Assistive Systems

Ethics & Legal Aspects, Economics

Human Computer Interaction Group (HCI)

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Content

Introduction – Sequence of Course

I. Demarcation and Definitions

- Umbrella term AAL
- Technical Aids vs. Assistive Systems

II. Active User Interface (HCI)

- Active Support

III. Assistive Robots – Movement

- Human Robot Interaction (HRI)

IV. Sensors – are entering the living area

- Saftey and Support

V. Ethics, Law and Economics

VI. Requirements Analysis and Evaluation

V. Ethics, law and economy

Ethical aspects in AAL research projects, Products and services

Legal framework conditions of AAL

Economical considerations and business models

Goals

Get to know ethical issues in the context of AAL systems and services

Learn about legal parameters for AAL systems and services and being able to classify them

Understand current challenges and problems in economy

Ethical aspects
As introduction: technology and ethics

Technical acting …

Concentrates first on technology

- Primary goal is solving problems with technology
- Correct function according to a specification
- Achieving a goal and improvement of performance
- Economical and ecological considerations are normal

Should also deal with effects of application of technology

- Technology changes a situation for people and society
- Technology affects the people using it
- Technology also has effects on other people
- (Vulnerable) people might not understand implications

=> Also ethical considerations are necessary

Technical acting …

- … belongs constitutively to humans
- … uses specific technical means, procedures, institutions, to achieve first non-technical, later also technical goals
- … **creates ordered structures** of big obtrusiveness and range
- … leads aside from desired goals also to **undesired consequences**, which
  - … are difficult to predict (Collingridge dilemma)
  - … are adopted after weighing-up of risks (or not)
- … inspires expectations and hopes, which in the area of health and disease easily get inflationary and unfulfillable, but nonetheless justify big investments
- … needs because of the **far reaching implications and often unclear moral constellations** an ethical reflection, which steps in as early as possible in research and development processes

Ethics: reflection about moral issues

»Serious moral issues are such, with which it gets decided, who and what we are as humans and in which society we as humans want to live together «.

Gernot Böhme: Ethik im Kontext. Über den Umgang mit ernsten Fragen, Frankfurt (Suhrkamp 1997)

»Applied ethics is the attempt, to help humans by means of ethics, to behave morally correct in certain situations, in which there is uncertainty on what in this situation would be morally correct«.

Ralf Stöcker, Christian Neuhäuser und Marie-Luise Raters: Einleitung. In: Dies. (Hrsg.): Handbuch für Angewandte Ethik, Stuttgart/Weimar 2011, S. 1–11; S. 4.

Ethics means: reflecting moral

- Increase quality of life
- Human dignity in all phases of age
- Self determination and social participation
- Technology structures societal regime
- Technology shall not replace human care

Ethics analyses the development and application of technical devices in view of the individual and the society as a whole and asks for **balance** between **ability to do** and **responsible willing and acting.**

Ethical perspective on technology

- Understanding technology and dealing with it does not end with listing and comprehending its features
- Analysis and assessment of technical arrangements demands reflection of the conditions of structural principles of technology
- Technology in the AAL context is normatively charged
- Different to the **engineering perspective**, which uses technology in a strategic way for solving problems, the **ethic perspective** asks for the **balance between feasibility and responsibility**
- This distinction creates freedom of thinking and (technical) acting

Technology as improvement of…

- Technology is a **means for the purpose** of improving human life
- Since long ago man uses technical acting also in the area of health and care to improve the lives of caregivers and those cared for (make life easier, safer, healthier, less suffering…)
- The specific about **caring for body and mind of man** can be **supported by technology,** but not likely created (self-produced) by it
- Conversely, technology can alienate such caring and **establish itself as an end** – this applies on both an individual and a social scale

AAL is not …

AAL understands itself as extensive, mainly technical help system, which shall allow people with temporary or permanent restriction in autonomy a largely self determined life.

It (AAL) is to be differentiated from:

- ***Enhancement*** – surpassing of to date existing abilities
- ***Help as total usurpation***, not asking anything anymore from the individual
- It is about an **intelligent combination** of **technical** and **social** elements with the aim of restoring or maintaining people's autonomy
- In so doing also moments of „natural“ losses of vitality and autonomy have to be regarded

Ethical implications of AAL?

Technological progress always is ambivalent.
AAL as technical application changes our view of the individual as well as of our living together.

Here, moral questions on status and form of living of humans are concerned:

- Dignity and identity of persons
- Safety and freedom of individuals and society
- Support and incapacitation
- Control and apathy / indifference in society
- Standardisation pressure and individualism in helping
- Burden and relief as social task

Socio-technical implications

- Not just **the application of technical artefacts** poses moral questions
- **Technical design** already is a morally loaded decision
- The technical design of artefacts and arrangements directs the user already into a certain way of acting and creates moral implications
- Currently reflection arenas for socio-technical transformation processes are largely missing

Socio-political implications

These technologies are laid out in **generation overarching** way.

Boundaries of health assistance, comfortable lifestyle and physio-psychical enhancement become blurred.

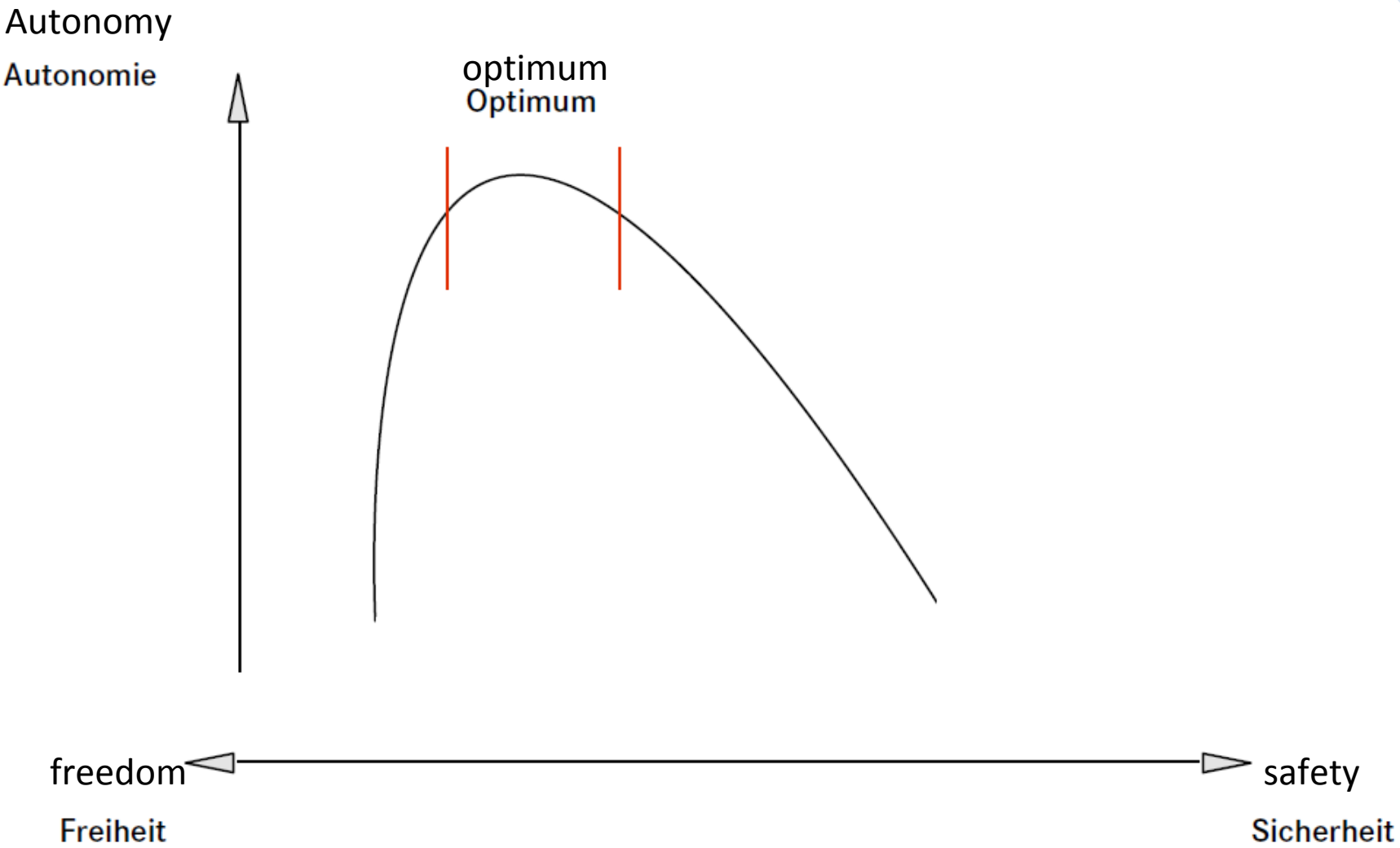
- How to protect ourselves individually and societally from loss of **(bodily) self-experience**?
- Which **social adaptive performance** will come out of the technical standardization / norms ?
- What does this trend mean for the old age phase and for the phase of dying?
- How does **societal cohesion** develop, when social responsibility – at least partly – is delegated to technical systems?

Critical closer examination: Is helping always beneficial?

AAL understands itself as comprehensive help system.
Helping is a morally an ambivalent phenomenon; helping is not unconditionally fine.
Down sides are:

- Help can incapacitate
- Help can paralyze existing skills
- Help systems produce „helpless helpers“ (Schmidbauer)
- Help can delay the process of dying
- Help can increase the pressure to be satisfied with some help (AAL) and otherwise remain socially unsuspicious.
- Help as a market tends to stimulate demand

Ethical Aspects



Short video: Uninvited Guests

Explores the frictions between an elderly man and his smart home. https://vimeo.com/128873380

Thomas, aged 70, lives on his own after his wife died last year. His children send him smart devices to track and monitor his diet, health and sleep from a distance. But Thomas has always been fiercely independent, happy to live in an organised mess. He struggles with the order and rules imposed on him by the objects that are meant to make his life easier. In a world where 'smart objects' will increasingly be used to provide care at a distance, how will we live with these uninvited guests?
For further information visit: http://superflux.in/index.php/work/uninvited-guests/#

A sentiment on: Integration of ethics in development

»If we could get designers of technology to think about the ethical and social implications of their designs before they become a reality, the world might be a better place«

Deborah G. Johnson: The Future of Computer Ethics. In: Göran Collste (Hrsg.), Ethics in the Age of Information Technology, Linköping (Centre for Applied Ethics) 2000, S. 17–31, 18f..

Medical ethics,
Robot ethics & machine ethics

Medical ethics

This ethical system is called “Principlism” and consists of four ethical principles (Beauchamp, 1979):

- **Autonomy**: Respect the autonomy of the person.
- **Beneficence**: Your action should bring benefit to the person
- **Non-maleficence**: Your action should not harm the person.
- **Justice**: Consider in your action the social (=fair) distribution of benefits and burdens

AAL robotics and ethics

AAL robots as AS pose additional questions, because of the following properties:

- They are complex
  - Many engineers, companies, etc. contribute to SW and HW. It is difficult to backtrack to the origin of failures
- Decide autonomously
  - Ethics but lies in the architecture/code of the decision processes, not in the behaviour/result
- Ubiquitous
  - Not only in the production hall but in same room with users
- „nice“
  - They soon get „anthropomorphised“, also e.g. Roomba

Robot Ethics vs. Machine Ethics

Robot Ethics

is concerned with the **moral behavior of humans** as they design, construct, use and treat such beings.

Machine Ethics (or machine morality)

is the part of the ethics of artificial intelligence concerned with the **moral behavior of artificially intelligent beings**.

Robot ethics

Robot Ethics is a branch of engineering ethics. Aside from the code of conduct for RTD in robotics also specific guidelines for Human Robot Interaction (HRI) have been developed

Ethics of Human-Robot Interaction: (cf. Rieck & Howard, 2014) sees 4 areas:

- Therapeutic robots
- Physical assistance
- Integrators of robotics
- Wizard of Oz (WoZ) experiments

Riek and Howard: HRI

Riek and Howard 2014 composed considerations for HRI related ethical guidelines, e.g.

- Continuous respecting of emotional needs of persons
- Continuous respecting of human right on privacy / data protection
- Respect human frailty, physically and mentally
- The tendency to develop bonding and to anthropomorphise the robotic system should be considered carefully in design
- ….

Machine Ethics

Ethics for „intelligent machines“:
A robot as „partner on workplace“ or as „companion/butler“ of old people or disabled persons needs moral competences.

It has to have an „ethical system“, to be able to:

- cooperate, especially in complex social situations
- “understand” human decisions

Machine Ethics

Robots follow ethical principles, because

- These result implicitly from the design process
- Or as consequences from an explicitly developed ethical system

- Ethical principles for robots and the ethical principles for designers, developers and integrators do not necessarily need to be identical.
- The „ethical system“ will also be different for an autonomous vehicle and for an AAL robot in the flat of an old user.

Asimov's Three Laws of Robotics

Early foresightedness in SF literature

- **First** Law: A robot **may not injure a human being**, or, through inaction, allow a human being to come to harm.
- **Second** Law: A robot **must obey orders given it by human** beings, except when such orders would conflict with the First Law.
- **Third** Law: A robot **must protect its own existence** as long as such protection does not conflict with the First or Second Law.
- Later introduced a further law:
  Zeroth Law: A robot **may not injure humanity**, or, through inaction, allow humanity to come to harm.

These laws do not enable a robot to act ethically by itself = "slave".

Machine Ethics - Implementation

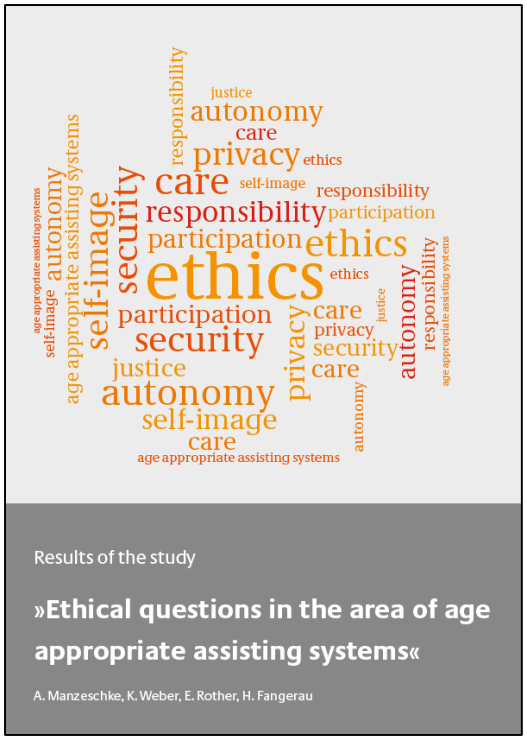
- Driverless cars make clear that „ethical systems“ are needed.
  - At any time dangerous situations can occur, demanding immediate decisions, e.g. if an animal or a pedestrian should be harmed; if a big, safe car or a small car (or motorcycle), the driver or other people on the street.
- For robots in the AAL area the situations can be more subtle but still dangerous
  - E.g.: considerations between autonomy and health of users, e.g. to call for external help or not.

Source: Benefit potenziaal, 2015

MEESTAR: Example of a toolkit for ethical evaluation

Results of a study on ethical issues in the area of „age appropriate assistive systems“

- Comprehensive final report: https://www.nks-mtidw.de/dokumente/meestar-studie-englisch
- **Ethical-normative guidelines** for the application of age appropriate assistive systems
- **Ethical evaluation** instrument called:
  ***M**odel for the **E**thical **E**valuation of **S**ocio-**T**echnical **AR**rangements*
  (=MEESTAR)



Ethical-normative guidelines

In this study 15 guidelines were formulated:

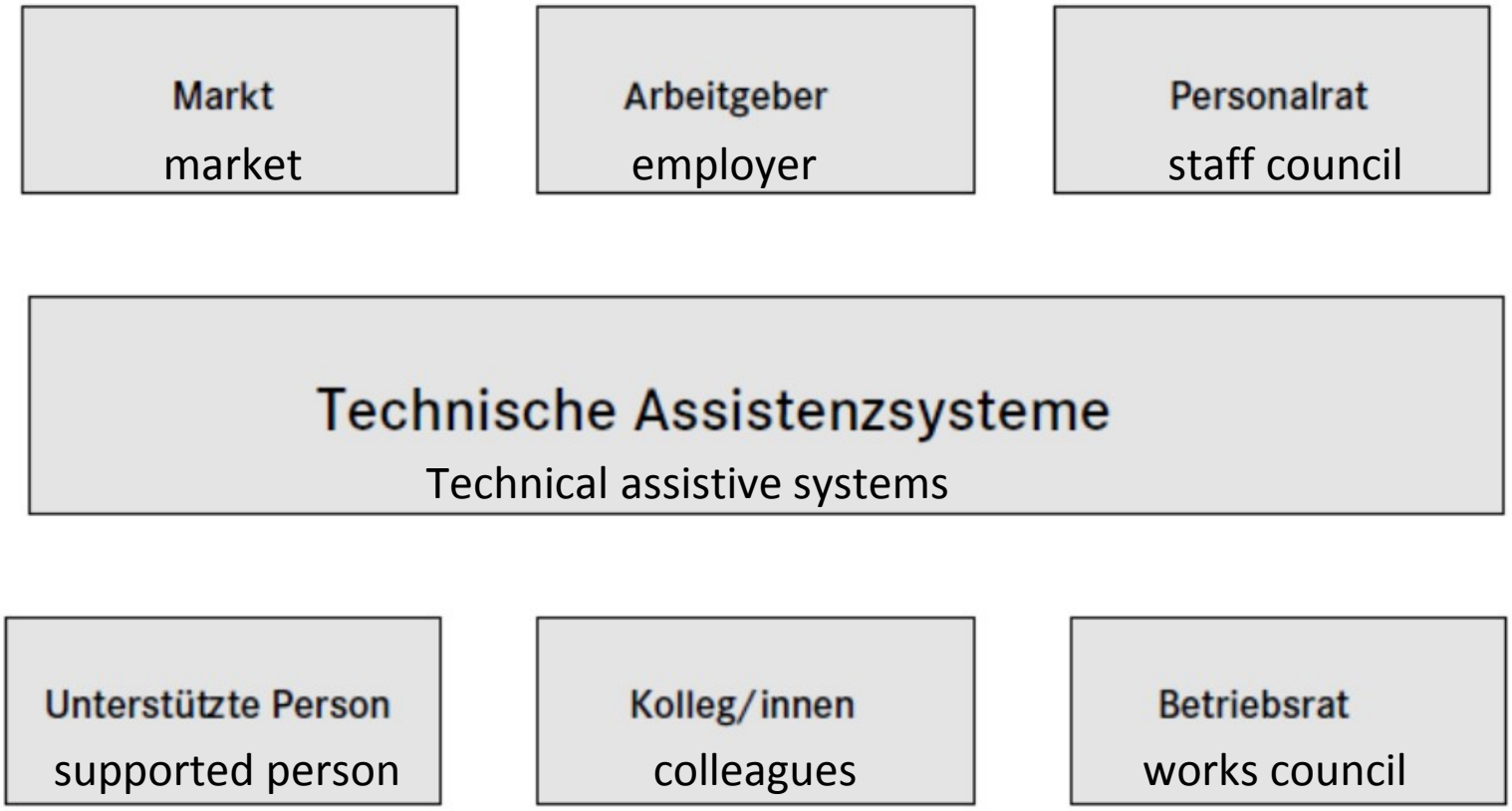
- Related to seven ethical dimensions
- Differentiated by
  - research & development
  - supplier
  - user
- Addressed are mainly suppliers, which want to make use of an AAL system – design mission
- The majority of guidelines concentrates on the individual level - consequent user orientation

Ethical socio-technical arrangements

- No technology assessment
- No professional ethics
- No principlism
- onsideration of the concrete social situation and its change through technology
- Evaluation by affected people
- Evaluation on different layers
- Analysis of the range of implications of action and actor specific responsibility
- Synopsis of individual preferences and socio-political goals
- Ethics ≠ majority appealed moral

Systemtechnologischer Ansatz
System technological approach

VC&HCT



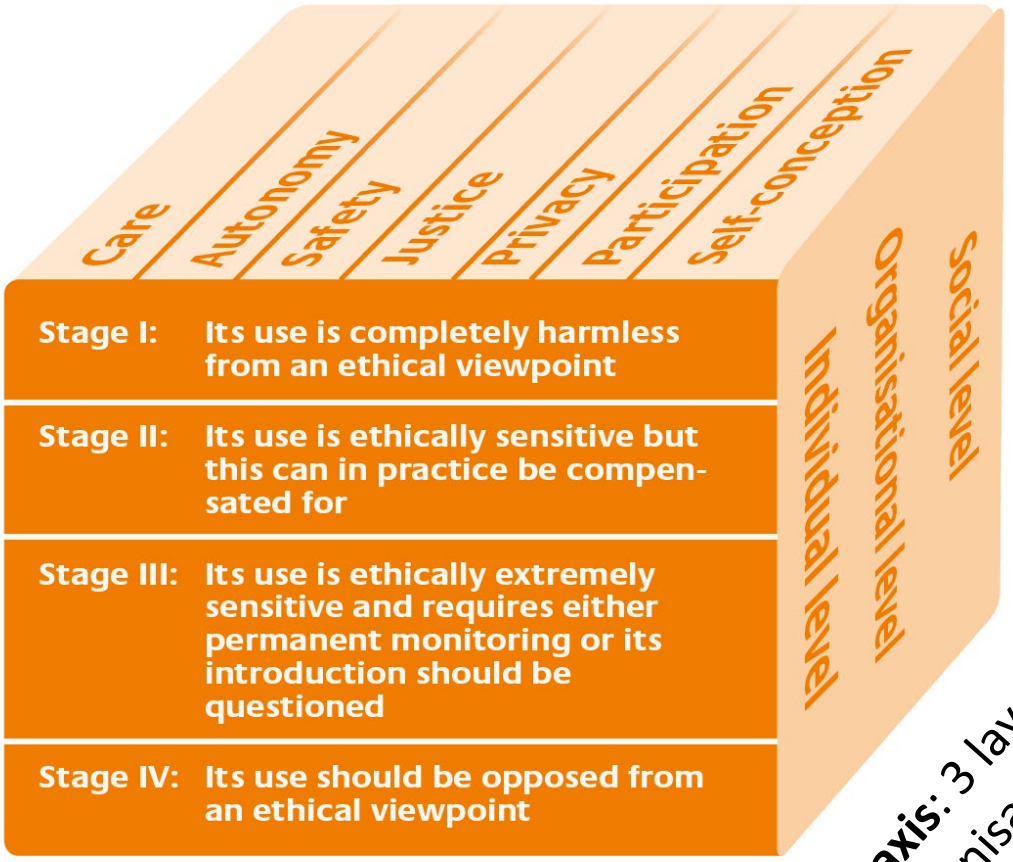
Technical coupling of body and world

- The coupling of body and environment by ICT means a technical normalisation of the body
- This normalisation is more direct, more subtle and more objective than existing social normalisations
- On the long term a blending of inner and outer nature by ICT can be imagined
- Technology extinguishes the traces of its application
- Loss of these traces leads to a loss of self-experience (body experience)
- Loss of self-experience causes loss of intellectual reflexion and deliberation

MEESTAR: Model for the Ethical Evaluation of Socio-Technical ARrangements

VC&HCT

x-axis: moral dimensions



y-axis: 4 levels of ethical sensitiveness (I-IV)

z-axis: 3 layers of observation (individual, organisational, societal)

Source: Arne Manzeschke, LMU Munich

VO Assistive Systems

Assistance for ethical judgement

The ethical reflexion in a MEESTAR workshop shall open up room for structured reflexion for actors in this area (research & development, providers and users), to strengthen the **own ethical judgement**.

The purpose is to make visible and processable the moral problems of the partly very extensive interventions into privacy and lifestyle of people in the funded projects.

The moral institutions and the experiences of the project partners should form the starting point for a **structured ethical reflexion**.

Identification and evaluation of ethical problems

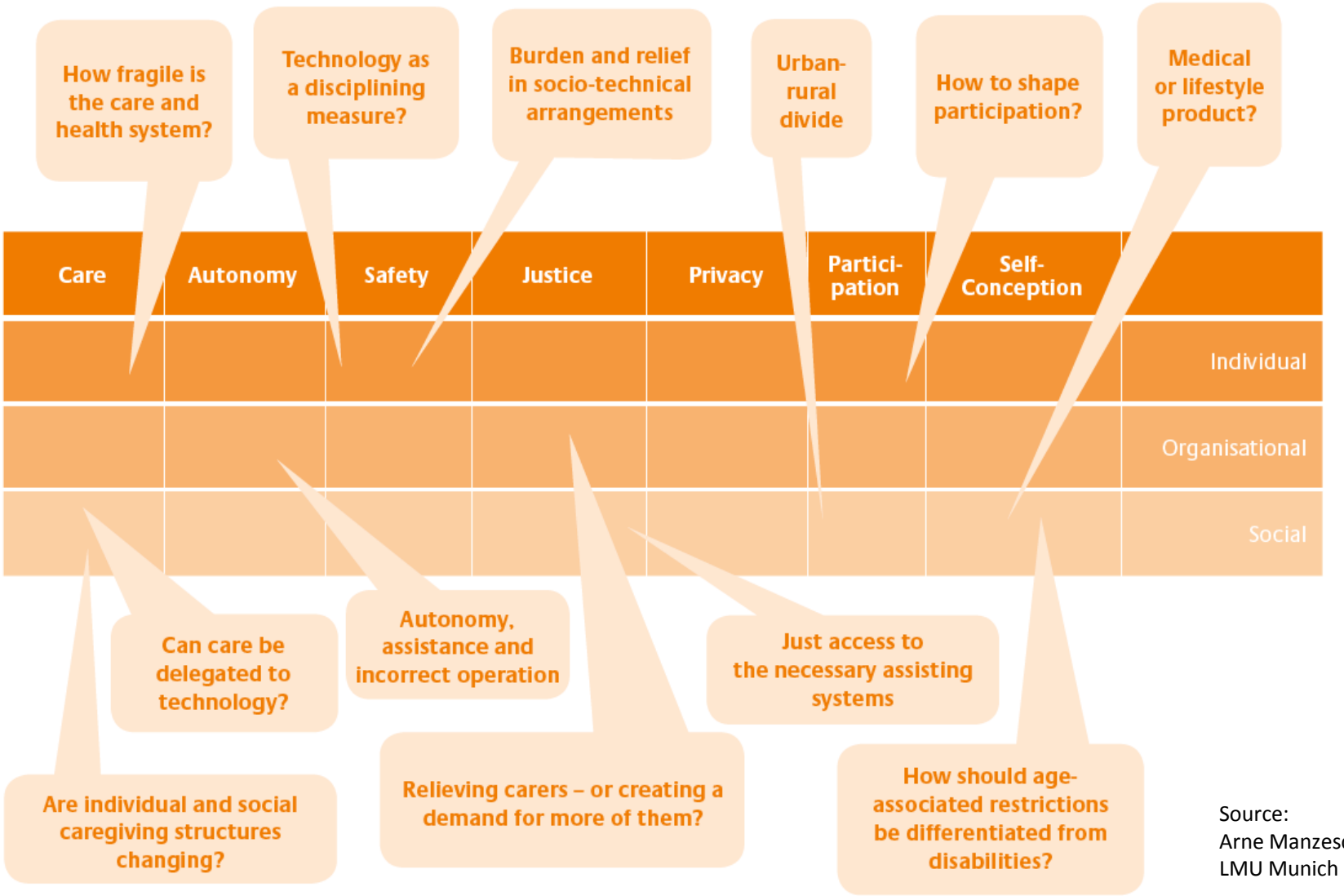
Identification of ethical problems

- Associating moral emotions
- Describing moral problems
  – i.e. allocating the problem to one ore more moral dimensions (care …)

Evaluating ethical problems

- Estimate and justify the degree of ethical sensitivity regarding a problem
- Consider coherence and interaction of different factors in the evaluation

Ethical tipping points and areas of conflict— illustrated as examples in the MEESTAR structure



Source:
Arne Manzeschke, LMU Munich

Evaluation of a Scenario

VC&HCT

Group work results in a MEESTAR Workshop are presented and discussed

Evaluation of a Scenario

MEESTAR offers	Does not offer
Opening many perspectives	Quantitative assessment
Creation of sensitivity	Ethical assessment with universal validity
Joint discussion on ethical problems	Avoid/replace own reflection
Assessment of a concrete scenario	
Development of solutions for ethical problems	

Ethical Aspects: example GPS-Tracking

VC&HCT

Example: simvalley MOBILE GPS-/GSM-Tracker GT-340.sk für Senioren & Kinder,
Source: http://www.simvalley-mobile.de/

Ethical criteria for AAL

- AAL means supporting and re-establishing human capabilities, not their replacement or surpassing
- AAL must not overwhelm or incapacitate the assisted person
- Voluntary consent to the use of AAL, no compulsory application to „own best“
- Robotics and replacement of people (job replacement at workplace) must be well considered
- Human-bound, transparent and intervenable decision hierarchies.

Ethical guidelines for assistive systems

(after A. Manzeschke et al., 2013)

Ethical guidelines for application of age appropriate assistive systems

Purpose of the guidelines is to provide orientation on the use of assistive systems in daily life of old people and to create sensitiveness for ethically orientated deciding, judging and acting.

Source: A. Manzeschke, K. Weber, E. Rother, H. Fangerau (2013) Ergebnisse der Studie »Ethische Fragen im Bereich Altersgerechter Assistenzsysteme«, Berlin (VDI/VDE)
online: http://www.mtidw.de/grundsatzfragen/begleitforschung/dokumente/ethische-fragen-im-bereich-altersgerechter-assistenzsysteme-1

Ethical guidelines for application of age appropriate assistive systems

1 Self-determination

Age appropriate AS shall help users to live a self-determined life

2 Restricted self-determination/autonomy

Application of age appropriate AS for cognitively impaired persons should only be done after separate examination of the presumable will of the user

3 Participation

Age appropriate AS shall support the participation in societal life and integration in societal and social groups

Ethical guidelines for application of age appropriate assistive systems

4 Justice

Access to age appropriate AS should be designed free from discrimination

5 Safety

Use of age appropriate AS has to be safe for all user groups, both in normal use and in case of potential malfunctions and failures of the whole technology or parts of process chains

6 Privacy

Age appropriate AS shall not negatively affect the personal lifestyle

Ethical guidelines for application of age appropriate assistive systems

7 Data protection

Person related data or data in other ways to be handled confidentially, which are collected, documented, evaluated or stored in the context of age appropriate AS, shall be protected against misuse by third parties in best possible ways.

8 Informing& informational self-determination

Users of age appropriate, technical AS shall be fully informed about function and collection of data about them and the functions of the system and only based on this give informed consent

9 Liability

Assumption of responsibility and liability in case of a malfunction of age appropriate AS have to be arranged in transparent and compulsory way.

Ethical guidelines for application of age appropriate assistive systems

10 Picturing age

Age appropriate AS shall allow manyfold role depictions of age

11 Avoid discrimination and normalisation

Stigmatisation or discrimination in the context of using an age appropriate AS are undesireable. Equally undesirable are normalisations (direct or indirect) originating from the systems

12 User friendliness

Age appropriate AS shall be designed such that for the users they are easily, intuitively and well understandable useable

Ethical guidelines for application of age appropriate assistive systems

VC&HCT

13 Contractual provisions

Users of age appropriate AS shall have the possibility to exit from the contract

14 Qualification and advanced training

All agents in the area of age appropriate AS shall regularly partake in advanced education and training

15 Responsibility & best possible support by technology

Vendors of age appropriate AS shall act responsibly; assistive technologies always should be applied for the advantage and good of the users

Ethical aspects and guidelines

(Ethical checklist for prototype tests with old people)

Ethics checklist

Ethics checklist worked out by the team of Institut Klinische & Gesundheitspsychologie, faculty Psychology of Universität Wien (Prof. Kryspin-Exner)

Shall support researchers, which investigate the application of all kinds of new technologies with old people, to be able to check planning and performing studies concerning important ethical aspects

Note: pursuant to the specific researched technology different ethical aspects must be considered

Source:
https://www.ffg.at/sites/default/files/allgemeine_downloads/thematische%20programme/programmdokumente/ethik-checkliste_endred_autoren.pdf

Ethics in recruiting

Purpose is the recruiting of suitable test persons (TP)

- Personal recruiting
- Use of advertising media (e.g. flyer, information folder, announcement in newspaper)

Important from ethical viewpoint: disclosure of

- Purpose/goal of the study and
- Requirements, test persons must fulfil

Recruiting - information

For the older test persons (TP) it has to be clear,

- Why participation is important,
- How participation is planned,
- How long it will take,
- In which place it is planned,
- Who are the contact persons and how they can be reached (e.g. by telephone, by eMail).

Also make transparent:

- Possible risks and costs
- The type of compensation (if applicable)

Recruiting - information

New technologies should be **coarsely explained** at the beginning, to ensure at the one hand enough information for users but also to establish trust in the investigation and increase motivation to participate.

Especially with old people it has proven to be helpful to briefly introduce the used technology already in the recruiting documents, because this enables first of all the older generation, which has not grown up with such a variety of technological offers, to express concerns and ask questions in advance.

Recruiting – priming effects

Priming effects: affecting the behaviour of test persons by preceding information

In the recruiting it has to be observed, that too detailed information given about the study (e.g. concrete assumptions about hypotheses) can lead to a sort of „priming“, possibly jeopardising validity of results.

For this reason it has to be weighed in advance, how much and which information is given to the test persons, in order to, at the one hand, inform them well enough, but also not to create too much “prior knowledge” able to endanger the study.

Welcome (and farewell)

- Signs leading to the test room with barrier-free access
- Personal welcome
- Friendly gestures and facial expressions
- Address test persons by their name
- Introduce oneself as test leader (TL) of the study by name and explain the role
    - a too individualised contact at the welcome (the test leader adapts his/her behaviour to the test user) is on the expense of the quality factor of objectivity – especially the executional objectivity (independence of test leader) => standardised interaction

Estimation of benefit and risks

Identifying risks of the participation already during planning phase:

- Eliminate risks a priori or
- Establish rules to handle problematic situations

Possible risks and potential benefits of the study:

- Benefits should prevail, it has to be avoided to create more harm than benefit for the test users because of their participation

Possible risks and possible benefit for test persons

Risks	Benefit
Physical damage	Access to (free) treatment
Social or emotional damage	Emotional support
Stigmatisation	Psycho-social support
Loss of privacy	Contribution for society (knowledge)
Lack of sensibility against vulnerable groups	

WHO ERC - Research Ethics Review Committee (2012). *Guide for principal investigators.* http://www.who.int/entity/rpc/research_ethics/Guide%20for%20PIs.doc

Pilot tests

Identification of possible risks can be achieved by pilot tests („rehearsal“).

Risks identified by this as well as measures to eliminate or minimise them are explained in the following (by the example of a project)

Risk minimisation (examples)

Identified Risks	Steps to eliminate/minimise risks
Possibly excessive demand on test person when filling online questionnaires because of missing experience with PCs	Use of paper/pen for older test persons; Use online questionnaires for younger test users
Possibly excessive demand on test person if to use smartphone for control	Detailed instructions, how control via smartphone is working and offering verbal help during initial setting-in phase

Dilemma

The question, if **benefits outweigh the risks**, has to be answered individually for every research project resp. each research question.

For investigations in the area of Assistive Systems there is the problem of **no immediate benefit** for the test person, but for product development which comes to the benefit of future generations or an older age class of users.

<u>This has to be expressly mentioned in the informed consent document</u>.

Dilemma real life test

Technology provided within a study is (hopefully) of immediate benefit to the test user (e.g. an Assistive System increases the feeling safer of an old person), but has to be withdrawn after the research project (e.g. for legal reasons – not yet a product, no after sales service).

From ethical viewpoint the test person has to be informed already before the start of the study, if and when the used technology will be withdrawn after the study and if there is a possibility to buy or rent it. (→ „Exit“ strategy)

Exit strategies:
(2 different):

- During project: Right of the test person (TP), to withdraw from the study at any time (even if IC has been signed)
  - Without having to state reasons, without consequences
  - Researchers always should be attentive regarding possible hidden wishes for withdrawal
  - Plan for handling consequences for the study
- At project end:
  - Consider, that the TP could have become fond of the social contacts created by the participation and the interaction with the prototypes (PT - e.g. robot) (→ avoid abrupt termination)
  - Early planning and communication, what will happen with the prototypes at the project end
    - E.g. note in the IC that the PT cannot be kept; or further use will only be possible with restricted functionality and some low fee; or that service will be provided free of charge for e.g. 2 years, than can be continued at some fee ….
  - Thank for participation, e.g.:
    - Final seminar for TPs with presentation of main results and explanation of the contribution by TPs for the project, outlook, written summary of project results

Informed Consent (IC)

- Written and signed document, **comprising all relevant information** about the study
  - E.g. purpose, procedure, duration, benefit, risks of the study, data declaration, responsible person
  - To be obtained from test persons immediately before the study

- Although test persons partly received information already during recruiting, the degree of knowledgeability when beginning the study still will be very different

Declaration of consent

Has the test person been thoroughly informed and is he/she willing to voluntarily participate, the declaration of consent will be signed (as part of the IC process). The written declaration of consent then has to be also signed by the test leader and stored in a safe place. Also afterwards the TP of course has the right to prematurely exit the study. In the IC therefore **it must be expressly stated that the TP can exit without giving reasons** and without having to fear detriments.

2 purposes of IC:

⇒ To inform user before signature

⇒ For legal consent

Withdrawal of consent

Furthermore, in the IC there must be stated that the TP has the **right to „withdraw“ his/her data after the study,** how such elimination will happen (e.g. shredding of paper questionnaires, purging of digitally stored data from all storage media) and to whom and in which form the deletion can be requested (by telephone, mail, eMail, personally)

Ensuring voluntariness

Particularly with vulnerable groups of the population it is important to ensure that they have understood all information and their consent is given voluntarily.
Older people (but also children) are considered vulnerable, because with age real and perceived dependencies increase, going along with losses in autonomy and self-determination.
Often dependent persons do not agree to a participation at their free will, but feel obliged to participate in a study because of institutional or group pressure.

Informed consent as process

IC and declaration of consent (part of IC) should be formulated as understandable as possible (no loanwords, simple sentences, explanation of special terms), structured clearly (use bold, italic fonts, paragraphs) and regarding length only contain as much information as necessary.

Think of sufficiently large print or other special needs.

The informed consent does not only comprise reading and signing a document but rather a process resp. dialogue, in the course of which questions of the test person can be answered

Execution of the study

Appropriateness and economy

- From ethical viewpoint with vulnerable groups the **quality criteria of appropriateness** has to be observed.
- This criteria is fulfilled, if the test persons **get spared „absolutely and relatively to the […] resulting benefit in temporal, mental […] and physical aspect“ from unnecessary effort**
- Longer time to fill the questionnaire, more pauses, lower span of attention → find optimal duration of test by pilot testing

Execution of study

Test atmosphere

- Pleasant test atmosphere
- Well lit
- Quiet, well ventilated

Design and specification of test procedures

- Characteristics of older TPs are e.g. possible physical restrictions, reduced vision and hearing
- Sufficient volume
- Sufficient font size and contrast
- Unambiguous formulation of instructions

Execution of study

Individual feedback

- Another ethical aspect concerns the possibility for the TP to give own **feedback to the participation in the study**.
  - E.g. feedback round how he/she has perceived the participation in the study.
  - This increases acceptance of the study and underpins again the importance of participation of every person.
- Some TPs expect during or after the study to get **individual result feedback on own performance**

Execution of study

Collective feedback

- Collective feedback: the general result of the study is presented to the TP after project end
  - Relatively low effort
  - Maintains anonymity and
  - Increases willingness of TPs, to participate in future studies.

Data protection and confidentiality

Anonymising of collected data

- Each TP gets a random alphanumeric code assigned
- One specific document lists the codes in case a TP wants to have his/her data deleted
- This document and the declaration of consent should be kept separate from the questionnaires in a safe place

Data protection and confidentiality

- Besides anonymization of the data it has to be ensured that all data are kept ***safely stored***, meaning not accessible by third parties or non-authorised persons, ideally in a locked place
- **Anonymization** and **safe storage** also apply to psycho-physiologic data (e.g. recordings of heart rate), performed with specialised devices (e.g. ECG) and stored digitally as well as for Video-/Audio recordings.

Data protection and confidentiality

- Digital data should generally be stored on hard disks and **not on removable storage devices which easily can be lost** or can be easily accessed, e.g. USB sticks, CDs or DVDs
- Furthermore, PCs or Laptops, on which sensible data is stored, should be protected by a firewall, to prevent unwanted access from the network or via Internet.
- Encryption of the hard disk has to be considered

Data protection and confidentiality

- All researchers and assistants have to be obligated to **secrecy**
- Secrecy concerns all data collected in the study as well as all private or other information disclosed by the test persons during participation in the study

Ethics Checklist example (1/3)

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Ethik-Checkliste für die Planung und Durchführung von wissenschaftlichen Studien im Bereich neuer Technologien	Ja	Nein
Rekrutierung		
Wurde beim Rekrutieren das Ziel der Studie erläutert?	❍	❍
Wurden die Anforderungen, die eine Untersuchung mit sich bringen, offengelegt?	❍	❍
Empfang (und Verabschiedung)		
Wurden vor Ort Hinweisschilder angebracht, die die Testperson zum Untersuchungsraum leiten?	❍	❍
Wurde die Testperson angemessen und freundlich empfangen?	❍	❍
Erfolgte eine angemessene, persönliche Verabschiedung mit Dankesworten am Ende der Untersuchung?	❍	❍
Einschätzung von Nutzen und Risiken		
Wurden mögliche Risiken identifiziert?	❍	❍
Wurden alle Schritte unternommen, um die Risiken zu minimieren?	❍	❍
Rechtfertigt der Nutzen die Risiken?	❍	❍
Informed Consent		

Ethics Checklist example (2/3)

Informed Consent		
Wurde ein Informed Consent (IC) vorgegeben?	❍	❍
Beinhaltete der IC folgende Punkte:		
- Ziel der Untersuchung	❍	❍
- Dauer und Ablauf der Untersuchung	❍	❍
- Hinweis auf Freiwilligkeit der Teilnahme	❍	❍
- Hinweis auf Möglichkeit, jederzeit die Untersuchung abbrechen zu können und wenn ja, wie	❍	❍
- Erläuterung des Nutzens	❍	❍
- Hinweise auf Risiken	❍	❍
- Art der Vergütung (falls vorgesehen)	❍	❍
- Zusicherung des Datenschutzes	❍	❍
- Erläuterung des Rechts auf Löschung der Daten nach Abschluss der Untersuchung	❍	❍
- Kontaktperson für Rückfragen	❍	❍
Sind die Informationen verständlich formuliert?	❍	❍
Wurde eine Einverständniserklärung unterschrieben?	❍	❍
Untersuchungsdurchführung		

Ethics Checklist example (3/3)

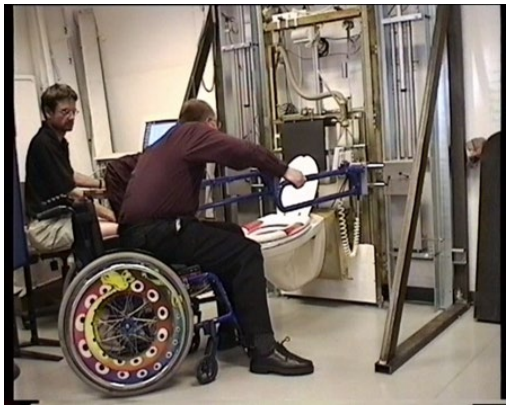
Untersuchungsdurchführung		
Wurden ökonomische Testverfahren ausgewählt?	❍	❍
Ist die Befragungs- bzw. Testdauer für die Testpersonen zumutbar?	❍	❍
Wurde die Möglichkeit, Pausen zu machen, einkalkuliert?	❍	❍
Bei älteren Testpersonen: Wurde das Layout der Fragebögen an die Bedürfnisse älterer Menschen angepasst?	❍	❍
Wurde eine angenehme Testatmosphäre geschaffen?	❍	❍
Erhielten die Testpersonen genaue Instruktionen (z.B. beim Ausfüllen von Fragebögen oder beim Hantieren mit technischen Geräten)?	❍	❍
Hatte die Testperson eine Möglichkeit, Feedback zu geben (mündlich oder schriftlich)?	❍	❍
Wurde der Testperson angeboten, Ergebnis-Feedback zu erhalten (individuell oder kollektiv)?	❍	❍
Datenschutz und Vertraulichkeit		
Wurden die Daten anonymisiert?	❍	❍
Wurden die Daten sicher aufbewahrt?	❍	❍
Wurde von allen ForscherInnen eine Verschwiegenheitserklärung unterschrieben?	❍	❍

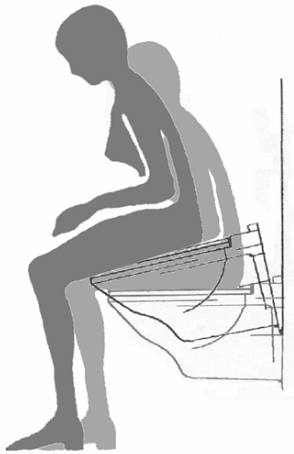
Excursus – experience with ethics in the EU project “Friendly Restroom” , 2002-2005

Friendly Restroom – intelligent & self adapting toilet

- Sensitive research area: Intimate, taboo-theme
- Research design: Laboratory environment, Audio/Video recording,
- Research staff present, more or less still „raw“ prototypes
- Step-by-step development of an ethical support/ management

- (MEESTAR not yet available)





Rauhala, M. (2011) When Ethical Guidance is Missing and Do-It-Yourself is Required: The Shaping of Ethical Peer Review and Guidance in the FRR Project

Experience in FRR opened up themes

- Opened up some themes related to ethics
- Some of them are typical for AT / AAL R&D and have to be handled systematically, to do „good research“ in the field
- Different ethical dimensions:
  - Related to technology itself
  - In the research context, e.g. in approach and choice of methods for user involvement
  - „policy level“ – as e.g. in ethical assessment in the framework programmes (FP7, Horizon 2020)

Rauhala, M. (2015) Ethics and Assistive Technology: Some lessons learned in the contexts of AT/AAL R&D and ethics assessment, STOA Workshop, Robots: Enabling the disabled or disabling the abled?, European Parliament Brussels; http://www.europarl.europa.eu/stoa/webdav/shared/2_events/workshops/2015/20150623/Marjo%20Rauhala.pdf

Ethical dimensions

- Target group may be (but not necessarily) vulnerable users
- Context of the application
- High potential to enable participation in the society, to enable independence
- But also potentially invasive character of the technologies
- Possibility to delegate decisions to complex machines
- Ethics on the program code level

Ethical dimensions

- „Inscriptions“ into technologies:
  - Images of users, their abilities, talents, preferences
  - Ideas/imaginations on „living well“
- Systems used by people influence, how they are perceived by others
  - Mobility aids
  - Hearing aids
  - Communication devices
- Technologies play an active role:
  - Can prescribe behaviour and roles to persons
  - Can restrict actions and choices
  - Recommend decisions (decision support systems)

Ethical dimensions

- The choice of methods is ethically relevant
  - The used methods determine, what users can give as input
- Approach defines the role of the users and their voice in the project
  - Example: Participatory design and qualitative approaches vs. questionnaires
    (= active co-design vs. mere data source)
- Timeplan: the design/concept can fail if the users are involved too late
- The research setting has to be appropriate and respectful

Experience/ lessons learned

- It is best to integrate ethics into research and it should be continuously present
- If not, then there is the risk of „externalisation“ of ethics, a form of outsourcing
  - Possible even with clear ethics tasks or ethics work packages
  - Ethics gets „done“, „checked off“, the persons responsible for ethics come and go with proceeding work, but have no chance to participate in the process or shape it
  - Resource question (who pays for ethics?)
- Ideally, ethics shouldn‘t be seen as additional module but as integral part of the whole job
- Anticipatory models are not very helpful, because unexpected ethical questions can come up at any time in a research project

Ethics manager in the project team

- Embedded member of the developer team
- Translates ethical requirements into hands-on instructions for the team
- Contributes to establishing a good work practice
- Special focus: activities for involvement of users
  - (most important aspect of work from our view of ethics)
  - Goals: safe research settings for test participants, confident and safe participants
- Advantages for the team
  - Dedicated team member, which deals with research ethics in daily work practice
  - Frequent regular reviews: are there new themes coming up in our work?
  - Continuous, ad-hoc support for ethical questions

Summary

- Awareness of ethical dimensions in AT / AAL is growing, but more could be done
  - Mostly it is not lack of interest, but lack of time
- Funding organisations, user and research community are in a central position
- They have to be encouraged to actively contribute to shaping research guidelines and formal assessment processes, so that the requirements of AT / AAL research is covered in a better way.

Legal framework conditions

Legal framework conditions

- Application of Assistive Systems (AS) spans different legal areas:
  - Fundamental rights
  - Simple legal ruling
  - Legal ethics aspects
- Different according to environment
  - Research project
  - Private area
  - Care home / sheltered housing
- User
  - Health state
  - Legal state

Legal framework conditions

- In fundamental rights area mostly affected:
  - Fundamental right on privacy
  - Fundamental right on data protection
  - Fundamental right on personal freedom
- In simple legal regulations:
  - Liability law (civil law fault-based liability, product liability, but also criminal sanctions)
  - Warranty rights
  - Data protection regulation
  - Care home/involuntary commitment law
  - Legal guardianship
  - ….

Legal framework conditions

- Legal ethics aspects play an important role outside the private use
  - (e.g. in care institutions and in research projects)
- To be observed particularly:
  - Maintain freedom of decision of users
  - Integration of users e.g. in recruiting
  - Exit strategies;
  - Handling of user data
  - Avoid legal „twilight areas“

Distinction: Medical products

- Medical products are objects, used for therapeutic or diagnostic purposes which are no pharmaceuticals
  - Instruments, apparatus, substances, …
  - E.g. plaster, blood pressure meter, MRI scanner
- Development, production and selling of medical products are governed by special legal and standardisation rules (Medical Device Directive = MDD / Medizinproduktegesetz = MPG)
- *AAL solutions can be* medical products, *but do not need to*
- **Distinction is by purpose of the AAL solution!**

Legal framework for medical products

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Legal framework Austria MPG BGBl. I Nr. 59/2018 (Regulation (EU) 2017/745 entering into force 2020):

- Definition of purpose in § 2
- Fulfilment of „basic requirements“ according to § 8 MPG - RL 93/42 EWG
- Usage of harmonised standards as proof of fulfilment „**Basic requirements**“
- **Clinical trial/assessment** § 38
- Fundamental: assessment of **benefit-/risk ratio**
- Machines RL 2006/42/EG (if „Machine“)
- Conformity assessment according to BGBl. II Nr. 144/2009 / CE marking according to § 28 MPG

(exemplary excerpts)

When do AAL systems become medical products?

- Systems for support in the household, social interaction, communication
  - Usually not
- Systems for medical application (tele-medicine systems, patient files, …)
  - Usually always
- Overlap areas
  - E.g. system for activity detection / - monitoring
  - E.g. user interfaces / base stations with medical sub-functions
  - **Intended purpose decides** – inform user!

Data protection: fundamentals

- Right on informational self-determination
  - Derived from general personal rights and established in constitution!
- Additional to general data protection requirements in case of data especially worth being protected (e.g. health records)
- Professional obligations on protection (e.g. medical obligation to secrecy, social secret, …)

<u>New GDPR 2016/679 entered into force in 2018</u>!

Data protection: fundamentals

- Legitimacy and consent
- Earmarking, necessity and data economy
- Transparency and rights of affected users
- Data safety
- Audit

- Detailed discussion following

Seven golden rules of data protection

1 Legitimacy

Every processing of data needs a legal foundation in form of a legal base, a contract, a company regulation or consent of the person affected

2 Consent

Consent is only valid, if the affected person has been sufficiently informed and the consent is given voluntarily

3 Earmarking

Person related data must only be used for the purpose for which they were collected

Quelle: Johann Bizer, Die Sieben Goldenen Regeln des Datenschutzes. In: DuD 2007, 350-356.

Seven golden rules of data protection

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4 Necessity

Data processing has to be restricted to the necessary scope for the purpose of its collection

5 Transparency

Collection and processing of data has to be transparent to the affected person

6 Data safety

Data protection is only guaranteed if person related data is processed in a safe way

7 Audit

Data processing has to be internally and externally auditable

Johann Bizer: Die Sieben Goldenen Regeln des Datenschutzes. In: DuD 2007, 350-356.

Example: Activity monitoring systems

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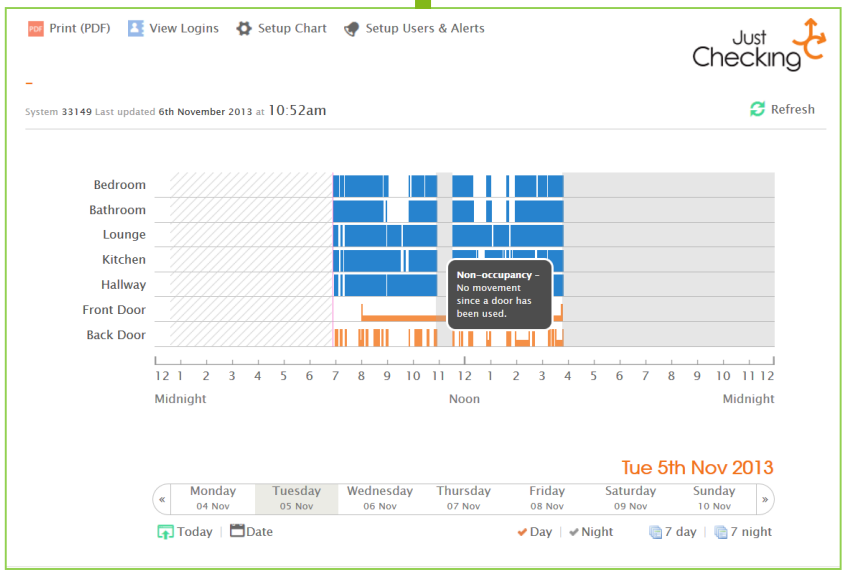
Example 1: Just Checking



Example 2: LOC.SENS

Visualisation of data: example on the left shows many more details

Anonymisation and pseudonymisation

- Data protection rules apply to person related data
- They do not apply to *anonymised* or *pseudonymised* data
  - Anonymisation: association with person deleted
  - Pseudonymisation: association replaced by key and much more difficult to find correspondence

Problems with consent

- Consent
  - Has to be voluntary
    - Alternatives? Consequences?
    - Prohibited to be coupled to reward
  - Limited ability to reason
    - Understanding? Foreseeing consequences?
    - Obligation for thorough information
  - Revocability
- Limits in practical implementation
  - Not yet solved today
    - (e.g. transparency vs simplicity)
    - Systems should be unobtrusive, work not noticeably in the background <-> transparency?

Commissioned data processing

- Responsible entity for data protection is who is collecting, using, processing or commissioning processing of person related data
- Commissioning of data processing
  - All kinds of IT outsourcing, e.g. backup, Email provider, Web software, cloud-based solutions, …
  - Special requirements (consent, contractual regulations, ..)

Conflict of goals: Maintaining privacy and safety

Often heard: The **“Wash me but do not make me wet!!“** attitude**:**

Conflict between hoped-for help and feared side effects.

During an introduction of an AAL systems to a group of social workers and caregivers the following statements were given:

- „We welcome this technology as a kind of guardian angel for the home”.
- „But we categorically decline application of all kinds of sensors “.

Protection of privacy

In order to detect dangerous deviations from usual procedures ...
... to be able to provide help (detect wishes and intentions) ....

... a lot of data has to be collected.
... a lot of personal data about the behaviour of the inhabitants must be collected and processed.

Protection of privacy – many questions

- What happens with the data?
- Where is the data stored?
- Which conclusions are drawn from it?
- Where does data get forwarded to?
- Who has access to the data?
- When and how the data gets anonymised?
- How long is the data stored?
- When does the data get deleted?

Protection of privacy

To all these questions honest and clear answers must be provided.
For these questions also technical solutions have to be found such that they will pass examination by ...

- an ethics commission ...
- a data protection commission ...
- the law …
- and of course the user (!)

Privacy By Design – The 7 Foundational Principles

1. Proactive not Reactive; Preventative not Remedial
2. Privacy as the Default Setting
3. Privacy Embedded into Design /privacy in design
4. Full Functionality – Positive-Sum, not Zero-Sum
5. End-to-End Security – Full Lifecycle Protection
6. Visibility and Transparency – Keep it Open
7. Respect for User Privacy – Keep it User-Centric

Ann Cavoukian (2009, revised 2011)
https://www.ipc.on.ca/wp-content/uploads/Resources/7foundationalprinciples.pdf

Insurance for damage and harm

While systems of course have to comply with technical standards and product safety (for which insurance can be found), the **concurrence of vulnerable persons with often experimental technology** is new ground, therefore it is hard or impossible to get coverage by affordable insurance, because risks are hard to estimate.

Especially in the area of research coverage against involuntary damage from testing novel AAL systems, mainly for the users, should be sought.

Safeguarding against damage

Additional to a recommended insurance against involuntary damage by research work it is of utmost importance, **to first extensively test applied technology in the laboratory and, together with experts, review its practicability – in a traceable way**, before an application in real environment with real users is envisaged.

Only if after thorough checks neither endangerment nor burden of the users has to be expected, a real deployment should be planned!

Informed Consent – legal aspects

As stated an „Informed Consent“ is required from ethical viewpoint

From legal viewpoint there additionally is the question who, after all, can consent on his/her own.

This especially concerns projects in the area of persons with dementia. Even if the project wants to support the users and can plausibly argue this (given benefit, prevention of damage considered, etc.), the legal aspects of ability to consent has to be clarified.

Intervening into fundamental rights & ability to consent

- Deployment of AAL applications normally is associated with (grave) infringements of fundamental rights. Affected are
  - Privacy,
  - Freedom of movement and
  - Right on data protection
  - If users are prevented from leaving some area by electronic means this is a form of restriction of freedom.

    (relevant e.g. in case of dementia)

- Such interventions can be justified only by consent of the affected person, whose rights are infringed

Intervening into fundamental rights & ability to consent

- This implies appropriate information about purpose, way of working and possible risks of the system.
- Legally valid consenting can only a person which is able to reason and judicious.
- For persons lacking ability to consent, the approval of a proxy (custodian or attorney) is needed.
- User trials with AAL systems for research purposes generally are only allowed with users able to consent.

Dilemma

This poses a difficult problem for projects involving people with dementia, nevertheless a research call of the EU has been announced on this topic.

Maybe institutions, warranting legal framework boundaries, can allow trials with appropriately verified devices by their internal (or national) commissions, so that experts can collect data for research projects.

This has to be considered in the design of the research projects.

Summary

- Important legal framework conditions are
  - Fundamental right on informational self-determination and derived data protection regulations
  - (for some applications) the medical product regulations
- Concrete legal procedures and ethical aspects are widely unclear because of the novelty of the topic

Checklist of legal requirements (1)

- Is warranted that trigger levels of the system can be adjusted **individually at any time**?
- Is provided, that such **adaptation** (which also comprises **deactivation** of the system) can be **done without delay** on demand of the user?
- Is guaranteed, that effective and state-of-the-art **data protection** and audit measures prevent unauthorised third parties from access to and getting knowledge of health related data?
- Is the identity of persons verified to whom health data is forwarded?

Checklist of legal requirements (2)

- Is **data forwarded** to outside the (care) institution? In this case there might be additional data protection measures to be considered.
- Are the test partners and all their employees **aware**, that the system **affects fundamental rights** (privacy, freedom to move, data protection)?
- Are the affected persons (inhabitants) **informed** about the fundamental way of working of the system and about the purpose and the connected risks? Have they been expressly pointed to the implied influence on their rights?
- Has the **consent** of the affected persons to these infringements been achieved?

Checklist of legal requirements (3)

- Was the **consent** of the affected persons to the processing of their **health related data** given? Have the affected persons been informed that they can revoke consent at any time?
- Have the affected persons been **informed** that the most important parameters of the system can be individually adjusted at any time?
- Was the **ability to reason and power of judgement** verified?
- Is there a **data protection and data safety concept**?
- Has the application been registered with the **data protection authority**?

Literature:

Bachinger/Fuchs (2013), Rechtliche Herausforderungen des Technikeinsatzes in der Altenpflege – Eine rechtssoziologische Perspektive auf Ambient Assisted Living, SWS-Rundschau 53, 73-94.

Ganner/Schmidt (2014), Ambient Assisted Living – Rechtliche Aspekte der Anwendung neuer Technologien zur Unterstützung pflegebedürftiger Menschen, Interdisziplinäre Zeitschrift für Familienrecht 9, 118.

Economy

Economical considerations, Problem of argumentation

Many problems, big chances

- The market potential of AAL is undisputed.
- This is shown by numerous studies.
- Because of the demographic change a growing, profitable target group is developing – from the active 50+ generation to old age people.

Many problems, big chances

- AAL is topic of numerous national and international research projects since ca. 10 years.

- In order to develop AAL solutions in an successful economic way, **innovative, modular business models** are needed.

Many problems, big chances, some fails

Unfortunately there already were some dropouts by insolvency or stopped production in Austria, e.g.:

- HomeButler (comprehensive Smart-Home solution with services, safety components and communication)
- iResidence (fall detection and tele-medicine)
- James (door opener for retrofitting)

Main reasons:

- Market does not trigger early enough
- Acceptance problems (price, design, stigmatisation)

Economy – the potential

Viele Probleme aber auch große Chancen

Deutsches Ärzteblatt 2009

Deutsches Ärzteblatt

Für die Volkswirtschaft geht man von einem Einsparpotenzial von rund **drei Milliarden Euro** aus, wenn nur etwa ein Zehntel der älteren Menschen mithilfe von Assistenzsystemen **ein Jahr länger** als bisher im eigenen Haushalt verbleiben könnte …

Dtsch Ärztebl 2009; 106(7)

(estimated potential of 3 milliard € if assistive systems can make people stay one year longer in their homes)

Viele Probleme aber auch große Chancen

Saarbrücker Zeitung, 13. Nov. 2014

Mit moderner Technik den Alltag zu Hause erleichtern

Netzwerk will Senioren mit Geräten und Dienstleistungen unterstützen – Service-Büro soll in Dudweiler eingerichtet werden

(…) Laut einer aktuellen Studie könnten nämlich mehr als fünf Milliarden Euro jährlich eingespart werden, wenn von 750.000 Heimbewohnern ein Drittel zu Hause gepflegt werden könnte.

(5 milliard € could be saved if 1/3 of inhabitants of care homes could be cared for at home)

First guesses

Starting from a simple calculation based on German suggestions a „naive calculation“ for Austria is tried:

- Coarse estimation, without claiming accuracy
- All values are based on 2012 data
- All values are pessimistically rounded off
- For nursing only the minimum hours per level are calculated

Source: Prof. W. Zagler, 2014

Current financing

Attendance allowance 2012

Stufe Level	Personen persons	€ pro Monat € per month	€ pro Jahr € per year	Summe Sum
1	99.000	154	1.848	182.952.000
2	131.800	284	3.408	449.174.400
3	76.400	442	5.304	405.225.600
4	62.500	664	7.968	498.000.000
5	43.800	902	10.824	474.091.200
6	18.000	1.242	14.904	268.272.000
7	9.000	1.656	19.872	178.848.000
	440.500		Total 2012 >	**2.456.563.200**

First estimation

For a first coarse AAL scenario the following assumptions are made:

50% of all receivers of attendance allowance (this would be 215750 persons) get some amount xy for financing AAL technology.

Because of this, persons who freshly would get into the first level or would proceed to the next higher level do this with a **delay of one year**.

For 2012 we such get the following calculation:

Calculation 1

VC&HCT

Pflegegeld - Szenario: 50% bleiben 1 Stufe tiefer

Allowance Scenario: 50% stay one level lower

Stufe	Personen	Pfl.Geld/M	Pfl.Geld/Jahr	Summe
1	115.400	154	1.848	213.259.200
2	104.100	284	3.408	354.772.800
3	69.450	442	5.304	368.362.800
4	53.150	664	7.968	423.499.200
5	30.900	902	10.824	334.461.600
6	13.500	1.242	14.904	201.204.000
7	4.500	1.656	19.872	89.424.000
	391.000		**Total 2012 >**	**1.984.983.600**

Balance of first estimation

The number of receivers of allowances would shrink from
440500 to
391000 , which means
49500 persons less
The spending of allowances would shrink from
2.456 Mrd. € to
1.985 Mrd. €, which means they are
471.6 Mio. € less

What does/can this mean?

The question which cannot be answered precisely today, without big studies and trials:
How much should be the amount xy for AAL-investments, to trigger this effect?

For this scenario a realistic amount of € 2000,- per person (resp. household) is estimated.
2000,- € for …
215750 flats to be equipped with AAL result in 431.5 Mio. € total costs for 2012.

Total balance

If one calculates the savings of
471.6 Mio. €, minus
- 431.5 Mio. € costs for AAL
= 40.1 Mio. € remain as profit.

Which means an interest rate of 9.3%

Second estimation

A second scenario uses the real value (national economic costs) of care/attendance allowance:

- By the care allowance only a (small) part of the real costs is covered.
- e.g. in level 1 this are 2,57 € per hour (2012).
- The rates calculated service organisations are between 35,- and 45.- €.
  - The true monetary costs of informal care (e.g. by relatives) are lower. We still will use the full amounts to cater for loss of income, opportunity costs etc.
- If we only calculate the minimum hours for every care level …

Real care costs (on national level)

Stufe	Min. Std.	EUR/h	Wert/Mo	Wert/Jahr	Gesamte Stufe
1	60	35	2.100	25.200	2.494.800.000
2	85	35	2.975	35.700	4.705.260.000
3	120	35	4.200	50.400	3.850.560.000
4	160	35	5.600	67.200	4.200.000.000
5	180	40	7.200	86.400	3.784.320.000
6	180	40	7.200	86.400	1.555.200.000
7	180	45	8.100	97.200	874.800.000
					21.464.940.000

Assumptions for 2nd estimation

For the 2nd scenario again the following assumptions are made:

- 50% of all receivers of attendance allowance (this would be 215.750 persons) get some amount xy for financing AAL technology.
  Because of this, persons who freshly would get into the first level or would proceed to the next higher level do this with a **delay of one year**.

For 2012 we such get the following calculation:

Calculation 2

Real costs scenario: 50% stay 1 level lower

Stufe	Min. Std.	EUR/h	Wert/Mo	Wert/Jahr	Gesamte Stufe
1	60	35	2.100	25.200	2.908.080.000
2	85	35	2.975	35.700	3.716.370.000
3	120	35	4.200	50.400	3.500.280.000
4	160	35	5.600	67.200	3.571.680.000
5	180	40	7.200	86.400	2.669.760.000
6	180	40	7.200	86.400	1.166.400.000
7	180	45	8.100	97.200	437.400.000
					17.969.970.000

Balance of 2nd estimation

The number of allowance receivers would again shrink 440.500 to
391.000 , that is
49.500 persons less
The value of care provision would shrink (independent if professional or informal) from
21,465 Mrd. € to
17,970 Mrd. € , that is
3,495 Mrd. € less.

Assumption of extra allowance

For this scenario we can allow an AAL investment of € 5000,- per person (resp. household).
5000,- € for …
215750 flats to be equipped with AAL
1.078 Mrd. € total costs for 2012.

The investments per household could be done by some „Investment-cheque“ (Senior cheque), and such be beneficial for the economy.

Total balance

The calculation for this estimations would lead to a „national economic“ profit of …

3.495 Mrd. € savings, minus the

- 1.078 Mrd. € costs for AAL

= 2.416 Mrd. € resulting profit.

This is an interest rate of 224 % !!

Source: Prof. Wolfgang Zagler, 2014

Other considerations

Costs for 24/7 care (simple support, prepare meals, support in grooming, housework, not qualified nursing) on 2018 base are at least 2000-2500€ per month (plus provisions). (Total allowance for care level 5 – more than 180h/month - plus extra funding for 24/7 care in Austria are ca. 1500€ per month.)

If an **AAL solution together with short support per day** e.g. 2 hours (at ca. 25€/h = 60h or 1500€/month) can provide the same quality of support and safety, this could be cheaper in the long term and provide more privacy.

… big chances

These calculations are coarse simplifications and can only depict the scale.
The fit surprisingly well with values calculated in Germany.

It would „just“ need companies to risk this by using the research funding available.

AAL business models

Definitions

- **AAL System**: technical system (product or networked system) for an AAL application (e.g. fall sensor, Smartphone application, …)
- **AAL Service**: service on base of an AAL system, fulfilling a user need (e.g. senior alarm service with callback and emergency service)
- **AAL solution**: AAL system configured (and maybe adapted) according to individual requirements

AAL System vs. AAL Service

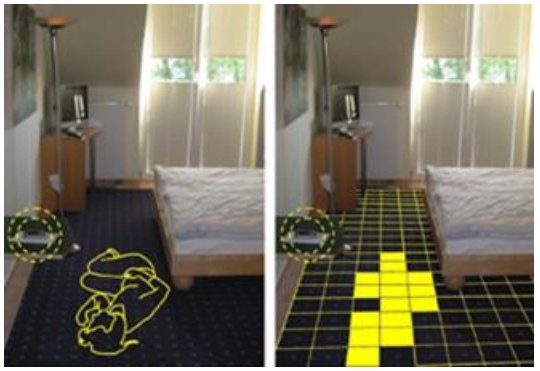
Device vs. Service

Medikamenten-Dispenser?

Disease-Management Service?

Internet-Fernseher?

Kontact-Service?



Fall-Sensor?

Emergency-Service?

Possible AAL services

- supervision, consulting and coordination of support offers
- Installation, maintenance and training
- Every day support (Mobility service, household support)
- Safety and emergency services
- Technology based ambulant care

What are services?

- What designates services vs. products?
  - Services cannot be product in advance and/or stored – delivery and consumption usually happen at the same time
  - The client usually cannot check the quality of a service before purchase/ signing up
- The linkage of services and products is possible

What are business models?

- Business models rest on 3 pillars:
  - Value proposition: **What** does the client benefit from the business?
  - Architecture of the added value: **How** is the business accomplished? (supplier, service provision, market access, …)
  - Profit model: Whereby the money is earned (**profit**)?

Target groups for AAL systems and services

- Directly profiting clients (primary end-user)
  - Improvement of QoL by AAL
  - Seniors, care recipients, sick/disabled people
- Indirectly profiting clients (secondary end-user)
  - Care persons, profit by gaining QoL or resources (time, …)
  - Relatives, ambulant and stationary care services, doctors, hospitals, employers of care persons, …
- Additional target groups (tertiary end-user)
  - Insurances, municipalities/communities, manufacturers, …

Primary end-user: willingness to pay …

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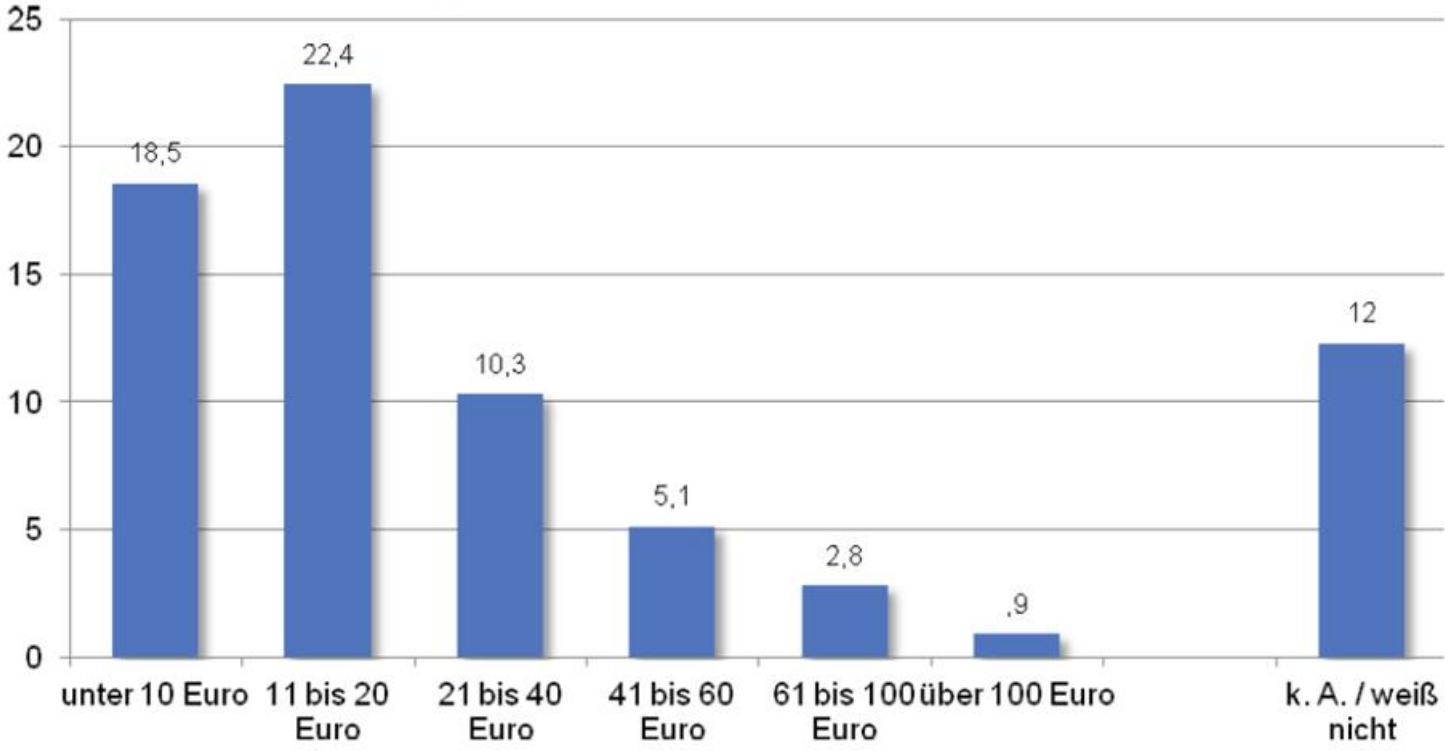
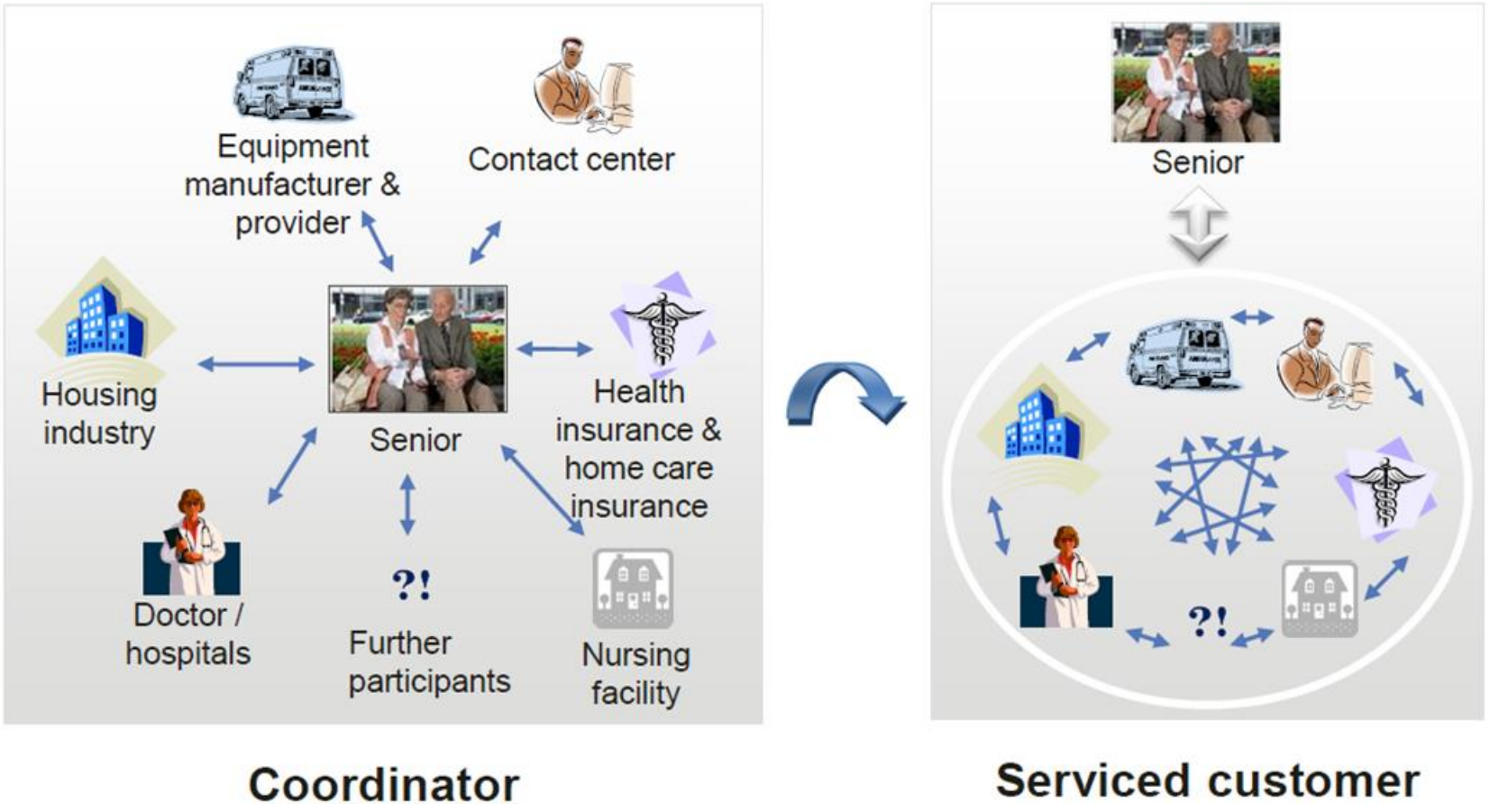
Acceptable payments per month

Abbildung 4: Monatliche Zahlungsbereitschaft privater Haushalte für altersgerechte Assistenzsysteme mit einer 50-Jährigen oder älteren Bezugsperson in Niedersachsen in Prozent



Fachinger et al. 2012

Service models



Summary

- AAL-Systems often require innovative business models for a solid implementation, also across boundaries of classic business sectors
- Main components of business are value proposition, architecture of the added value and profit model
- Typical AAL business models are based on e.g. orchestration (housing industry, care provider, community, IT provider) or customer loyalty effects

Study: business model development for the AAL market in AT

VC&HCT

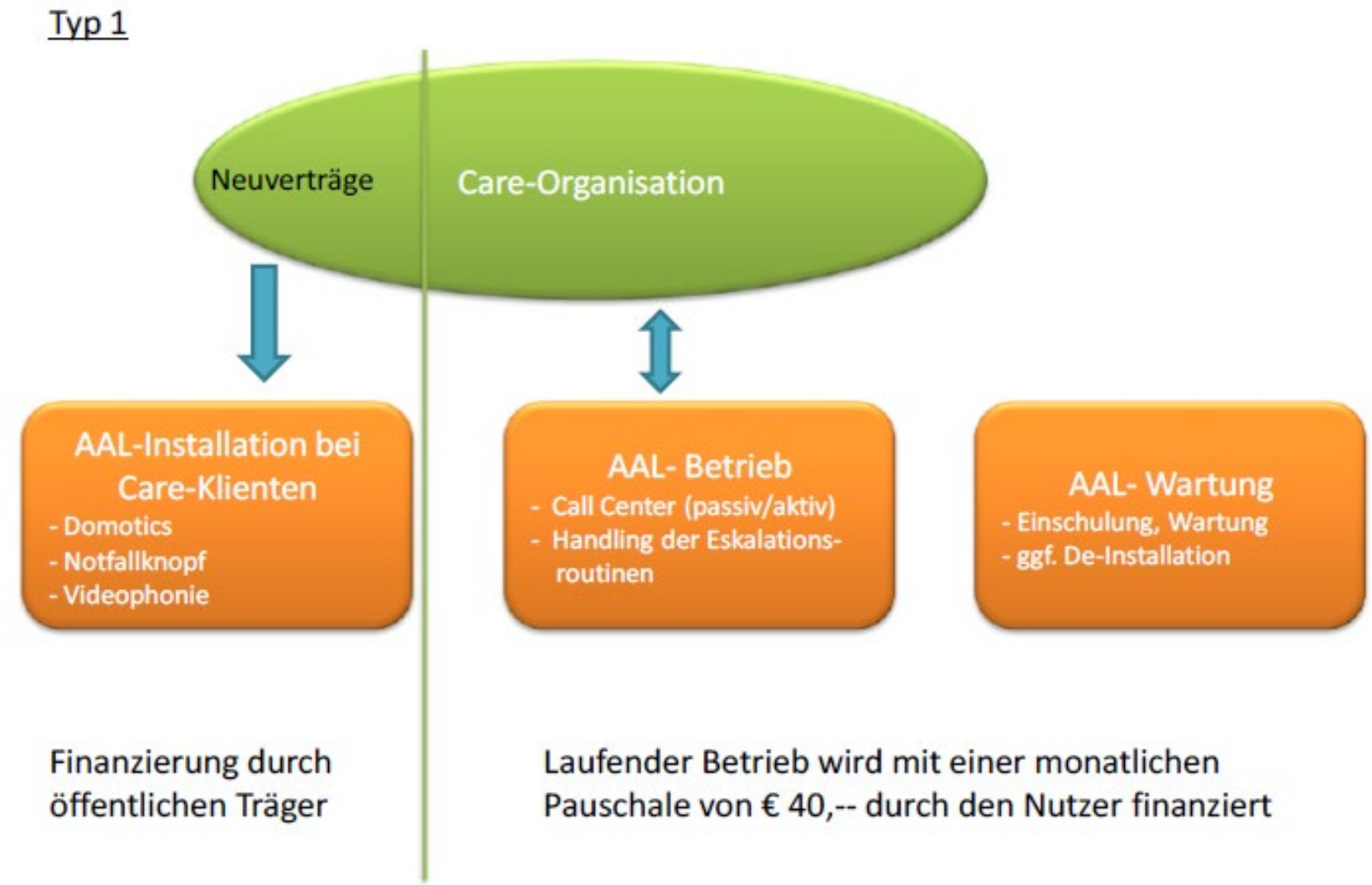
- Market for AAL-Products and services existing
- DE: sales potential ca. 5-87 (!) Mrd. Euro
- AT: sales potential ca. 840 Mio. Euro und yearly demand potential ca. 350 Mio. Euro
- Marketing of AAL applications in AT in the beginning
- Discussed is
  - How and from whom AAL should be financed
  - What an end user can or shall get for some maximum monthly amount of 40 Euro – which is understood as threshold value for customer acceptance

Andreas Kumpf: Studie zur Geschäftsmodellentwicklung für den AAL-Markt unter Berücksichtigung der österreichischen Rahmenbedingungen, benefit, 2013

Geschätztes Markt- und Nachfragepotenzial für AAL in AT

Quelle: Kumpf 2013

Business Model Type 1



Quelle: Kumpf 2013

Business model development

- **Model type 1**:
  - AAL solution: Domotics like smoke detectors, fall sensors etc., emergency button, tele-medicine applications and video-telephony for care and enabling more social interactions,
    2.800 €
  - Cooperation small enterprise with care organisation
  - Start-up financing (2.800 €) by public sector
  - monthly 40 € by public sector or user privately
- **Model type 2**:
  - AAL solution as above
  - Big enterprise without care organisation
  - 100% financing by user

Business model development

- **Model type 3**:
  - Here the focus is on health promotion and comfort; financing here also is by user

- Results:
  - Models 2 + 3 do not appear promising
  - Analysis of model 1 shows, that exploitation of the AAL market with a demand of 354 Million Euro comes close to feasibility
- Next necessary steps:
  - Persuasion and involvement of important stakeholders

It is hard to prove

The assumption, AAL solutions could offer better QoL at the same costs, still has not been proven in real application.
There is too few offers, buyers and experience.

Test regions in Austria are an approach to further practical application and evaluation of AAL solutions by research funding (50…100 users, 1..1,5 years of testing).

modulAAr West-AAL ZentrAAL RegionAAL
Smart VitAALity WAALTeR fit4AAL

Overview on AAL Austria: http://www.aal.at/pilotregionen-3/

Test regions Smart Home –Smart Service

- In rural area since 2012
  - ModuLAAr: Burgenland, 50 betreubare Wohnungen, 60+J, max. Pflegestufe 4
    - http://www.modulaar.at/
    - http://www.aal.at/pilotregionen-3/modulaar/
  - West-AAL: Vorarlberg & Tirol, 74 Wohneinheiten, 2 Musterwohnungen
    - http://www.west-aal.at/
    - http://www.aal.at/pilotregionen-3/west-aal/
  - ZentrAAL: Salzburg, > 60 Haushalte, 60-79J, max. Pflegestufe 1
    - http://www.zentraal.at/
    - http://www.aal.at/pilotregionen-3/zentraal/

Testregionen Smart Home –Smart Service

- In urban area since 2015
  - RegionAAL: Graz + Umland, 100 Testhaushalte
    - http://www.regionaal.at/
    - http://www.aal.at/pilotregionen-3/regionaal/
  - WAALTeR: Wien, 83 Testhaushalte
    - http://www.waalter.wien/
    - http://www.aal.at/pilotregionen-3/waalter/
  - Smart VitAALity, Kärnten, Klagenfurt – Villach – Ferlach, 100 SeniorInnen-Haushalte
    - http://www.smart-vitaality.at/
    - http://www.aal.at/pilotregionen-3/vitaality/
  - FIT4AAL, Wien, Stadt und Land Salzburg, 100 Haushalte der Generation „Baby-Boomer“
    - http://www.aal.at/fit4aal/

Conclusions

- AT and AAL have an **increasing market potential** based on the demographic change

- There is need even for simple starter products – but first **important questions** on suitable **business models,** fitting **forms of financing** and good **acceptance** have to be answered.

Ethics – Assistive Systems

Outlook, following parts:

- VI Requirements Analysis and Evaluation

Literature

Videos - Ethics

Uninvited Guests
https://vimeo.com/128873380
Uninvited Guests is a short film that explores the frictions between an elderly man and his smart home. Thomas, aged 70, lives on his own after his wife died last year. His children send him smart devices to track and monitor his diet, health and sleep from a distance. But Thomas has always been fiercely independent, happy to live in an organised mess. He struggles with the order and rules imposed on him by the objects that are meant to make his life easier. In a world where 'smart objects' will increasingly be used to provide care at a distance, how will we live with these uninvited guests?
This film was created by Superflux Lab for the ThingTank project. For further information visit:
http://superflux.in/index.php/work/uninvited-guests/#

Literature - Ethics

Munteanu, C. et al (2015) “Situational Ethics: Re-thinking Approaches to Formal Ethics Requirements for Human-Computer Interaction. CHI 2015.

Rauhala, M. (2011). „When Ethical Guidance is Missing and Do-It-Yourself is Required: The Shaping of Ethical Peer Review and Guidance in the FRR Project. In: J.F.M. Molenbroek, J. Manta and R. de Bruin (Eds.): A Friendly Rest Room: Developing Toilets of the Future for Disabled and Elderly People. Amsterdam: IOS Press, pp. 49-59.

Silvers, A. (2010) “Better Than New! Ethics for Assistive Technologists.“ In: Meeko Mitsuko.K. Oishi, Ian M. Mitchell and H. F. Machiel Van der Loos (Eds.). Design and Use of Assistive Technology. New York: Springer, pp. 3-15.

Rauhala, M. (2015). Ethics and Assistive Technology: Some lessons learned in the contexts of AT/AAL R&D and ethics assessment, STOA workshop, European Parliament, available http://www.europarl.europa.eu/stoa/webdav/shared/2_events/workshops/2015/20150623/Marjo%20Rauhala.pdf

Arne Manzeschke, Karsten Weber, Elisabeth Rother und Heiner Fangerau (2013) Ergebnisse der Studie „Ethische Fragen im Bereich Altersgerechter Assistenzsysteme“, Berlin (VDI/VDE) 2013

Arne Manzeschke (2015) Angewandte Ethik organisieren: MEESTAR – ein Modell zur ethischen Deliberation in soziotechnischen Arrangements. In: Matthias Maring (Hrsg.): Vom Praktischwerden der Ethik in interdisziplinärer Sicht: Ansätze und Beispiele der Institutionalisierung, Konkretisierung und Implementierung der Ethik, Karlsruhe (KIT Scientific Publishing) 2015, S. 315–330 (Schriftenreihe des Zentrums für Technik- und Wirtschaftsethik Bd. 7).

W. L. Zagler, P. Panek, M. Rauhala (2008) Ambient Assisted Living Systems - The Conflicts between Technology, Acceptance, Ethics and Privacy, Dagstuhl Seminar Proceedings 07462, Assisted Living Systems - Models, Architectures and Engineering Approaches http://drops.dagstuhl.de/opus/volltexte/2008/1454

Literature – Ethiks (continued)

Ulrich H. J. Körtner (2011) Lebensräume und Lebensträume aus ethischer Perspektive, in: M. Horneber/H. Schoenauer (Hg.), Lebensräume – Lebensträume. Innovative Konzepte und Dienstleistungen für besondere Lebenssituationen (Dynamisch Leben gestalten, Bd. 2), Stuttgart 2011, S. 74-87, Auszug auch hier: https://www.diakonieneuendettelsau.de/fileadmin/images/Diakonie_Neuendettelsau/%C3%96kumenisches_Geistl._Zentrum/Diakonie___Spiritualit%C3%A4t/DiakonieSpiritualit%C3%A4t_2-11_web.pdf

Anna Felnhofer, Oswald D. Kothgassner, Nathalie Hauk, Elisabeth Kastenhofer, Ilse Kryspin-Exner (2013) Ethik-Checkliste zur Evaluation ethischer Aspekte von Studien im Bereich neuer Technologien unter Berücksichtigung älterer Menschen, online verfügbar auf https://www.ffg.at/sites/default/files/allgemeine_downloads/thematische%20programme/programmdokumente/ethik-checkliste_endred_autoren.pdf

Kricheldorff, Cornelia; König, Peter; Klobucnik, Teresa, Schmidt, Stefanie, Tonello, Lucia (2017): Ethische Guidelines für Forschung und Entwicklung im Bereich Alter und Technik Grundlagen für die Arbeit in Ethikkommissionen, Pabst Science Publishers, Lengerich

Oishi, Meeko Mitsuko K., Mitchell, Ian M., Van der Loos, H. F. Machiel (Eds.) Design and Use of Assistive Technology - Social, Technical, Ethical, and Economic Challenges, Springer, 2010

Literature – Law

Bachinger/Fuchs (2013), Rechtliche Herausforderungen des Technikeinsatzes in der Altenpflege – Eine rechtssoziologische Perspektive auf Ambient Assisted Living, SWS-Rundschau 53, 73-94.

Ganner/Schmidt (2014), Ambient Assisted Living – Rechtliche Aspekte der Anwendung neuer Technologien zur Unterstützung pflegebedürftiger Menschen, Interdisziplinäre Zeitschrift für Familienrecht 9, 118.

Literature - Economy

Peter Georgieff (2008) Ambient Assisted Living - Marktpotenziale IT-unterstützter Pflege für ein selbstbestimmtes Altern, FAZIT-Schriftenreihe, Bd. 17, MFG Stiftung Baden-Württemberg, verfügbar: http://www.fazit-forschung.de/ambient.html

Andreas Kumpf: Studie zur Geschäftsmodellentwicklung für den AAL-Markt unter Berücksichtigung der österreichischen Rahmenbedingungen, benefit, 2013, verfügbar auf: https://www.ffg.at/content/benefit-unterlagen-und-pr-sentationen

ICT and Ageing - European Study on Users, Markets and Technologies, 2010, available on http://ec.europa.eu/information_society/newsroom/cf/dae/document.cfm?doc_id=952

AAL in der Praxis. Ein Leitfaden zur Implementierung von AAL-Testregionen und zur AAL-Effizienzmessung, benefit, integrAAL Leitfaden, 2014, verfügbar auf: https://www.ffg.at/content/benefit-unterlagen-und-pr-sentationen

Ökonomische Potenziale altersgerechter Assistenzsysteme , Ergebnisse der „Studie zu Ökonomischen Potenzialen und neuartigen Geschäftsmodellen im Bereich Altersgerechte Assistenzsysteme“, 2012, Universität Vechta, verfügbar auf http://www.mtidw.de/grundsatzfragen/begleitforschung/dokumente/oekonomische-potenziale-und-neuartige-geschaeftsmodelle-im-bereich-altersgerechter-assistenzsysteme-2

Michael C. Balasch (2010) Business Approaches in the German AAL Project SmartSenior – Intelligent services for senior citizens. http://www.smart-senior.de/pdf/pub/WDA_Forum_2010_Business-Approaches-of-SmartSenior_Balasch_100827.pdf

Zukunftschance Demographie – 2018/3 – Monika Riedel und Helmut Hofer
http://www.aal.at/wp-content/uploads/2016/02/Studie-Zukunft-Demograpfie20180316.pdf

EvAALuation – Indikatorenhandbuch für die Messung von Wirkungen und Effizienzsteigerungen – 2017/05 – Julia Himmelsbach, Jan Bobeth, Markus Garschall, Birgit Aigner-Walder, Johannes Oberzaucher, Albert Luger, Andreas Diensthuber, Martin Lichtenberger, Lea Schüßler, Stefan Schwarz
http://www.aal.at/wp-content/uploads/2016/02/EvAALuationHandbuch.pdf

Assistive Systeme - Abkürzung

VC&HCT

AAL	Active and Assisted Living (Ambient Assisted Living)
ADL	Activity of Daily Living
AS	Assistive System
AT	Assistive Technology
HCI	Human Computer Interaction
IC	Informed Consent
ICT	Information and Communication Technology
MDD	Medical Device Directive
MPG	Medizinproduktegesetz
QoL	Quality of Life
TL	Test Leader
TP	Test Person

Annex

Informed Consent (EU Directive on clinical trials (2001/20/EC)

- A (test-) person is giving "Informed Consent" if his/her decision to take part in a trial is ...
- ... given freely after that person is informed of the nature, significance, implications and risks of the trial and either:
- is evidenced in writing, dated and signed, or otherwise marked, by that person so as to indicate his/her consent, or
- if the person is unable to sign or to mark a document, his/her consent is given orally in the presence of at least one witness and recorded in writing.

Informed Consent conditions

- The subject has had an interview with the investigator, in which s/he has been given the opportunity to understand the objectives, risks and inconveniences of the trial and the conditions under which it is to be conducted.
- The subject has been informed of his/her right to withdraw from the trial at any time.
- The subject has given his/her informed consent to taking part in the trial.
- The subject may, without being subject to any resulting detriment, withdraw from the trial at any time.
- The subject has been provided with a contact point where he/she may obtain further information about the trial.

Ethical aspects of projects

VC&HCT

	Research on Humans	YES	Page
*	Does the proposed research involve children?		
*	Does the proposed research involve patients?		
*	Does the proposed research involve persons not able to give consent?		
*	Does the proposed research involve adult healthy volunteers?		
	Does the proposed research involve Human genetic material?		
	Does the proposed research involve Human biological samples?		
	Does the proposed research involve Human data collection?		
	I CONFIRM THAT NONE OF THE ABOVE ISSUES APPLY TO MY PROPOSAL		

Ethical aspects of projects

	Privacy	YES	Page
	Does the proposed research involve processing of genetic information or personal data (e.g. health, sexual lifestyle, ethnicity, political opinion, religious or philosophical conviction)?		
	Does the proposed research involve tracking the location or observation of people?		

	Dual Use	YES	Page
	Research having direct military use		
	Research having the potential for terrorist abuse		
	I CONFIRM THAT NONE OF THE ABOVE ISSUES APPLY TO MY PROPOSAL		

Checklist ethical clearance

- Will the research project involve human subjects, with or without their knowledge or consent at the time? (Note: 'Human subjects' includes yourself if you are the main subject of the research.)
- Is the research project likely to expose any person, whether or not a participant, to physical or psychological harm?
- Will you have access to personal information that allows you to identify individuals or to confidential corporate or company information?
- Does the research project present a significant risk to the environment or society?
- Are there any ethical issues raised by this research project that in the opinion of the Principal Investigator (PI) or Student Researcher require further ethical review? http://www.sussex.ac.uk/