistive Technology and eAccessibility for People with Disabilities and the Aging Population (AAATE), Sept. 2015.

Elderly Carers, Technologies, Privacy and Data Protection:

Challenges in Matching User Needs and Ethics Issues.

Selected Papers

1. Turkka Keinonen. 2008. User-centered design and fundamental need. In *Proceedings of the 5th Nordic conference on Human-computer interaction: building bridges* (NordiCHI '08). ACM, New York, NY, USA, 211-219.

2. Zarla Ludin. 2011. On ethical problem solving in user-centered research: an analysis. In *CHI '11 Extended Abstracts on Human Factors in Computing Systems* (CHI EA '11). ACM, New York, NY, USA, 791-798.

3. Joseph Lindley and Dhruv Sharma. 2016. Operationalising design fiction for ethical computing. *SIGCAS Comput. Soc.* 45, 3 (January 2016), 79-83.

contextual.interaction.design.research

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"
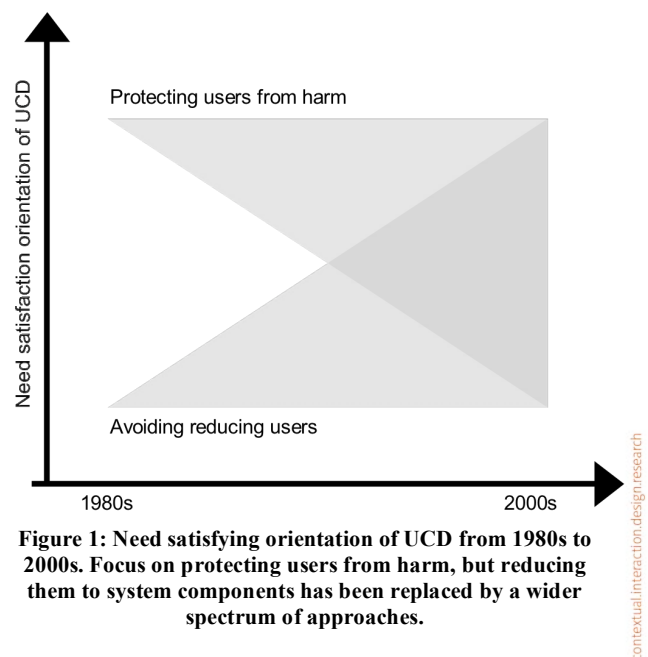
Figure 1: Need satisfying orientation of UCD from 1980s to 2000s. Focus on protecting users from harm, but reducing them to system components has been replaced by a wider spectrum of approaches.

Rationale

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

Contact

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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
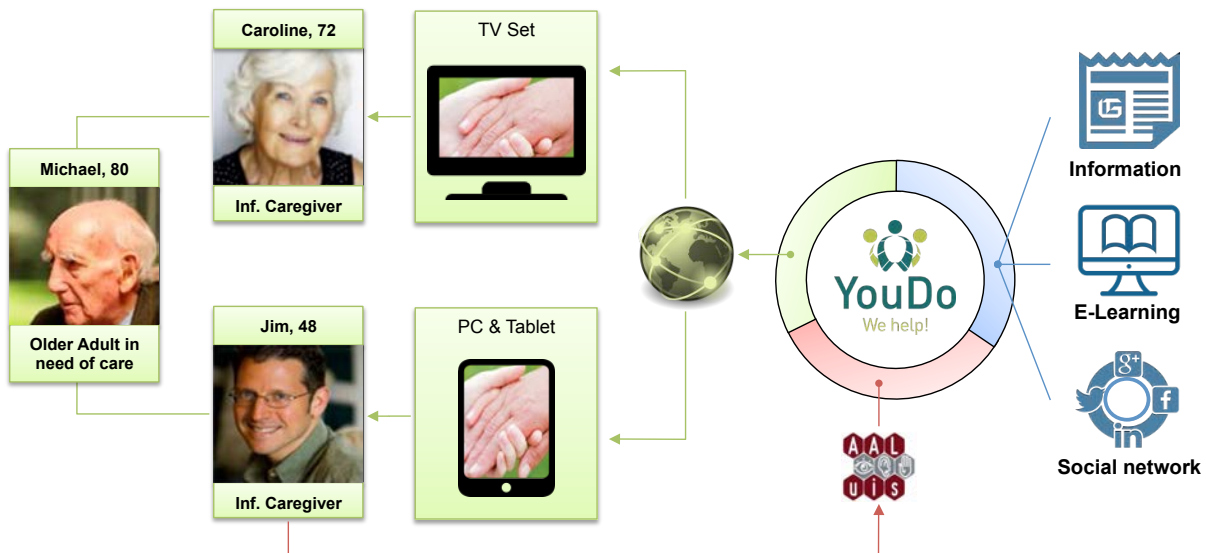
Sili, M., Bolliger, D., Morak, J., Gira, M., Wessig, K., Brunmeir, D., & Tellioğlu, H. (2014). YouDo-we help!-An Open Information and Training Platform for Informal Caregivers. Studies in health technology and informatics, 217, pp. 873-877.

YouDo

Sili, M., Bolliger, D., Morak, J., Gira, M., Wessig, K., Brunmeir, D., & Tellioğlu, H. (2014). YouDo-we help!-An Open Information and Training Platform for Informal Caregivers. Studies in health technology and informatics, 217, pp. 873-877.

ibi - "ich bin informiert"

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
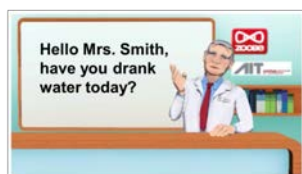
Hanke, S., Tsiourti, C., Sili, M., & Christodoulou, E. (2015). Embodied Ambient Intelligent Systems. *Recent Advances in Ambient Assisted Living-Bridging Assistive Technologies, E-Health and Personalized Health Care, 20*, pp. 65-86

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"

Morandell, M., Dittenberger, S., Koscher, A., Sandner, E., & Sili, M. (2016). The Simpler the Better: How the User-Inspired Innovation Process (UIIP) Improved the Development of RelaxedCare–the Entirely New Way of Communicating and Caring. International Conference of Design, User Experience, and Usability, pp. 382-391

RelaxedCare

Morandell, M., Dittenberger, S., Koscher, A., Sandner, E., & Sili, M. (2016). The Simpler the Better: How the User-Inspired Innovation Process (UIIP) Improved the Development of RelaxedCare–the Entirely New Way of Communicating and Caring. International Conference of Design, User Experience, and Usability, pp. 382-391

Thank you!

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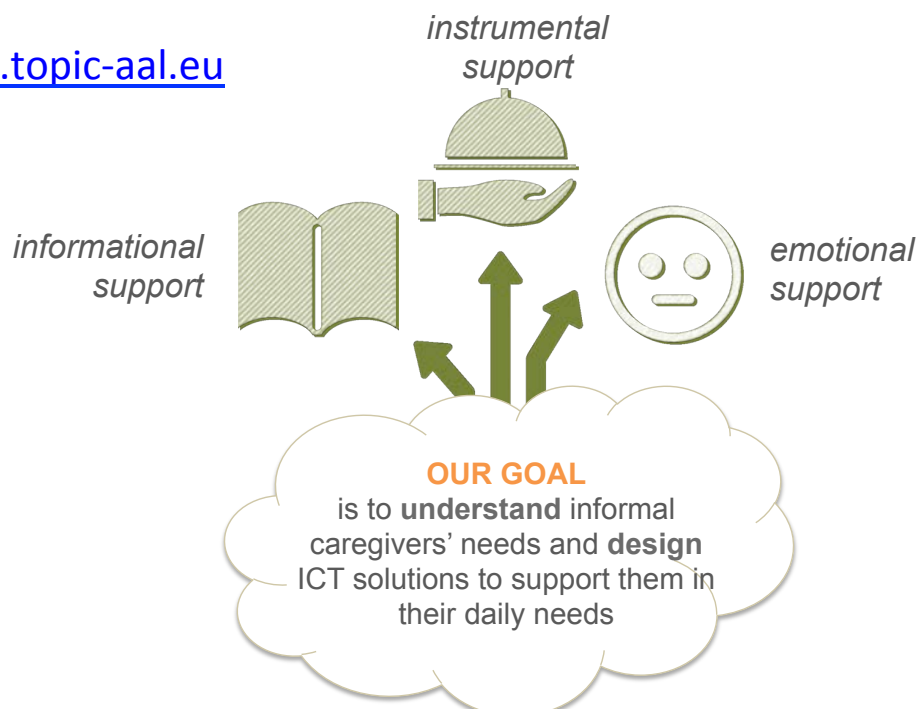
Hilda Tellioğlu
Vienna University of Technology

The Online Platform for Informal Caregivers TOPIC

www.topic-aal.eu

instrumental support

informational support

emotional support

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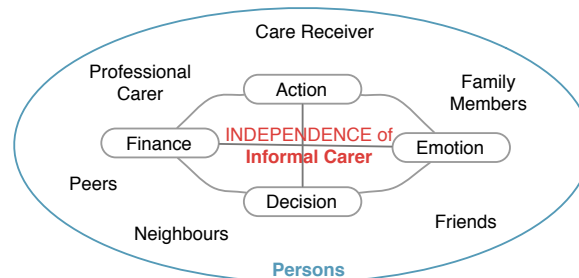
Independence – How?
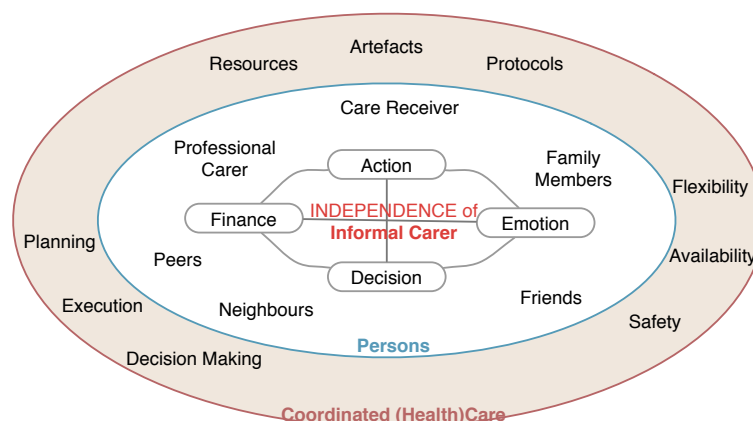
Independence – How?
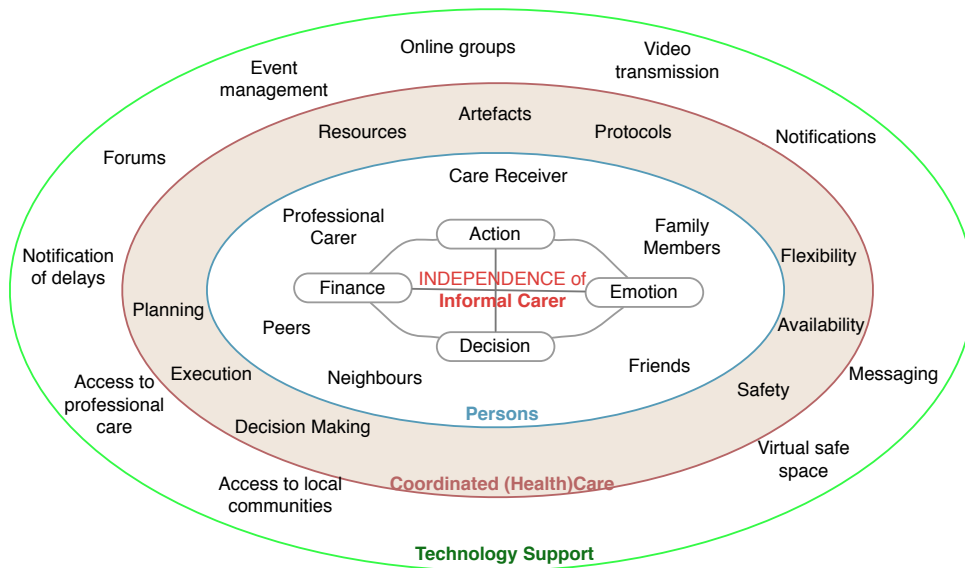
Independence – How?

Further considerations …

- Ethical core dimensions:
  Care, autonomy, safety, justice, privacy, participation, self-conception (Marzeschke & Diehl)
  Safity, 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?
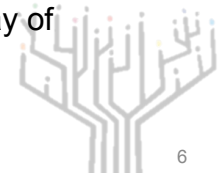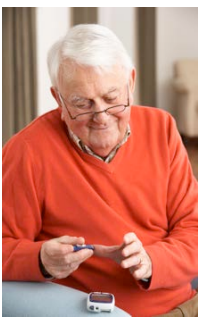
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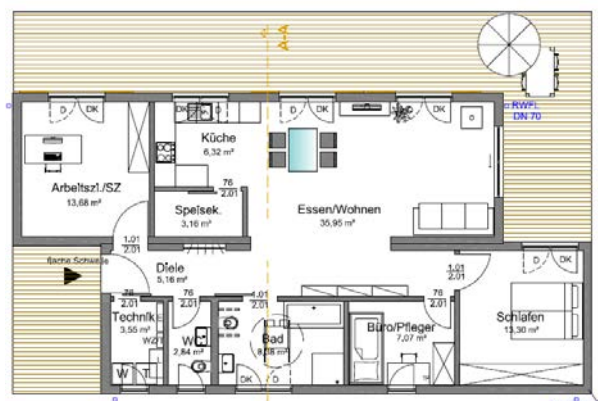Vienna University of Technology

www.topic-aal.eu

TOPIC

Lessons learnt in
TOPIC and other
European and national
AAL projects

AAL Forum St. Gallen
28.10.2016

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 busines-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?

Living Room   Kitchen
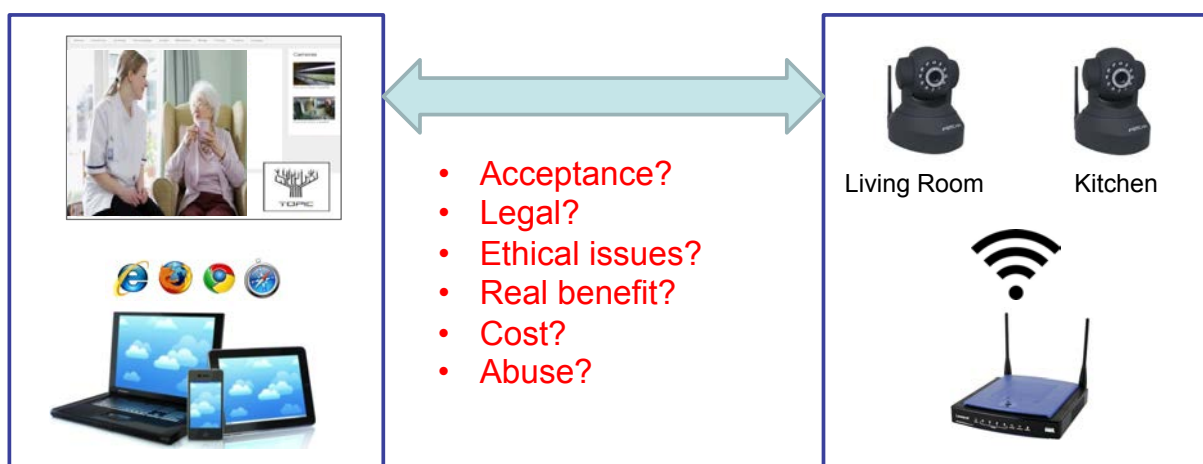
The AAL funding and research policy („with high speed to the market") evades public responsability for a better social practice!

Thank you for your attention

Anton Zahneisen

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