

# Literature review of responsible research and innovation on assisted living technologies for the Assisted Living Project

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## Table of Contents

Foreword.....	3
Review of the literature on RRI and ALT .....	4
Methodology.....	4
The searches.....	4
Structuration approach.....	6
Findings.....	6
Public engagement,.....	6
Gender equality,.....	10
Science education,.....	10
Open access.....	11
Ethics.....	11
Governance.....	18
Sustainability.....	20
Social justice/inclusion.....	20
Significant societal needs and challenges.....	20
Engages and responds to a range of stakeholders.....	21
Anticipate potential problems, identify alternatives, and reflect on underlying values.....	23
Relevant actors to act and adapt.....	31
RRI projects.....	31
Responsible Industries.....	31
ETICA & FRRICT.....	38
PRISE and EuroPriSe.....	40
Technolife.....	41
PRESCIENT.....	42
PATS project.....	44
ETHICAL.....	44
EFORTT.....	45
ALwEN.....	46
References.....	47
Reviewed papers.....	47
General references.....	53
RRI projects.....	54

## Foreword

This literature review on the literature on responsible research and innovation (RRI) and assisted living technologies (ALT) has been prepared for the Assisted Living Project, circulated between the members, presented, and discussed. Its aim has been to identify good practices and central themes in the literature on how one best can aim at producing a learning process and to evaluate products in line with central thinking in the different disciplines constituting or being part of RRI.

I conducted and finalized the literature searches from February 2016 to April 2016, and finalized the description of the RRI research projects in May 2016.

I have chosen to structure the material according to dimensions and keys of RRI. This will give readers easier access to the theme that might interest them. However, this choice also creates some duplication for the reader who wishes to read the review in its entirety.

Oslo, March 27, 2017

## Review of the literature on RRI and ALT

In order to present this review on the literature on responsible research and innovation (RRI) and assisted living technologies (ALT), I see it as useful to structure the content around the core concepts of RRI both as a policy discourse and as research area. Before entering into the structure of the review, I feel the need to present the approach I used to gather the articles.

### Methodology

Prior to the searches, I consulted the research librarian for my research institute; we discussed different approaches as well as where to conduct searches. I did some tests, and experienced that searches that included conjunctions (AND) in addition to RRI, health and ICT gave almost no hits. Consequently, I had two themes and a conjunction. I had two main search strings: one for a narrow search and one for a wider search.

### The searches

For the wide search, I had to be rather strict in how relevant the different articles were for the topic I wished to analyze. Both search strings were used on EBSCO, Web of Science, and Science Direct on the 2<sup>nd</sup> of February 2016, and the searches are illustrated in figure 1 and figure 2.

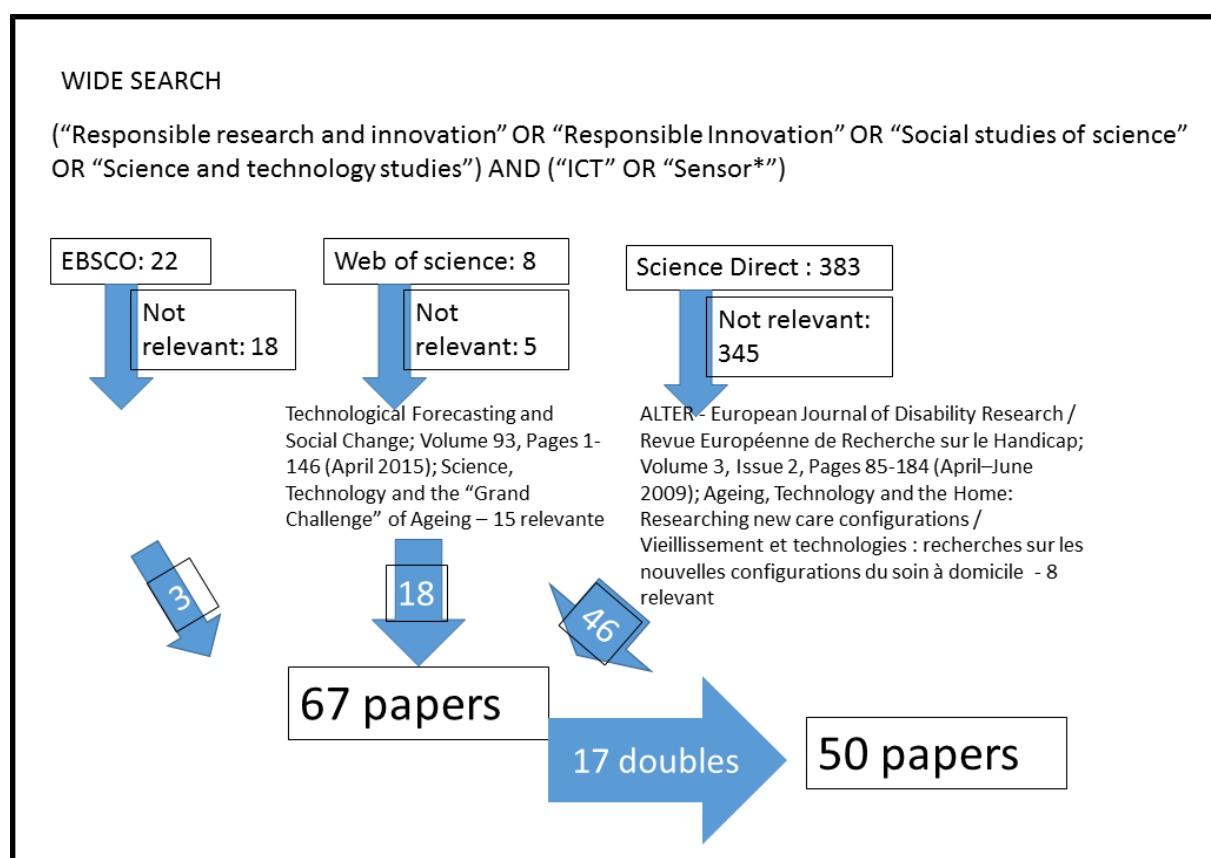


Figure 1. Illustration of wide search ("Responsible research and innovation" OR "Responsible Innovation" OR "Social studies of science" OR "Science and technology studies") AND ("ICT" OR "Sensor\*") and the outcome.

In this search, I found two special issues that were of interest to the review, and included these in the review.

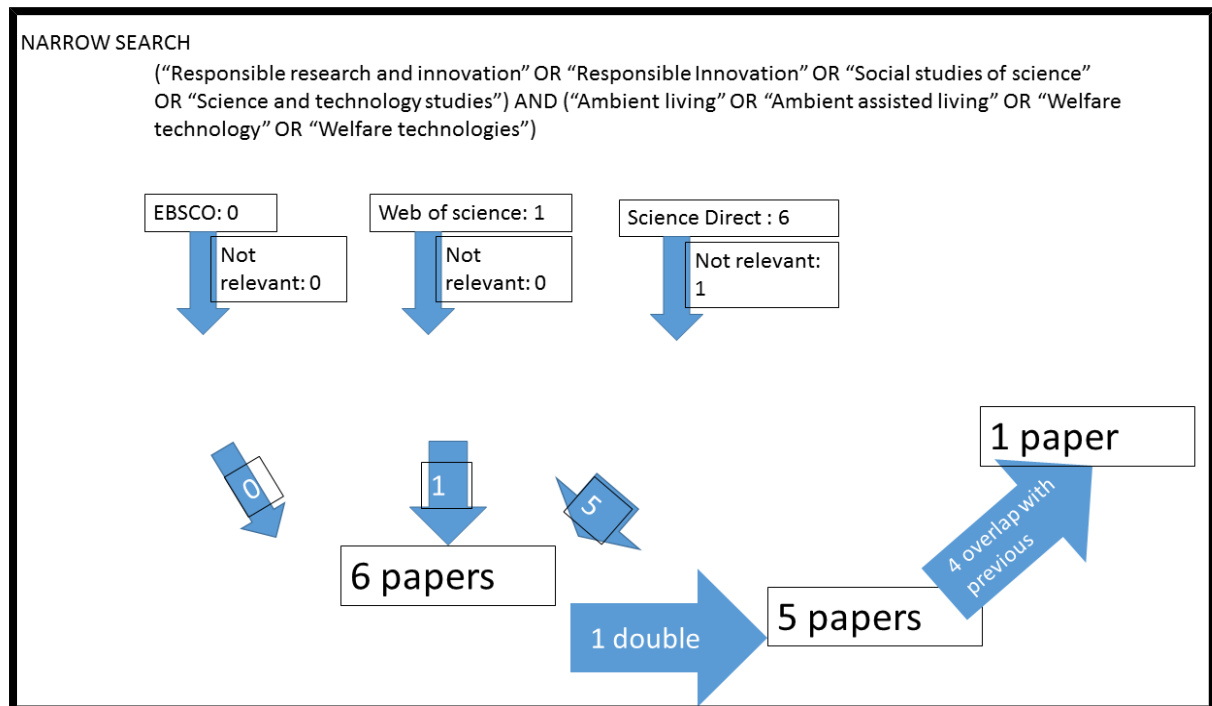


Figure 2. Illustration of wide search ("Responsible research and innovation" OR "Responsible Innovation" OR "Social studies of science" OR "Science and technology studies") AND ("Ambient living" OR "Ambient assisted living" OR "Welfare technology" OR "Welfare technologies") and the outcome

Since these three databases to a large degree contain articles that are not open access, I also searched the Directory of Open Access Journals (DOAJ) on the 21<sup>st</sup> of April 2016 as well as Google Scholar that also points to open access articles. In addition, Google Scholar also encompasses PhD and Master Theses as well as research reports – and what is called the "grey literature". For the wide search, DOAJ gave 183 hits and Google Scholar gave 8900. Whereas for the narrow search DOAJ gave 0 hits and Google Scholar gave 58. Consequently I chose pragmatically chose the articles from the narrow search string on Google Scholar and the articles from the wide search string on DOAJ. I assessed the relevance of the articles, and found that none of the articles from DOAJ were relevant, and 32 from Google Scholar were relevant. Among the articles from Google Scholar, there were 4 that overlapped with the selection from the databases, so 28 papers were carried into the review. From earlier readings, I was aware of two recent literature reviews on the ethics of ALT – and one specifically on dementia (Hofmann 2012; Novitzky et al. 2015), and chose to include these rather than to conduct my own reviews of this part of RRI. Furthermore I also used what is referred to as "snowball" method (see e.g. Van Ham et al. 2006), that is I went through references of the papers originally included to identify papers, books or book chapters that are of special interest to RRI in the context of ALT. 13 articles or book chapters emerged from this study. In total 94 articles, theses, reports and other documents. The large majority are peer reviewed.

Furthermore, this review has been expanded by research projects on RRI and ICT and/or ALT. Among the most relevant publications, are the ones by Responsible Industry and the anthology edited by Rene von Schomberg (2011).

In addition to this, a review or a summary of the inputs from other RRI research projects in ICT and health or ALT will be included at a later stage.

### Structuration approach

The European Commission proposes six keys of RRI: public engagement, gender equality, science education, open access, ethics and governance. Further, the European Commission has recently published a report on indicators for RRI (Strand et al. 2015). In addition to the European Commission's RRI keys, Strand et al. suggest to include sustainability and social justice/inclusion as central elements of RRI. Wickson and Forsberg suggest including the different definitions and concepts of RRI under four points. RRI then includes:

1. A specific focus on addressing significant societal needs and challenges
2. A research and development process that actively engages and responds to a range of stakeholders
3. A concerted effort to anticipate potential problems, identify alternatives, and reflect on underlying values, and
4. A willingness from relevant actors to act and adapt according to 1–3. (Wickson & Forsberg 2014, 1164)

I will hence tentatively try to sort out the central findings from the literature review under the taxonomy proposed by Wickson and Forsberg (2014) and Strand et al. (2015).

## Findings

### Public engagement,

Guston and Fisher (2002) suggest opening up for lay people to engage with scientists and developers concerning the visions for future use of technologies. Tinker and Lansley (2005) engaged 67 elderly in the assessment of needs of ALT. Their findings document that older people welcomed ALT to the extent that it addressed a need. This point is repeatedly taken up in the literature that need must come before technologies (De Rouck, Jacobs & Leys 2008; Pols & Moser 2009; Bailey & Sheehan 2009; Bechtold and Sotoudeh 2013; Prescott et al. 2013; Heidingsfelder et al. 2015; Loe 2015; Pritchard and Brittain 2015;). Novitzky et al. (2015) warns that technology push is likely to be greater than demand. There is further the point (Peine & Moors 2015) that to frame the life situation of a person as a "need" to some extent neglects that this person has a complex life situation with a range of preferences and values in which the task that the ALT (or ALT system) is to solve only is a miniscule part of a multifaceted life. Peine & Moors (2015) argue that the understanding of design and functional preferences need to be channeled into an approach that actually empowers the elderly in terms of agency. Ertner (2016) further problematizes the notion of the user, similar to Peine & Moors, and adds that today's users are different from future users. She finds that one project aimed at generalizations through contrasting them to younger, while another project tried to order different practices of the elderly in order to make them into a generalizable whole.

Peine et al. state that "the challenge is not so much the absence of knowledge about older technology users and later life; rather, it is to find the tools and channels to keep innovation processes focused on this knowledge" (2015, 6). Lassen, Bønnelycke and Otto (2015) present an interdisciplinary project with a large quantity of interviews, participant observation and ethnographic

studies. However, their experience was that “in the innovation processes, some aspects of health and users' health practices were downplayed while others were strategically or pragmatically emphasised” (Lassen, Bønnelycke and Otto 2015, 11). This form of “cherry-picking” of input is detrimental to the idea of engagement. Callén et al. (2009) argue that even though public engagement can serve important epistemic, social and instrumental roles in the development of ALT, the methods are still problematic since they tend to lack representativity and often also do not have much impact.

Heidingsfelder et al. (2015) present a methodology from the research project Shaping Future. It is both a participatory foresight and a participatory design. The following four attributes distinguish Shaping Future from existing participatory foresight methods:

- Expanded role of lay input.
- Lay input as a key driver
- Utilization of design know-how.
- “Delayed” professional evaluation: the “method turns to professional evaluation at a later stage of the innovation process and initially utilizes participatory exploratory processes, which it later combines with selective analytical ones” (Heidingsfelder et al. 2015, 294)

From their experiments Heidingsfelder et al. formulate two principles for participatory processes:

1. utilize diversity to address public preferences
2. choose egalitarian working formats and guide interaction

This form of participatory process where as much as possible is left to the participants then suspends professional or academic judgement until the participants themselves have experienced the different obstacles and drivers in the innovation process.

Pols and Moser (2009) show that a vital part of understanding the users is to see their full life situations. In their analysis of two care robots, the “non-rational, playful and erratic characteristics” (Pols and Moser (2009, 167) of a robot dog created ties between the users and the technology, while a very functionalistic robot cat that could not engage in play did not arouse any enthusiasm. If care then is seen as something that can only be provided by humans while technologies should provide fixes, ALT systems and devices will become entrenched in an opposition between humans and technologies which they actually try to overcome. Pedersen (2011) conducted interviews with respondents working at dementia care centers, distributors, and governmental advisory organizations. He also found that there are a range of individual idiosyncrasies that influence the extent to which the elderly wants to interact with the robot. Care workers regulate and provide access to the robot through a series of institutional logics.

Bailey and Sheehan see the “‘user perspective’ to be a composite of the older persons’ life world: as recounted by them, as observed by the ethnographer and as contextualized by their life course” (2009, 100). Their studies show that the introduction of ALT should give ample time for the elderly to get acquainted with the systems and without immediate pressure to provide feedback to the developers. Loe (2015) suggests that that it is important to link ALT solutions to their views on technology as well as their life history in addition to what is described as medical needs. Suopajärvi

(2015) documents how elderly are users – and competent users of technology, albeit different users. Technological changes are not foreign, but rather a natural part of the life world of the elderly.

Torrington (2009) presents an iterative design process conducted with people with dementia and their supporters. In addition, she evaluates how different types of home environments might support people's initiatives to be active. The project used focus groups and qualitative interviews with people from different types of housing. These activities produced a "wish list" of technologies that were then tested by 31 participants under methodological supervision of Torrington's team. She concludes laconically that "people with dementia, not surprisingly enjoy the same kind of activities as everyone" (Torrington 2009, 126). The products were iteratively tested and assessed according to different types of home setting. It proved that there are far fewer barriers in private homes than in residential care homes. Wallace et al. (2010) see it as important to provide feedback from the users in order to alleviate errors. They recommend small focus groups for feedback when including persons with dementia (1 researcher & 3 persons). They suggest that it is important to focus on the consumer products and the systematic technologies in homes to be designed for use of all types of people. Meiland, Dröes et al. (2010) report on the experiences from the COGKNOW project where they included persons with dementia in three iterative cycles over a 3-year period. They had between 12 and 18 persons in community care and their care givers involved. They made lists of the expressed needs and the favored ICT-based solutions on a limited field. They organized some workshops that consisted uniquely of people with dementia and others were reserved for the caregivers in order for them to be able to speak freely. They also conducted interviews at home with the users employing standardized questionnaires. The output from these activities went into technology development, and they ended up with end user in vivo testing. Meiland, Hattink et al. (2014) describe a similar approach, but here with simple aids: "To help people recall their habits and need(s) of support during a normal day, time-specific pictures from waking up until going to sleep were shown in a PowerPoint presentation" (Meiland, Hattink et al. 2014, 771). All the users provided valuable input. The care partners were further asked to prioritize the functionalities of the proposed solutions according to their usefulness for people with mild cognitive failure, one the one side, and for those with severe dementia on the other. Francis, Balbo and Firth (2009) suggest methods such as self-photography, video photography, role play and thinking aloud as strategies for engaging people with poor or lacking memory. Robinson et al. (2009) also engaged users with dementia and care givers in a participatory design process with three tiers:

1. scoping stage (five focus groups, 10 people with dementia and 11 carers);
  2. participatory design stage (five workshops, 22 participants) and
  3. prototype development stage (four meetings with two people with dementia and one carer).
- (Robinson et al. 2009, 494)

The study shows that the inclusion of people with dementia could lead to more acceptable solutions, and that the participants were capable of providing feedback on functionalities, appearance & design as well as issue of privacy and security. Barriers to use were integration into daily activities as well as usability, design, weight. The participants expressed the importance of two-way communication, and also that devices or systems that can continue to function as the illness progresses – and central to their wishes was technologies that can guide them home.



Mangione (2013) explores how museum educators meet people with or groups of people with Alzheimer's disease. She documents through ethnography and interviews how Alzheimer patients are met with a focus on form and aesthetics rather than meaning and interpretation. These unconscious frames that people have in meetings with dementia patients contribute to the outcome of the encounters and discussions.

Compagna and Kohlbacher (2015) have conducted ethnographies on participatory technology development (pTD) in ALT. They are critical towards scenario-based methods that involve people with dementia when these pTD arrangements also involve some adjustment process of the scenarios. In complex settings such as scenario development and adjustment, persons with mild cognitive impairment will be discriminated against since they might lack the capacities to follow these conceptual changes. Consequently, this will be against the principles of fair bargaining. They suggest that in the ALT domain, there are three main factors that make pTD difficult:

- The ALT systems have a much longer history and pedigree than the one available to discuss and modify in a scenario-based development
- Older people are seen as a weak user group; they are not well enough understood as technology users
- Participatory methods try to mediate between different user groups instead of accepting diversity

Compagna and Kohlbacher's recommendations are:

- To diminish the degree of participation in the first stages of the innovation process and dramatically increase usability trials in the middle stages combined with a distinctive use of rapid prototyping.
- To decrease, or even refuse intermediary/mediating methods. Instead, the aim should be for the most direct interaction possible between the user and the developer.

The authors find that care workers were the user group that received most attention at the cost of the elderly.

Tinker et al. (2013) highlight that the inclusion of persons with dementia needs to be conducted according to the particular needs of these persons.

McLoughlin et al. (2013) sought to use the concept of co-production in a development project where elderly directly engaged with IT professionals in order to make a custom-fit telecare system for those users. This is then, an example of trying to make the users drive the whole process. The authors report that they encountered large problems in the project that they present as technological problems. It is difficult to ascertain if the design of the total project was in any way related to the processual difficulties.

Östlund et al. use insights from STS and design studies to suggest that these combined can help create a "proactive technology that meets the needs and demands of today's senior citizens" (2015, 82). They propose to include users of products to be included in the whole development and testing phase since this can ensure that the developed product actually enable the user and does not stigmatize the user. They comment upon sensor technologies and the assessment of these that "awareness of being monitored changed the users' behavior to a certain extent" (Östlund et al. 2015,

87). In an article written together with Susanne Frennert, she further finds that seniors develop an identity through participation in eHealth project as more tech savvy than those who do not participate. They also identify potential barriers to participation. The first barrier is when relatives and/or caregivers do not actively engage. The second barrier is more orientated towards the device and occurs when the technology does not invite people to engage in it due to lack of functionality that creates passivity. The second barrier also consist in a lack of empowerment through the device and lack of feedback, what Peine and Moors (2015) called prosthetic devices (Frennert and Östlund 2015).

### Gender equality,

Roberts and Mort (2009) find that women in this case see loss of physical coping as loss of independence while male sees it as irrelevant (because they are used to wives taking care anyway of medication etc.). They further conclude that telecare systems do not sufficiently take into account that the physical aspect of care remains the domain of female informal caregivers and low-paid females doing this work.

Rommes, Bath and Maass (2012) argues for an inclusion of feminist design and gender analysis as integral parts of ICT development processes, and mention some methods to achieve this goal such as “mind scripting” and “undesigned design”. Dahler, Rasmussen and Andersen (2016) identify gender as one central factor in adapting ALT education and training to the users.

### Science education,

Xie (2012) presents an e-health literacy intervention that aimed at empowering elderly with regards to health and to computer knowledge. Xie finds that learning is most effective in a familiar setting, like a library, but mainly the need for a structured approach based on high quality sources written in an accessible language. Xie documents that health literacy and computer literacy, interest and efficacy increased and that a clear majority of the participants reported to be more engaged in their own health and had less anxiety towards computers.

Saborowski and Kollak (2015) see the training of nurses and caregivers as a partly ignored field in their study of care professionals’ experiences with ALT. This theme is also touched upon by Tinker et al. (2013). Hellesen and Bisgaard-Nøhr (2013) argue that since employees and technologies interact, the employees need a situational understanding of the technology – consequently the most fitting learning environment is the workplace. They suggest that one has to take as a point of departure the competence level of formal and informal caregivers. Based on Nickelsen’s (2013) observations, one should include some meta-reflections on the different rationales in ALT in such training.

Nielsen, Andersen and Sigh (2013) in their study of vacuum cleaner robots found that the municipality did not offer training to the formal caregivers since the robots were seen as the property of the elderly. However, the caregivers had the opportunity to test the robots in their own homes and this increased the acceptance of the robots. In their study, all stakeholder groups experienced the use of “welfare technology ambassadors as an appropriate way to support robot implementation” (Nielsen, Andersen and Sigh 2013, 17). Frennert (2014) shows that participation in the technology development constitutes a forceful way of creating learning.

Rosseland (2014) demonstrates how computer training can be included as part of a research project on the uses of ICT among elderly people. In a study at Kampen Care+, Oslo, he documents that the

inhabitants have technological know-how and that systems might be set up (by both carers and relatives) that are not responding to the life situations of the inhabitants.

### Open access

Krischenbaum (1987) in an early review of subsidized technologies found that almost all R&D for disabled was publicly funded and that public funding is more successful in generating prototypes than private funding. Independent living projects were only funded by public institutions and they are not very likely to have a commercial impact. He further finds that “subsidized technology research to a great extent matches potential need” (1987, 343).

Constantinides and Barrett (2006) document how unsolved issues on intellectual property rights contributed to the failure of a telehealth project.

Callén et al. (2009) suggest Participatory Action Research as a means to strengthen participation and improving research on the needs. They see it as important to map out the different actors in the network surrounding technological implementations and innovations. By engaging the different actors to construct meaning of the device in relation to “other involved agents like relatives, caregivers, volunteers or operators” (Callén et al. 2009, 118), the participants themselves become researchers of the potential uses of the device in a social setting.

Prescott et al. see open science as the way of addressing “[s]ocietal concerns about technology” (2012, 11). Here Prescott et al. refer to Nowotny, Scott and Gibbons (2001) who emphasize the co-production of science and society for common goods and solutions.

There are projects aiming at open platforms for ALT, such as ReAAL and UniversAAL<sup>1</sup>

### Ethics

Topo (2009) documents that consent in some cases only was obtained from the family and not from the persons with dementia. Topo finds a “bias toward caregiver needs” and suggests that this is because caregivers are the main source of information. He states that there is a need for studies involving persons with mild forms of dementia using technologies or being involved in technology developments for and with solutions that aimed at living a more active life.

Hofmann (2012) makes an inventory of all types of technologies and devices that fall under the umbrella term “welfare technologies”, and uses a “Socratic method” (Hofmann 2005; 2008) that addresses the purposes of a technology in order to systematize the different ethical issues. A similar approach is also used by Godwin (2012). Hoffman finds that the technologies might be meaningfully systematized depending on purpose, and he lists these to be communication support, compensatory technology or assistive technology, help to everyday practical tasks, disease monitoring, remote treatment, rehabilitation technology, entertainment, and social and emotional support and stimulation. For Hofmann, there are five main ethical issues with ALT. First, as they are to be installed in peoples’ homes, there can be an issue of alienation and that people no longer feel safe in their home because of the technology. Second, there are a range of stakeholders who might benefit from ALT, and this opens up for more analysis of who will benefit from its use and who is responsible for the full ALT system. Third, there are issues of privacy and confidentiality as amounts of data are

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<sup>1</sup> <http://www.cip-reaal.eu/about/project-description/> and <http://universaal.sintef9013.com/index.php/en/>. See also Ferro et al. 2015; Salvi et al. 2015; Zentek et al. 2015.

involved. Fourth, there is the issue of distributive justice, and the digital divide, where it is not clear if the technologies are distributed in a fair manner that is consistent with considerations of justice. Fifth, ALT might be introducing an instrumental rationality into homes and peoples' lives in a manner that challenges fundamental values such as care, dignity and vulnerability.

Wiederhold presents a privacy impact assessment (PIA) tool from the PRESCIENT project which is defined as "a process of engaging stakeholders in order to consider how privacy might be impacted by the development of a new technology, product, service, project or policy and what measures could be taken to avoid or mitigate unwanted effects" (2015, 1).

The following subsection is based in its entirety on Novitzky et al. (2015) who have reviewed the ethics of ALT. They find that regarding persons with dementia user involvement should be adapted to their needs and requirements, and it is important with feedback. Technology that the users have not developed might be rejected. The needs of persons in this category are often not well understood – and there is great variation based on personalities, cultural background and history. Motivation is a large factor for acceptance. Relatives are good at motivating, and training is important. Products with a lot of sequential steps should be avoided. Foreign objects like cables and wires should be avoided, and didactic approaches should be employed in communicating about the tools. When it comes to the issue of trials, the technologies might be so complex that it is beyond the range to talk about informed consent. Further, some technologies might impact the autonomy since it might lead to people trusting the system in a way that they do not report errors because they think that they themselves have made an error. Dependence on an intelligent system might thus reduce autonomy. Co-habitants will need to give consent as well. One could also argue that reliance on others is a human condition, and that to provide for home dwelling is in itself so valuable that it makes up a large part of a person's self-determination. When it comes to the issue of control and customization, some people will just be foreign to the use of technologies; they will see it as irrelevant. The issue of false alarms or false positives is also a consideration – and further the degree of control the user has over the system vs. the system over the user. There are different preferences as to input: some prefer touch, others speech. And it is the issue of turning the system off – or opting out – without repercussions in any way, and this is especially difficult regarding persons with dementia. People should also be protected from too much information. There might further be conflicts between user and care-giver when it comes to how the system should work, and that control over the system is an important issue. The prevention of falls, or the quick intervention in case of falls, is one of the positive dimensions of ALT. This reduces both fear and harm. There are considerations of privacy and of "medicalisation of the home" – and the issue of privacy should be solved through encryption or similar techniques. There seems to be agreement that ageing at home is preferable to institutionalization since privacy, personal space, integrity, dignity and positive effects of self-reliance are important for selfhood. Nevertheless, the actual degree of autonomy that people feel or have through ALT is discussed since the systems can lead to inactivity and passivity. People need further to place much trust in the technologies, and in case of emergencies people might become passive. Defects due to power failure also create vulnerabilities. It might be embarrassing for people if indications of their disease become public either through the instalments or through the leakage of data. This can be avoided through design. ALT that can be used in public can also prove stigmatizing if discovered by outsiders. This might increase isolation. It is further an issue of security with surveillance technologies since it is difficult to assess the normal activity pattern of people with dementia that can be used as a baseline. It is an open question, and to be decided on individual basis

whether an ALT includes or excludes if the technologies open up for more social encounters that in return scare persons. There is also the issue of the “digital divide”, which follows already existing societal differences and amplifies these – and they can serve to solidify differences between young and old. Some people also feel alienated by technologies, and communication technologies might be used for abuse or dishonest purposes. Adult digital literacy is then a challenge. Some persons also lack interest in technological devices. Affordability, feasibility, cost of ICT systems are all issues that might serve some to be included and others then again to feel more excluded.

Regarding formal and informal carers, defined by Novitzky et al. as nurses and family proxies, the benefits for the caregivers is not well documented. The caregivers should also be given opportunity to consent/dissent to clinical trial where data are collected about them – and also have some benefit from the data collected. There exists a skepticism about the inherent technological rationality in ALT among scholars, and that people are left in a vulnerable situation where technologies take the place of human contact. Technology can also make the caregivers insecure. There is also the special status of “home” as place, and the issue is raised whether one can transfer every kind of equipment into a home and keep its symbolic meaning. The issue of agency is also raised with reference to Hofmann (2012) who wonders whether the introduction of technologies into the homes also entails a type of rationality that can diminish the care-givers capacity to increase the patients’ agency (see also Pritchard and Brittain 2015). Caregivers might also be concerned about the legal liability connected to operating technological devices. Further, the notion of care changes from the familiar dimensions of “hope, coping, vulnerability, dignity, meaningfulness or proximity” (Novitzky et al. 2015, 743) towards something unknown. The interaction between persons is mutually valuable for givers and receivers of care and its replacement by technologies can be offensive. Giving care also holds value for the caregiver, and social support should not be reduced to a task or burden. The replacement of persons with databases can cause objectification. On the opposite side, caregivers can also be overly protective and paternalistic, and the needs or values of the user might not be in line with those of the care-giver - for example when it comes to introducing technology that a patient desires but the care-giver rejects. Formal caregivers tend to be reluctant to use care systems developed elsewhere or that is not strictly a care-intended technology.

Researchers and clinicians should be aware that persons can take part in clinical trials for a range of motivations. Some in order to please the researchers, others to gain status through participation and others again feel an obligation to participate – or just to get away from boredom or loneliness. Elderly can also have less faith in their own judgement and might defer decisions to others. The quality of the data that are produced are important to researchers. They should also be aware that most devices tested actually provide both experienced and real safety. In the clinical applications, ALT should address the health and technology aspect together with the need for wellbeing of the patients. It is also necessary to consider if the ALT is in the best interest of the patient. For researchers and clinicians, the issue of distribution of technological resources – and who decides about this – should also be considered. ICT devices are often used to prevent rather than to cure, a change in rationale for physicians. Automated diagnoses might provide new ways of false positives, and are also hindered by legal constraints through data protection.

Engineers should involve the persons with dementia in the development and research. They also hold the obligation to protect data and secure the systems against attacks, and the Quality of Life aspects should be assessed as part of the system assessment. Installation should not hinder people

in their homes, nor transform the homes. They should also be aware that human companionship extends beyond its mere functionality. Just to transfer one application into a home as ALT might cause serious problems. Technicians tend to see work with elderly as low status. There is also the case of lack of coherent expectations between technicians and users – a broader social analysis is necessary than just introduction of a device or a system. The developed systems must be adaptable to other systems, and the engineers should reflect upon the issue of making experiments with humans.

For the clinical trials, all types of third parties that are critical to the functioning of the technology must be scrutinized (internet, power, heating, water). Privacy concerns are central, and accountability should be thematized. The testing of ALT should meet high standards.

During the clinical application data protection is vital, as are issues of infrastructure for the data. Further, the harm and burdens that can be induced should be appropriate to the benefits (and for the same persons) – the proportionality principle. The ALT should be easy to use and to learn – and as flawless as possible. There should be awareness that products have life-cycles and are mass-produced – as opposed to health and services. The technology push is likely to be greater (or different) than users' needs. The technology itself will take over part of human agency. Barlow, Bayer and Curry (2006) document this kind of push in their studies of telecare implementations:

A fundamental problem observed in both the Columba and COPD projects was the absence of a *clear set of users* who expressed a demand for the service and were able to drive it forwards during the initial project phases. The COPD project arose because a coincidence of interests—Qinetiq had funding available and a local clinician had knowledge of telecare—rather than a specific need identified within local policy. (Barlow, Bayer and Curry 2006, 402)

Designers should have user-centered approach which means universal design meeting a range of needs and requirements. The users should be included in all phases – even though it is costly and laborious. Safety – and privacy and security – should be a priority. User involvement means to design the process according to the specific capacities of the intended users. The user is the domain expert, and all features from material to presentation should be taken into account. The design should aim to abilitify the users instead of meeting them as disabled. The clinical trials should provide some kind of impact assessment on a socio-economic scale as well as comprehensive in situ testing and with sensibility to differences depending on backgrounds, gender or cultural differences. There should also be a type pf WRE analysis where also the rationales for assigning value or responsibility in cases is discussed.

During the installation of the devices, technicians must be sensitive to the situation. This sensitivity and the respect for the persons should be upheld throughout the application phase. The technician, who enters someone's house should be ready to engage in social enquires and discussions of the device, and also maintain a dialogue with the carers since these have little technological competence as technicians might lack care-givers' qualities.

What are then the values of ALT? Some, notably Hofmann (2012), argues that ALT can benefit caregivers rather than persons in need of care. If the case is that those in need of care take most of the risks and are deprived of privacy while others gain, then ALT would lack an important part of its justification. The goals of using ALT are aligned to meet other societal goals such as policy goals of

“living at home”, to introduce telecare and telehealth, and to cut health costs. Novitzky et al. emphasize their agreement with a point that the benefits from ALT (and other types of healthcare) must be found to be valued by their users in some form in order to be legitimate. This value provides the basic justification for the research into ALT. The data from ALT devices might provide further insights into dementia – and this benefit could be a justification for such deployment, but this should be aligned with the proportionality principle. ALT systems should provide greater benefits than simple reporting of incidents – they should add to the well-being.

The elderly is a heterogeneous group. The goals of ALT and ALT systems should have a possibility to meet the preferences and needs of the individual users through customization, and persons with dementia should not be expected to shoulder the burden of maintaining devices or to detect flaws or errors. The freedom to adapt a system has to be open. The goals of ALT “aim to give assistance, support, empowerment, a sense of security to vulnerable persons, and aim to facilitate them staying longer at home whilst maintaining their comfort, social connections and security.” (Novitzky et al. 2015, 754). Nevertheless, the category of people with dementia is vulnerable, and ALT are non-therapeutic technologies so a main motivation is to introduce a surplus of benefits to potential harms.

According to Novitzky et al., the ALT systems are aiming at a level of finesse and functioning that should abolish humans as a safety net. This means that ALT should be required to have a higher level of safety than other technological devices. ALT should empower and render persons more active. ALT systems need clear guidelines so that responsibility is not placed on the “system”, but there has to be accountability at all levels and at all nodes.

The methodology to engage users should be proportionate to the development costs, and good enough to ensure quality feedback. Likewise, the quality of the installed products should be good enough to provide the data needed for research, and researchers need to be careful and “judicious” in their assessment and interpretation of the data. With a clear purpose, the testing of ALT is likely to be both stress-free and human-centered. They cite Hofmann (2012) who has pointed to the lack of testing for ALT and medical devices in general.

The issue of informed consent is given prominent place by Novitzky et al. because all the three factors of competence, understanding and voluntariness might be challenged in the case of ALT, as described above, and since dementia diminishes persons’ cognitive capacities. They introduce here the concept of a “rolling informed consent” which consists in the (a) providing repeated information at several times and unsolicited – and asking consent each time; (b) assessing the speak of the persons to consider if they still can be said to participate with competence, understanding and voluntariness; and (c) tell the patient that he or she can opt out every time.

Clark and McGee-Lennon (2011) held scenario-based focus groups with stakeholders, both with individual stakeholder groups, and mixed groups. They drew the following ethical concerns from the stakeholders concerning home care technologies:

- Failure of technology
- Who is accountable for negative impacts
- Privacy
- Access to information

- Security of health data
- Lack of informed consent of technology receivers

Bechtold and Sotoudeh (2013) discuss the issue of technological paternalism vs. user empowerment. Without a true empowerment, it remains doubtful whether the quality of life of older persons can increase. In order to achieve such empowerment, they propose to conduct “ethical technology assessments”. An ethical TA consists in pronouncing more clearly or render more apparent different possible conflicts, and it is based on the operationalization of a checklist:

1. Dissemination and use of information
2. Control, influence and power
3. Impact on social contact patterns
4. Privacy
5. Sustainability
6. Human reproduction
7. Gender, minorities and justice
8. International relations
9. Impact on human values. (Palm & Hansson 2006)

Detweiler and Hindriks (2015) conduct a large literature study of pervasive computing in elderly care and analyze possible connections between values, technologies and contexts. They identify six value categories: physical well-being, social well-being, freedom, privacy, responsibility, and safety. They find four groups of stakeholders: elders, people with a cognitive impairment, professional caregivers, family and friends. The technologies they surveyed had the following set of goals: maintain health, guarantee safety, control surroundings, cope with memory loss, and perform activities of daily life. There were further four different types of environment: home, outdoors, residence (i.e., assisted living facility), and the workplace. A main contribution is the documentation of the uses of the concept of responsibility:

the concept of responsibility was most commonly used to convey that a certain hardware (e.g., a mobile device or a sensor) or software component (e.g., a software agent, an application, or a server) has a certain role to perform (e.g., collecting data). In some cases, it referred an individual's role or duty to do something (e.g., a caregiver's duty to do something), or to assume a duty (take responsibility for caring for one's own health). The term task was used to convey the same notion with regards to software or hardware components. With regards to individuals, the concept of task was generally used to refer to (household) activities to be done or performed by an individual as part of everyday life (e.g., washing hands), or as part of a job or role (e.g., caring tasks). The term “duty” was used in the same sense, exclusively with regards to caregivers. (Detweiler and Hindriks 2015, 6)

Detweiler and Hindriks open up the notion of responsibility as used in the literature on values and technology in ALT thinking.

Finch et al. (2006) question the assumptions if patients are empowered through e-health or if this increases the responsibility placed on the patients without the patients having the resources to empower themselves through such responsibilities.



Ballegaard (2011) examines the changing configurations of care and diagnostic work. She finds that ALT introduces novel responsibilities for care workers and for next of kin for diagnostic work and for quality of life. There will be diagnosis work done by lay people or home assistants if there are readings on the health devices that are close to threshold values etc. – what she calls “distribution of diagnostic work” (Ballegaard 2011, 67). This is especially important as we are aiming to loosen the tie between health, technology and institutions.

Doorn (2011) analyzed how responsibilities are distributed between the actors in a research network by using the method of wide reflective equilibrium (WRE), developed from the political and practical philosophy of John Rawls (1971). The WRE approach consists in

three layers of considerations: (1) descriptive and normative (moral) background theories, (2) moral principles, and (3) considered moral judgments about particular cases or situations. Reflective equilibrium refers to a state of coherence between one’s considered judgments and moral principles concerning a certain case (Doorn 2011. 7)

By application of ethics position theory (EPT), that places people’s ethical attitudes along two dimensions, 1) particularism (how skeptic one is to absolute moral principles) and 2) idealism (concern for good results), Doorn placed the participants inside a two-by-two taxonomy of ethical ideologies. When she discussed responsibility with the participants, she found that there was a correlation between the grounding for responsibility and the arguments for their moral positions. This then can be referred back to Rawls who sees it as valid in a liberal society to hold different conceptions of morality – and consequently of responsibility. In a later article with van de Poel, she applies the method developed in Doorn 2011, to create larger understanding of the legitimacy of holding different sets of moral judgements and conceptions of responsibility (van de Poel and Doorn 2013). In this approach, called ethical parallel research, they map the stakeholders and their agendas before using the WRE method. The WRE method is then a variety of reflective learning (Argyris & Schön 1978).

Stahl, Eden et al. (2014) analyze how computer ethics (CE) has had/been a “reference discourse” (shaping a discipline normatively) based in deontology, utilitarianism and virtue ethics, but with inputs from ethics of care, gender studies, and the capability approach. Further ethics has been analyzed through the newer notions of ontology of information and disclosive ethics<sup>2</sup> that are investigating the embedded ethics in technologies, as well as from thinking on value-sensitive design. In addition the fields of engineering ethics and technology ethics have been influential. The topics studied have been privacy and data protection in addition to intellectual property rights. They see RRI as expanding and enriching CE through a focus on

- grand challenges
- the early stage / primary stage of research
- democratic accountability in the innovation cycle
- broader social goals that can encompass computer ethics issues
- meta-responsibilities
- larger normative foundations (as human rights / EU declaration)

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<sup>2</sup> “Disclosive studies in computer ethics are hence studies concerned with disclosing and evaluating embedded normativity in computer systems, applications and practices” (Brey 2000, 5).

In sum, RRI can meet the developments in Information Systems better than the traditional CE.

## Governance

Krischenbaum (1987) documents that the organizational structure for the development of assistive devices is to a large extent tied to the national system of subsidies.

Finch et al. (2006) discuss changing notions of risk and governance – and traces the change in perspective from a focus of clinical evidence to a focus on organizational issues as important in e-health. There seems to have been a shift from clinical effectiveness to an emphasis on service effectiveness. They argue that risk has become much more diffuse, and that the new forms of ehealth risk are rather connected to privacy, security of data and record confidentiality. Those who look at the management dimensions of telehealthcare seem to not address risk as a problem. Risks are solved through auditing / evaluation or by clinical judgement.

Constantinides and Barrett (2006) in their analysis of the implementation of telecardiology in Crete found that a range of governance factors are involved such as power struggles; political reforms and changing governments; regional and organizational differences and competitions; and allocation of funds for training and/or changes to the services. They highlight the role of early enthusiasts in the development of ICT in healthcare. However, Constantinides and Barrett show that the “lead user” idea needs proper institutional backing in order to be successful. Barlow, Bayer and Curry (2006) argue that individuals play just as large role as organizations and structures.

Tjora and Scambler (2009) analyze why the implementation of electronic patient records has not happened as fast as envisioned. They see explain this by pointing to that digital services has not been helpful in establishing communications between the different professions in the health system. Organizations are not only functional units, but also a place for tension between persons identifying with different ideals and roles, and ICT systems might create new orders between existing professions. Tjora and Scambler propose that the health system as such can have different roles in the establishment and configuration of ICT systems: “(1) the health services as client; (2) the health services as user; (3) the health services as market; and (4) the health services as a symbol of political initiative.” (2009, 522). All these aspects must be taken into account – and analytically held separate – in implementations of ICT systems. This notion of sociologically based assessment of ICT in health through immersed approaches is also proposed by Aarts et al. (2010).

The modifications of goals on different organizational levels, and how strategies create novel forms of institutions through the implementation of technologies, is a point made by Shin and Lee (2011). Pols and Willems (2011) further analyze how the central goals for technology implementation are interpreted and performed with real people in a practical setting. Care workers might try to adapt the technologies to empower the agency of patients even though the political goal might be demographic challenges. They study how the practice of “public promising” is untenable in itself by drawing upon the sociology of expectations which “shows that public promises in the short term always overrate the practical possibilities of technologies, whereas in the long term they are usually completely wrong” (Pols and Willems 2011, 485). Frennert (2014) documents that expectations are possible to change depending on a range of factors, such as inclusion and discussions.

Neven (2015) contributes to the study of how the goals are translated and changed in health systems. Whereas the engineers saw a direct link between the ALT system and cost and harm

reduction and increasing safety, the health bureaucrat talked about a potential for these effects. The care organization accepted the needs for ALT at some time in the ageing process in order to “avoid moving to a care home”. They also acknowledge the need for more to live at home since it is cheaper. Whereas care workers want the elderly to live at home as long as the system (technological or otherwise) guarantees them safety. However, care workers are seen to be very sensitive towards malfunctioning of systems and to denounce them quickly. The children of elderly see it as desirable for their parents to live at home if it is safe, but some saw it as useful or positive to put mild pressure on parents to accept the care systems. The participants in the trial were either concerned of own or their spouse’s safety; or they were happy to be involved in the project because of the increased social contact with technicians and project members, or they installed it to make their children happy. Some also wanted different types of installations – but resigned themselves to the offer at hand while expressing desires for other solutions. Some also forgot what they had accepted. However, these different meanings and goals across different groups were no obstacle to giving assent to the idea of “older-people-want-to-live-at-home”. Neven explains the alignment with the concept of “ideograph” – concepts that are quickly recognizes as “good” – like freedom and democracy, for example. And in the discourse here, it is the word “innovation” that trumps everything, “Being involved in an innovative project like AIMS was seen as a good and prestigious thing” (Neven 2015, 39).

Nielsen, Andersen and Sigh (2013) find that different stakeholders interpret, give meaning and assess care robots in different manners. Inclusion of different perspectives on the technology in use will thus provide a richer image of the ALT or the ALT system.

Tinker et al. (2013) review a range of issues, especially those extra-technological ones of different types of living conditions – and the need to think seriously about whether the home in its current state is fit for the individual in question. They cite Demiriz and Hensel (2008) who in their review of smart homes could not find evidence of such technologies on the health of the residents, but also Bonner and Idris (2012) who find that ALT “can help with reminders and prompts, for safety, reminiscence and entertainment. It can also reduce stress on carers” (Tinker et al. 2013, 42), and Van Hoof et al. (2011) who document an increased perception of safety and security after the installation of sensors. In these smart homes, Tinker et al. write, “the user does not need to operate, or be trained to use, technological devices” (Tinker et al. 2013, 37). However, they consider a range of issues that can be implemented without or in addition to technologies such as

- Home sharing
- Home modifications
- Handyperson schemes

Or other alternatives to technological solution or institutionalization, such as

- Moving to a specially designed home
- Moving to specialist grouped housing
- Retirement villages
- Sharing a home with a family
- Adult placements/shared lives
- Cohousing

- Hotels and cruise ships

They recommend that houses and homes should receive extra public investment in order to make them fit for Lifetime standards, as well as for ALT, but also just to make them healthy places to live in since chronic diseases are linked to living conditions. This should be accompanied by greater information about living at home – and also about the possibilities for moving. Technological devices need not be high-tech, but can just as well be assistive devices for kitchen, bathroom – or just mobile phones.

Robinson et al. (2013) present a version of Forecasting Innovation Pathways (FIP) where indicators are established and studied in order to explore path dependencies. This can identify shared expectations and “emerging stabilizations” in the technology development process. This should mainly be understood as innovation governance for firms or organizations. The FIP framework includes four stages: (1) Understand, (2) Profile and Link, (3) Project and Assess and (4) Report. The FIP framework emphasizes that businesses need to have a reflective approach to their innovations and combine tools in order to decide what market segment to target. Endresen (2013) also studies the governance of innovations and point to the fact that in the health documents for the municipalities much of the funds are for knowledge development and competency building followed by measures related to ICTs – and that these in themselves are not innovation, but means to facilitate innovation activity – system innovations are consequently implicit. She finds a bias towards facilitation measures: “the processes of vision development and collective goal and norm setting could be included. In this lies a potential for conceptual innovations and policy innovations to take place” (Endresen 2013, 38).

### **Sustainability**

Except for mentions of sustainability as a general value (e.g. van de Poel and Doorn 2013), the general usage of sustainability in the reviewed literature referred to institutions’ abilities to implement and sustain changes (Dahl et al. 2013)

### **Social justice/inclusion**

In their study, Bechtold and Sotoudeh (2013) found that some raised the issue of who is benefitting from ALT, while Stahl (2011) presented the digital divide, the (increasing) gap in access to goods and services between those connected to online services and technology and those who are not, as one of the most pressing issues in ICT ethics in general.

### **Significant societal needs and challenges**

Almost all the reviewed articles written after 2006 mention ageing society as a societal challenge. However, there are some interesting differences in the literature between those authors who state that ageing is a demographic challenge, and those who state that there is a discourse on ageing as a demographic and societal challenge. However, only three papers use the phrase “grand challenge” (Doorn 2011; Coles et al. 2014; Peine et al. 2015). The difference between the position towards framing ageing as a societal challenge can be illustrated by two quotes: “Science, technology and innovation are widely perceived to provide the means for solving this ‘grand challenge’ of demographic ageing” Peine et al. 2015, 1) versus: “A very serious challenge in Germany, but which is not part of the *HTS 2020* immediate fields of action is the problem of ageing societies.” (Coles et al. 2014, 35). Peine et al. place inverted commas around the notion of grand challenges. In my reading,

they do this in order to distance themselves from this discourse of science and technology as means to solving societal problems.

Mort, Roberts and Milligan (2009) warn of that such a framing of crisis and recession or challenge might hasten the implementation of ALT projects and systems since these have the appearance of saving costs, while this cost-saving claim is not well documented. They describe “an ethical and democratic deficit” (Mort, Roberts and Milligan 2009, 85) as underlying the increased attention and research into ALT while neglecting the social contexts and dimensions. Peine et al. acknowledge that “the socio-material constitution of later life” (2015, 1) is a field that need to be further explored.

Hofmann (2012) is critical towards the lax testing of ALT, medical devices and health technologies. They do not need to meet the same standards of proof as pharmaceuticals. Much of the reviewed literature point towards that the devices simply do not help or even create new risks (Pritchard and Brittain 2015). This is a different point than the one made by several scholars in the field of science and technology studies who use notions like “domestication”, “taming” (Ballegaard 2011; Peine & Hermann 2012; Aceros, Pols & Domenech 2015; Peine & Moors 2015; Saborowski & Kollak 2015; Östlund et al. 2015). The latter authors refer to a process whereby technologies are put to use according to the life situation and the meeting between user and device. Whereas Hofmann takes seriously the claim by the producer and the authorities that the device should be able to assist with one or more functions without causing disproportionate harm, these latter authors investigate how the devices and systems actually are used (or not used). An example on how little thought is given to the actual function can be found in Beedholm, Frederiksen and Lomborg (2015) who document how the managers in their case study had as success criterion that nurses accepted the novel ALT.

Barlow, Bayer and Curry write, “controlled trials are often unfeasible” (2006, 396) due to the organizational complexity of ALT system. In their cases though the structural conditions were similar, there were a range of organizational and substantial changes between the interventions that make effect comparison difficult, but project comparison possible. They also warn about high tech projects without a clear user groups since this is likely to fail.

### **Engages and responds to a range of stakeholders**

Hellström suggests “cross-sector clearing houses’ involving public sector and industries driving critical and pervasive innovation processes” (2003, 381) as a means to reduce inherent risk. These should work to identify risks in a given sector, for example ICT which Hellström studies. He further elaborates on the idea from Funtowicz and Ravetz (1993) of “extended peer communities” where lay people are invited to present their opinions on a given scientific or technological issue.

The concept of user-centered design and/or participatory design is explored by De Rouck, Jacobs & Leys (2008). They suggest a combination of literature studies, engagement through storylines, and wide discussion in the research and development consortium. They suggest to perform and discuss the literature searches and the preparations to the study in a participatory manner. However, they excluded persons with dementia because of “the lack of and risks related to self-care” (De Rouck, Jacobs & Leys 2008, 592). Making a hermeneutical point, they suggest performing the qualitative interviewing before accessing eventual medical information about the participants in order to set the local use-context as a priority. The interviews were the basis for generating social use cases that gave the technical developers input to their work – and these cases could also be used to validate the final product. The authors highlight that the participatory approach had one major shortcoming – it did

not pay “sufficient attention to the requirements and interest of all stakeholders” (De Rouck, Jacobs & Leys 2008, 597) – as “the perspectives of the general practitioner, the specialist, the homecare nurse, the hospital” (De Rouck, Jacobs & Leys 2008, 597). Further, open-ended interviews tend to place and give a very abstract picture of the technology – and user-centered design demands a more iterative process. In order to achieve transdisciplinary understanding, the project developed a glossary, but this was not much used by the participants.

Further research is needed in and by multidisciplinary teams focusing “on mild to moderate dementia and community living and cooperate with organizations of people with dementia and their family members” (Topo 2009, 32) and a multitude of methods is encouraged.

Wright et al. (2011) introduce a “privacy impact assessment” (PIA) as a method of engaging stakeholders in ICT development. This type of forward looking assessment can be used to study alternatives to privacy-invasive actions through reconciliation of different sets of values held by stakeholders. PIA is arguing for “privacy-by-design”, that privacy is a concern throughout the research process. Novitzky et al. (2015) find that privacy is one of the central ethical concerns for engineers.

Andreassen (2011) shows how qualitative interviewing can contribute to more insights than mere statistics of use. It displays that health technologies can provide added social benefits or have unforeseen empowering consequences. This then addresses that care is reconfigured through telecare (Roberts & Mort 2009).

Bechtold and Sotoudeh (2013) conducted a participatory technology assessment (pTA) and made interviews with 26 stakeholders. The interviewees and participants expressed that it was an “urgent need to improve the exchange of information in order to better understand the needs of potential users» (Bechtold and Sotoudeh 2013, 526). They saw it as most appropriate to move beyond information, consultations or user analysis and move towards a mode where users and developers could spend time together. They further found that the participants felt the main issues connected to proper use of ALT were related to “trust, experience, self-perception, the influence of intermediaries and perception of one’s ageing in society” (Bechtold and Sotoudeh 2013, 525). For the technology development, it emerged that devices should have few but clear features that appealed to more than one sense. The testing phase need to be comprehensive, and with an eye for critical situations as well as for individual differences. In the marketing phase of ALT, there is a need for broader cooperation between producers, agencies, public bodies and patient organizations. Finally, it is important that the interconnectedness and coordination between different devices have been clarified. There were also concerns over privacy and security. In their article, they have a recurring emphasis on:

- Feedback loops
- Open access
- the risk of substituting human assistance by technology
- Reflexive approach
- Inclusion of all parties – co-determination
- Addressing distributional issues (digital divide)
- Critical investigation of quality of life
- Transparency

- Distinguishing economic perspectives and rationale from other aspects
- Integration of norms and values
- Open agenda that can include different views
- Focus on and responsibility for positive and negative consequences amongst actors
- Autonomy
- Security / surveillance (from different perspectives)

They see democratization of technologies as a goal that can be achieved through three axes throughout the research and development process: integration of norms and values between the different actors; integration of the issues different stakeholders hold; and co-determination through involvement of other actors than engineers or technicians. Also the outcome of every step in the process should be transparent.

Through the notion of participation in development of health services Nielsen (2015) finds that there is a distance in understanding of “information” and “responsibility towards care practices”. This highlights that there are sets of expectations and practices where there is need for some kind of translation.

Lassen, Bønnelycke and Otto’s (2015) descriptions of an interdisciplinary project can serve to demonstrate the difficulties in being involved in a project where they should be at once be observers of the elderly and intervene with advocacy for the elderly. Their critical cultural discourse analysis did not have much impact on the research project as a whole.

Nijboer (2015) documents how developments in brain computer interface (BCI) take place without consultation of health professionals that work with patients. BCIs are typically developed by people who are not necessarily familiar with the daily life of people with disabilities. Nijboer holds both these facts as central barriers to achieve usability of BCI (and other assistive technologies). Likewise Barlow, Bayer and Curry (2006) argue for the involvement of frontline stakeholders (workers) as more important to success than strategic stakeholders (decision makers); the frontline stakeholders should be enabled by the project and the project managers.

### **Anticipate potential problems, identify alternatives, and reflect on underlying values**

Guston and Fisher (2002) and their model of engaging researchers in reflection on the possible impacts of their innovations, called Real-Time Technology Assessment, Real-Time TA, could prove a valuable contribution to ALT development since it consists in discussions around scenarios based on analogical case studies. Kiran (2012) analyzes a conceptual approach to assessments, midstream modulation, which has similarities with Real-Time TA in that both methods enter into the innovation cycle after the basic research has taken place but before marketing of the products in order to create self-reflection among the involved parties (Fisher, Mahajan & Mitcham 2006). For Kiran and the Telecare at Home project which he analyzes, the main values to be considered are “the choices that facilitates or constrains the control and the autonomy of patients and nurses, or choices that might hamper adequate surveillance of the patients that are in focus” (Kiran 2012. 224–225).

Miettinen identifies the social changes post-2008 (financial crises) as leading to an “enabling welfare state” with increased emphasis on the “significance of associations, hybrid organizations, and institutional learning that crosses the boundaries between state agents, municipalities, civil society associations, and firms” (2013, 175). The potential reconfiguration of social institutions and

organizations that arise from the introduction of ALT or become the institutional framework for ALT can be the object for critical reflection.

Mort, Roberts and Milligan (2009) note that dependency on technology is constructed as a deficit for elderly while such technology dependency is seen as empowering for the young. Östlund et al. (2015) make the point that chronological age is not at all sufficient information to make judgements about older people's life situations, and suggest a focus on life course, history and situation rather than calendric facts (see also Faulkner 2015).

In their ethnographic studies of two different robots Pols and Moser (2009) show how technologies can be used to create affectionate bonds between persons and devices. They contribute to the "literature into social and affective relations people develop with, and through, medical or health care technologies" (Pols and Moser 2009, 161). By employing the analytical notion of a "script",<sup>3</sup> they see technologies "as prescribing roles and relations between different actors, enacting and making manifest particular normativities, and so also shaping the world the actors live in" (Pols and Moser 2009, 162), but this is not a view that suggests that technologies determine our lives (see also Neven 2015). Successful relations to technological devices depend upon the technology to be scripted to allow the user to create an affectionate bond to the device, and this depends on the extent to which the device can *bring something of value* to the user (Pols and Moser 2009, 166). The important issue to be addressed by home technologies are what social relations they create – and how this affects the overall health and well-being of elderly. Different people will experience different built relations by different types of technologies. In their study, the unpredictable and playful robot dog connected to the users while the servile and rational robot cat was not appreciated.

Peirce et al. investigate the notion of "technological identities" by which they mean the "multiple meanings that technologies acquire in their journeying through adoption space and are crucial to understanding their adoption or non-adoption" (2015, 69). They see this notion as a combination of a technology's biography, its cost effectiveness, its clinical effectiveness, its utility, risk and other requirements. They suggest that the notion "technological identities" is better suited to explain the adoption or non-adoption of health technologies than health technology assessment (HTA). It is especially when the infrastructure needed by the health technology is in disaccord with the existing health organization and infrastructure that one can see non-adoption.

Prescott et al. list some of the factors most likely to increase the demand for care in the UK:

deteriorating physical function, inability to care for self at home, mobility problems, need for assistance in personal care (hygiene, washing, dressing), difficulties in toileting, and general inability to cope with independent living — all factors that imply a need for physical assistance, and that could be addressed through the development of future RCCs [Robot Companions for Citizens] (2012, 4–5).

For future care robots, Prescott et al. (2012) suggest that intelligent interaction will create novel bonds between humans and the machines – they speak of "robot personality" – this is important for since it an intelligent solution might create social bonds with the humans. They acknowledge that

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3 Madeleine Akrich explains the notion of a "script" by comparing it to a film script: "Thus, like a film script, technical objects define a framework of action together with the actors and the space in which they are supposed to act" (1992:208).



such robots that are capable of understanding intentions or that can be said to be “general-purpose household assistive robots” are still years away from realization.

Pols and Willems (2011) document how user relationships are important in connection with the assessment of technologies. They state that it is difficult to find the unit that ought to be evaluated before one has observed how the intended goals have been set into practice through technology in use.

Roberts and Mort (2009) find that through the introduction of a telecare alarm system, the traditional notion of “care” as performed by humans in close proximity to a receiver has been rhetorically compartmentalized into three different forms of care: monitoring or checking, physical care, and socio-emotional care. This creates the impression that only the finer types of socio-emotional care is left to the families. However, they state, this ignores much of the valuable contact that takes place with persons at the alarm centers who provide services beyond monitoring or checking. They conclude, “this attempt to reshape care tasks denies several complexities, and discursively (and at least partially materially) works to sustain, and even deepen, a sexual, racial and classed division of care labour” (Roberts and Mort 2009, 153–154). Oudshoorn (2009) introduces the notion of “digital proximity” which is then a novel type of care that arises through telehealth-care technologies. The idea of “reconfiguration of care” entails novel relations that might be hurtful to the expectations of both patients and nurses. This new notion of digital proximity restrict nurses from making contact unless there is something amiss or wrong. In addition, the patient’s self-care changes. Oudshoorn makes a contrast between “illness” and disease” that is intriguing. Drawing on (Mol 2002), she explains the difference to consist in that “illness refers to health-care practices that include medical and psycho-social aspects and take into account patients’ stories and experiences, whereas disease refers to practices in which the treatment of disorders only relies on medical expertise of health-care professionals” (Oudshoorn, 2009, 403).

López Gómez (2015) builds on the insights from Roberts and Mort of the changing notion of care, but discusses autonomy and agency by underlining that living out autonomy is conditioned by practical arrangements in the life-world. López Gómez finds three different types “arrangements” in the study of a social alarm service:

- Pulling through arrangements – to deal with particularly troublesome situations, an occasional help
- Arrangements of trust – who should the user trust in time of need, (normally many persons were used to rely on family) – how to establish the trust of “telecare”.
- Arrangements for fatalities – the telecare enters into a constellation of what to do when an accident happens (prevention / reduction of harm)

Arrangement is a theoretical term that stresses “the materiality of agency, which may enable us to rethink the notions of autonomy and autonomy-enabling innovation” (López Gómez 2015, 93). Through the application of this term, López Gómez shows a vital and an important point in the ambient living discussion since it to some extent removes the barrier between dependence and independence.

Nickelsen and Elkjær (2015) observe how telecare establishes new relations between care givers and patients. They further identify reconfigurations of responsibilities and accountabilities where more of

the hands-on tasks are given to nurses – as opposed to doctors – places the nurses in a situation where they use resources over which they lack control and the demand for more knowledge might lead to insecurity. Nurses experience to be accountable but without having full discretion. Doctors and nurses have different views on what contact with the patients actually mean. This might address the issue that different types of health professionals might experience patient contact in different manners. Telemedicine is also implemented in different manners in different hospitals – depending on culture and resources.

Vesnic-Alujevic, Breitegger and Guimarães Pereira (2016) document how sensor data from units like FitBit create new communities, new conceptions of privacy, and new methods for sharing health information.

In a review of the literature on how research was conducted to meet user needs, Topo (2009) found that much of research was done on persons with moderate and/or severe forms of dementia and that this research also was conducted in care facilities. Studies further looked into safety issues and the concerns and well-being of care-givers while ignoring other issues as security, access to outdoor activities and social interaction – even though these were concerns in some of the studies. Only one study was identified that designed technology according to user experiences and needs. Very few studies aimed at supporting independent living – and the more involved people with dementia are in the projects, the more difficult and complex the study design would become. There is also a lack of documentation of the local environment and contexts for the technology, and there is a need of deeper understanding of contextual issues.

In their meta-study Dahler, Rasmussen and Andersen (2016) find that elderly see technologies as potentially providing assistance, but that they experience it as difficult to keep track of all the novelties and they worry about stigmatization when admitting for the need for technological aids. They tend to see technologies as more useful for others than for themselves. Sensors are seen as beneficial with regards to “emergency help, prevention and detection of falls, temperature monitoring, automatic lighting and stove and oven safety control” (Dahler, Rasmussen and Andersen 2016, 6), but there are concerns over privacy, ease-of-use and the potential lack of humans to respond to the signals from the sensors. The process of acquiring ALT seems to depend upon trust of experts and a final integration of the device(s) into everyday life. Feelings of safety with technology seems to depend upon a general feeling of good health, being able to depend on someone else, and to generally feel at home in the surroundings. Training must be made according to the needs of the persons, and sensibility should be shown towards different background variables – in particular, gender is mentioned. Support and aid is important in the acquaintance process with the device. The physical environment might conflict with the design of ALT. One should be careful not to confuse acceptance with enthusiasm: ALT might be used and accepted reluctantly, but deemed as useful and enhancing agency. The use of technologies seem to depend upon the physical limitations of family members as well as the design, user-friendliness, and their adaptability to the needs. Mobility devices, as other devices, might increase participation but this depends on other factors in the life situation as these might also require assistance for people with dementia. Other studies see the goal of independence and active ageing as a policy goal where dependency is seen as a burden. Fears of sending false alarms or guilt when someone responds to an alarm might hinder uptake of ALT. Devices that create secure and private spaces seem to be valued by persons with dementia.

Wang, Tucker and Rihll (2011) introduce the notion of “phatic technologies” by which they refer to technologies that are defined by their social purpose rather than by its technological build-up. For phatic technologies, it can only be the users that produce the technology through interaction. They suggest that the lens of phatic technologies can be used to make sense of communication technologies. Such a reconfiguration of the study of technologies could serve to look at the connectedness that is actually happening in the uses and interactions with and through technologies rather than a focus on the deficits of elderly in relation to technologies (Bachinger 2015; Vines et al. 2015). Barberá-Tomás and Consoli (2012) investigate how medical devices can be used as a translational tool between patients and diagnosis. They see medical devices from different generations and that are addressing similar ills as “hybrids”; they are in dialogue with each other. Bechtold and Sotoudeh (2013) see the potential for ALT to be social technologies that can empower and create new communities. This is much more an issue of the social context than finding or designing the correct technology. They further see much of the current debate on ALT as coming from an economic perspective rather than from a combination of disciplines.

Meum et al. present an investigation into the “interrelation between formal classifications (NANDA) and local practices” (2013, e364), and analyze how the caregivers and the patients need to develop their own cultural understanding of the ambient living technology. This calls for studies of how patients or users and others engage with the technology over time so that their embedded understandings can become inputs into the standardization process in the caring facilities. The local processes are influenced by global language and standards, but they need to form the standards into their own language and culture.

Stahl (2013) is one of several authors and researchers use scenarios in order to elicit the imagination and to think systematically about the possible ways ahead (Guston & Fisher 2002; Clark & McGee-Lennon 2011; Pols & Willems 2011; Maniatopoulous, Wilson & Martin 2011; Compagna & Kohlbacher 2014). Stahl, however, has created a piece of science fiction in order to engage in explorations into what could happen (Wright 2008). In Stahl’s case, it is the development of a care robot which is an instance of ambient intelligence. According to Stahl “[a]mbient Intelligence technologies are embedded, interconnected, adaptive, personalised, context aware and anticipatory. They provide novel technology and human interaction paradigms. They provide the framework in which other technologies can be integrated” (2013, 41). Stahl suggests that it is important to investigate a range of possible sources for the identification of possible (ethical) issues in ambient assisted living. Stahl, McBride et al. (2014) also employ science fiction like scenarios to analyze responsible innovation through a storyline of RRI inspectors coming to an ambient intelligence robot research site. Dahl, Pieper and Fahnøe (2013) present methods from 7th Framework project “Social Platform on innovative Social Services” (INNOSERV). The methods developed and used in this project were based on making visualizations of successful projects in social innovation or innovations for the social services.

Cuijpers and van Lente (2015) draw upon the work by Gamson and Modigliani (1989) and their concept of “interpretative packages” which are “clusters of topics, arguments and concerns that are articulated recurrently in relation to the innovation and thus create a web of understanding, through which is made sense of this innovation” (Cuijpers and van Lente 2015, 55). They study how methods for early diagnostics for Alzheimer’s disease are articulated with the basis in a biomedical model and a socio-cultural model in the setting of Alzheimer Cafés and a health technology assessment (HTA)

working group. They find then logics far beyond the simple opposition cure vs. care. Further, they find elements of the different types of discourses in the same interview. This suggests that people have complex views on the relationship between disease and treatment.

Vines et al. (2015) study the quantity and the quality of studies of age-related research in HCI (human computer interface). They find a stable, but low occurrence, on 2.8% to 4% of the papers addressing elderly. In the qualitative work, they find “four overarching areas of investigation that we present in the following as discourses: discourse of health economics, discourse of sociality, discourse of homogeneity, and discourse of deficit” (Vines et al. 2015, 9).

They present the discourse of health economics as “the worldwide ageing population is portrayed as an economic and social problem that will likely have a negative impact on us all” (Vines et al. 2015, 9), where ageing is presented as

- an uncontrollable issue
- with a significant impact, and
- technology can control these problems
  - by reducing costs and
  - enabling new healthcare practices
  - mitigating the perceived “risks” of growing old, and
  - designing safety measures that alleviate these risks

The discourse of sociality is “how they [elderly] engage in leisure pursuits with others, how they communicate with people through technology, and how they are threatened by social isolation as they grow older” (Vines et al. 2015, 11), and ageing is presented as including

- that people are at risk of becoming socially isolated – and this is explained by the transition from home to institution
- that technologies are framed as a means of increasing and improving communication between elderly and younger people, and
- that highlight the elderly as socially active and autonomous persons

In the discourse of homogeneity, the elderly are presented as a homogenous group, and this includes

- comparison of older people with younger people’s use and perception of technology, and
- lack of other biographical details than being retired or having grandchildren.

The discourse of deficits consists in a “focus on the relationship between growing old, changes in cognitive and physical capability, and the impact this has on interaction—both with others and with technologies.” (Vines et al. 2015, 14), and comprises

- a framing where it is necessary to grasp the deficits of elderly in order to create designs, ALT or services, and
- emphasizing the how the functional deficits could affect their use and experiences with digital technologies.

Vines et al. suggest that such discourses could influence science funding towards a biomedical paradigm. They suggest that viewing “the abilities, needs, and desires of older people from a life course perspective is useful to HCI research” (Vines et al. 2015, 19), since this

- avoids confusion of chronological age with specific abilities and competence
- offers insights for the ways in which one may engage with older people as participants in research and HCI design processes in the first instance.

They also echo Peine and Moors (2015) in thinking about what HCI researchers should do differently in order to conduct research more on the terms of the elderly. They suggest to

- Use different criteria of “success” and “efficiency”, as developed by the elderly or with the elderly
- Engage with how older people themselves might actively direct, shape, and contribute to HCI research

A disadvantage with Vines et al.’s method compared to Cuijpers and van Lente is that Vines et al. do not capture different discourses inside one and the same paper. However, the four discourses (discourse of health economics, discourse of sociality, discourse of homogeneity, and discourse of deficits) could be included in an RRI approach as “stories scientists tell about ageing”.

Bachinger introduces the concept “the deficit model of late life” which “establishes elderlies and late life itself in a negative framing of deficits and incapacities that demand adjustments and corrections” (2015, 85). This conceptual approach draws on science and technology studies, and what has been called “the deficit model of public understanding of science”. This takes lack of expert achievement in an area to connote lack of other competencies as well and assumes that there exists one dominant and “natural” way of approaching the surroundings (Wynne 1991).

The notion of “the good life”, which might be underlying much of the discourse of “living at home”, should be critically investigated: the question “what is good about living at home?” should be examined more closely – especially when it comes to the quality of “home” for people with cognitive impairments. Ootes et al. (2013) look into the notion of citizenship in mental healthcare and distinguish between a network citizenship and a Euclidian space citizenship. The network citizenship concept defines citizenship as taking part in society through a range of connections, while the Euclidian space concept sees citizenship as defined by living in a specific space, often “home”. These are expressed in the ideologies of social network diagrams and deinstitutionalization. They find both concepts lacking and suggest a more nuanced version where the materiality of the place encourages and stimulates to “being in-place”.

Aceros, Pols and Domènech (2015) analyze two ideals of ageing from policy discourses. They argue that policy texts present these two ideals simultaneously in the context of telecare as if they held the same content. According to the authors, the two sets of discourses are

- Active ageing (WHO origin), physically active
- Ageing in place (OECD origin), inhabit the same space, inactive

These two sets of discourses will of course entail a serious confrontation since they have different inherent goals – and assume different practices in the field of telecare. These two ideals define the zones of activity of the elderly and place them in a geographical space.

Nickelsen (2013) adds to the study of conflicting values in his ethnographic observation of the introduction of feeding assistant robots. His study documents one issue raised by Hofmann (2012), namely the need for proper approval mechanisms. He writes “after having started with the feeding assistance robot, three out of four disabled clients have lost weight” (Nickelsen 2013, 16). This should be a clear indication that the robots are not able to fulfill their intended function. Nickelsen shows that there are different values that are sought realized by different stakeholders, and just as important that their means of fulfilling these values as well as balancing between conflicting values are done in different ways from stakeholder group to stakeholder group. He concludes that “the housing institution studied has turned into a battlefield, where professional values of authentic care meet a strong governmental discourse of modernization of the public sector” (Nickelsen 2013, 2). Brandser (2015) likewise finds that there are many actors fighting for their interests in the implementation of novel technologies. There is a battle in the health professions as to whether to implement technologies – and the eventual role of these technologies. There are also political power issues and economic issues at play. Beedholm, Frederiksen and Lomborg (2015) document that the interests might also be aligned. They found that the introduction of a bathing robot saved the formal care givers from strenuous tasks, so they had an ulterior motivation for supporting this ALT that went beyond the well-being of the patient. Godwin (2012) used interviews and vignettes in order to elicit users and care givers’ views on ALT. She found that users expressed skepticism regarding monitoring and surveillance, and that they easily forgot about the existence of unobtrusive devices, whereas care givers held a pragmatic view where safety had highest priority and evaluated ALT as to whether they delivered the promised function or not.

Peine and Moors (2015) investigate *generification strategies* in personalized health systems. A generification strategy is a term that describes “the work necessary to export specific solutions from their context to make them generic in the form of predefined packages that can be produced and marketed” (Peine and Moors 2015, 70). They distinguish between prosthetic and habilitating generification where the former consists in adjusting the person to the technology and the latter in adjusting the technology to the person, to sum it up in a very approximate manner. They interviewed technology researchers and designers to find how these imagined how older people used technology. Indicators of attitudes towards prosthetic generification in the interviews were:

- The environment should be configured to the robot
- The homes and social situations were translated into needs
- Older people are contrasted to younger people

Indicators of attitudes towards prosthetic generification in the interviews were:

- The effectiveness of the robot is discussed relative to the wider social and technological setting
- Recognition of the user’s need to explore the robot in everyday life

Peine and Moors detected elements of both strategies among their interviewees, but with a overrepresentation of prosthetic generification. They conclude that ALT need to contain prosthetic

and habilitating strategies. The authors further argue that designers (engineers) profoundly understands that technologies are to be part of homes and lives, and not just after a technological fix. Since the ALT devices are both health and home devices, they are difficult to test using HTA or similar standardized methods. The authors suggest that it is of greater interest to reflect on the processes through which we estimate or value something, rather than to have a fixed apparatuses of values – especially since novel technologies might create new values and redefine what until now have been the situations of ageing and experiences of growing old.

Saborowski and Kollak (2015) highlight an important issue, namely that technical aids can only serve one function, according to ISO regulations, so multiple use is not possible. This is important in terms of allocation of funds and the institutional control of providing aids.

### **Relevant actors to act and adapt**

According to Guston and Fisher a “fundamental and testable hypothesis emerges: that participatory, deliberative processes will stimulate efforts to enhance desirable impacts and mitigate undesirable ones through decisions made by NSE researchers about research priorities and directions” (2002, 106). Consequently, Guston and Fisher intend to make researchers change priorities based on Real-Time TA, but there is no formal review that would put pressure on the researchers to do so. Hellström (2003) sees that ICT infrastructure as vulnerable since they are exposed to “just-in-time” thinking. According to Hellström such risk can be mitigated by changing the supply chains or moving the production. Reduction of such systemic risk is also the responsibility of the purchasers of ICT solutions.

Constantinides and Barrett (2006), with a particular emphasis on working life, sees the development and the use of ICT as requiring constant negotiation between the involved actors and the technological choices of these actors within the frame of their changing work and social contexts. It is precisely in this space, they argue, that the socio-technical realities are created.

## **RRI projects**

### **Responsible Industries**

The research project Responsible-Industry has published its “A Framework for implementing Responsible Research and Innovation in ICT for an ageing society” (Porcari, Borsella and Mantovani 2015). This framework is a general frame for conducting RRI and has been set up through consultations with stakeholders in workshops and a Delphi consultation. It has as its focus leaders or managers in industrial firms. The authors argue that RRI “could translate into economic benefits” (Porcari, Borsella and Mantovani 2015, 15).

The key questions asked by Responsible Industries are: “Who is responsible for what? How can RRI be integrated along the value chain? How can ethical and social impact analysis be performed? What tools can be used for RRI?” (Porcari, Borsella and Mantovani 2015, 10). These issues are first divided into an enterprise-internal wheel:

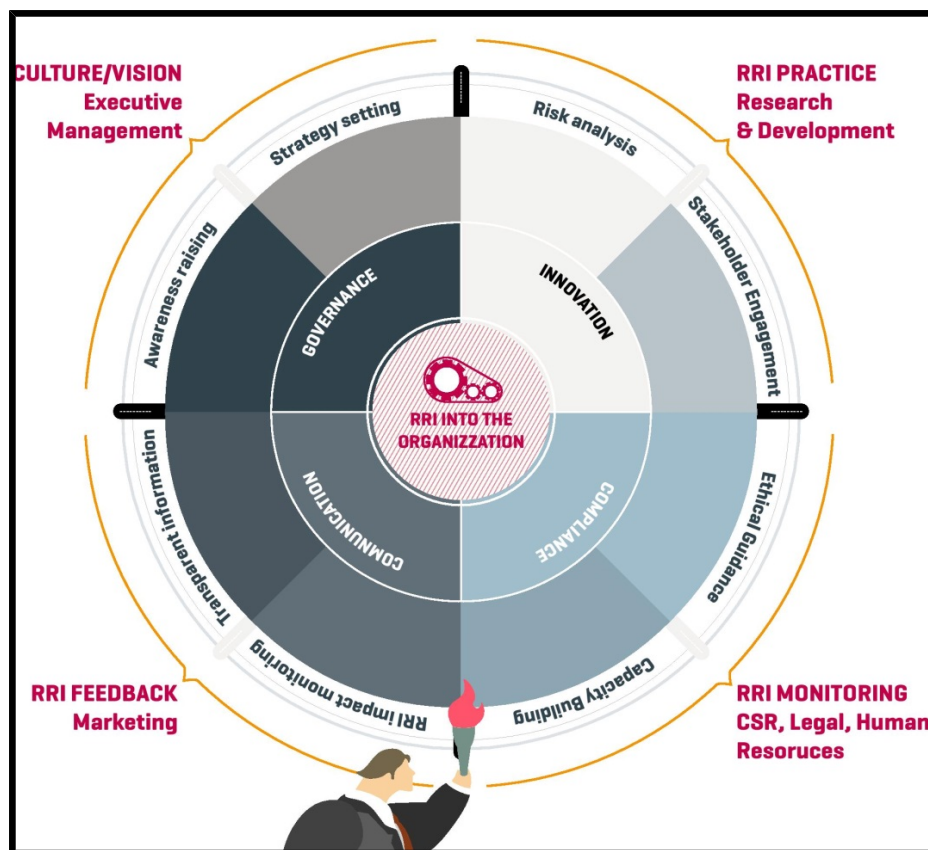


Figure 3 Key responsibilities for RRI within the organization (Porcari, Borsella and Mantovani 2015, 32)

RRI is then to implement a series of visions and measures (culture) for the leadership in an enterprise. Responsible Industries makes lists of what exact measures that could be taken for the different parts or stages in the research and development process (Porcari, Borsella and Mantovani 2015, 33–35). The integration of RRI into the value chain is primarily suggested to be achieved through dialogues with the stakeholders according to the following illustration:

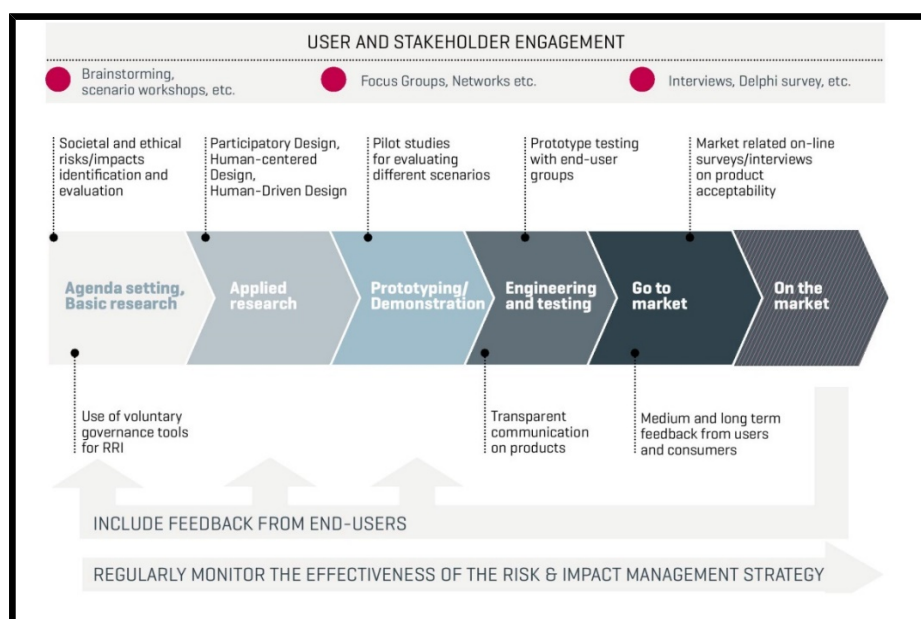




Figure 4 Activities to be undertaken for the integration of RRI along the value chain (Porcari, Borsella and Mantovani 2015, 38)

This tailor-made form of interaction with stakeholders is accompanied by several checkpoints, but most importantly, Responsible Industry suggests that there should be continuous monitoring along the whole process as well as reassessments of the strategies.

When it comes to including and performing ethical and social impact analysis, the main key is also to include stakeholders in the different phases of development as well as employing a range of tools or methodologies from applied ethics or technology assessment:

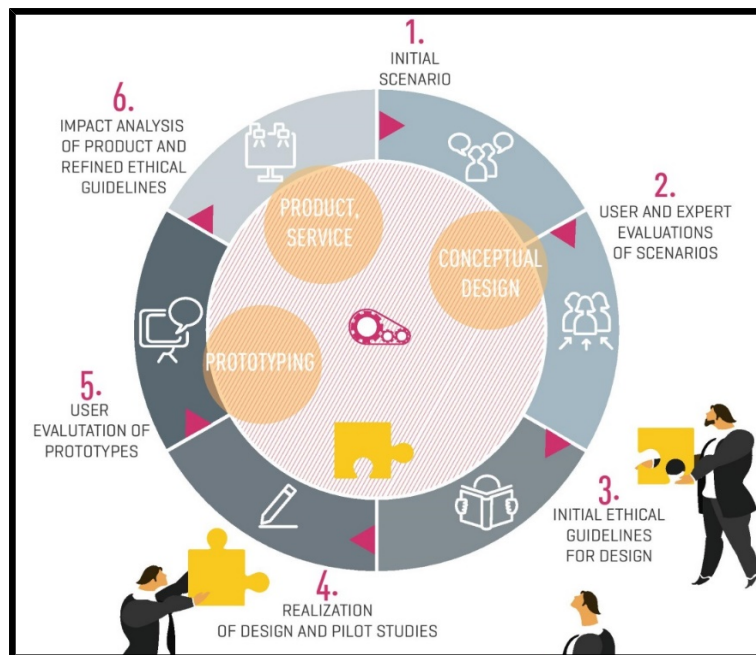


Figure 5 How to perform ethical analysis of new products/services through scenario workshops (Porcari, Borsella and Mantovani 2015, 42)

Responsible Industries are very outspoken on the importance of continuous dialogue with specific institutions such as ethics committees, civil society organizations and policy makers and regulators.



Figure 6 Stakeholders involvement in the different phases of ethical and social risk and impact assessment (Porcari, Borsella and Mantovani 2015, 44)

Based on Peine and Moors (2015), it seems that it could be useful with empirical investigations and initial dialogues with policy makers in order to conduct a proper risk management in the phase before “hazard identification” so that the legal framework is properly understood and discussed prior to engagements with other stakeholders.

As an add-on for further resources, Responsible Industry suggests to consider the use of a range of ISO standards corporate social responsibility (CSR) tools or conventional codes of conduct:

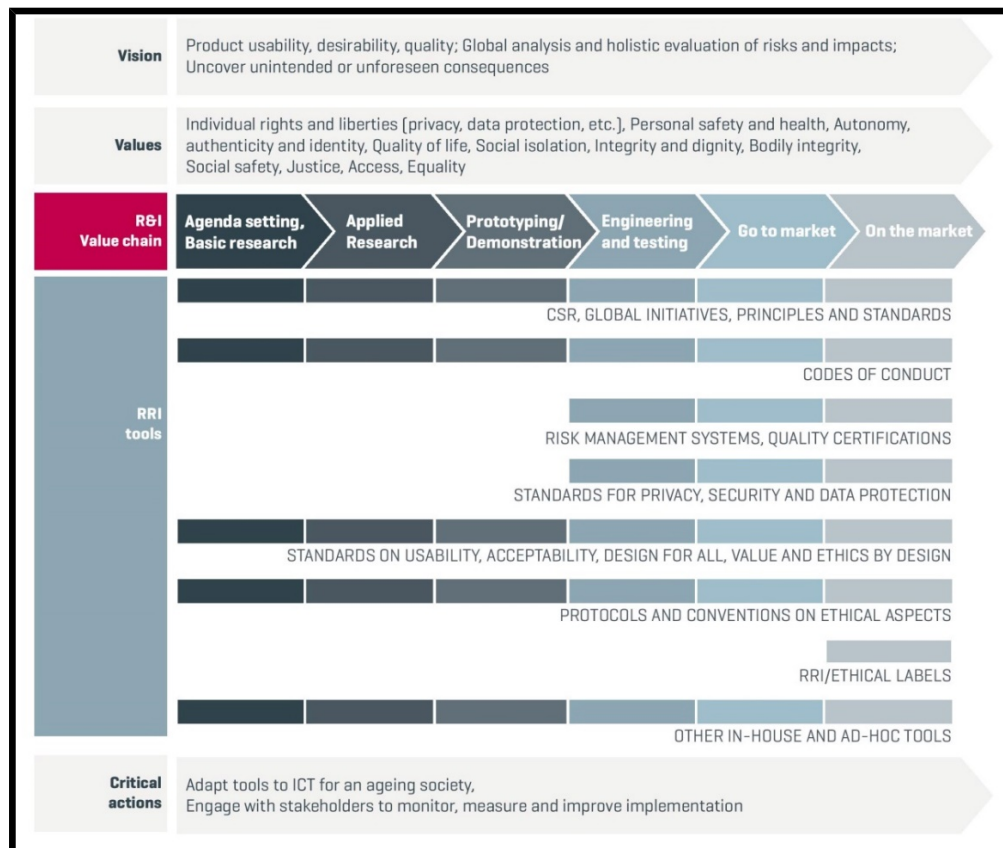


Figure 7 Voluntary governance tools for RRI along the value chain (Porcari, Borsella and Mantovani 2015, 47)

In addition, they advise firms to take due account of conventions, agreements, guidance documents and standards (see also Iatridis and Schroeder 2016).

Read exclusively on its own, it is general impression from the Responsible Industry’s framework that there is no hardwired connection between ALT / ICT for an ageing society as a societal challenge and the framework they propose. The authors do not explicitly embrace the goal of introducing ALT / ICT for the elderly as a political solution, but limit themselves to present the RRI framework in parallel to the case.

In an earlier deliverable from the project, Borsella, Mantovani and Porcari (2015) divide the technical ALT components into those for *sensing, reasoning, acting, interacting* and *communicating*. Relating to sensing they find that “the safety of implantable sensors and the personal data protection are the most critical issues”(8). Whereas for different type of reasoning, including machine learning models, they conclude that data security and data protection regarding personal data are sensitive issue, but the largest risk they find is connected to autonomy, privacy and freedom of movement.

The notion of acting is closely connected to robotics. Here they see that the storage of data, i.e. in “clouds”, represent a security issue and a trust issue, thus “strong integrity and confidentiality protection are needed to secure privacy sensitive data” (11). As for the function of interacting, the authors do not list any particular sensitive issues. This seems somewhat strange given the amount of person sensitive data that must be available to a machine that is to recognize a person through interaction (biometrics, voice recognition) and these should also be usable in public spaces. For the issue of communicating, they take the example of BAN (Body Area Network) communication, which would involve live monitoring of a patient’s health status in dialogue with a health provider. Here, they identify data and network safety, security and protection as central issues.

Analytically, Boresella, Mantovani and Porcari (2015) divide ALT into three different categories: telehealth, smart homes and telecare and connect these respectively to health care, housing and social care. They suggest that telecare is the most established market while telehealth and smart homes have large potentials for growth. The main barriers to development of ALT are below formulated as questions while the facilitator is marked with the “check” and is in italics:

- Uncertainty about the case for ICT-based solutions
  - Do the technologies meet human needs?
  - Can they replace the whole range of human services?
    - ✓ *Comprehensive promotional programmes*
- Value case
  - Does ALT provide value for the money?
    - ✓ *Reliable, flexible and easy to use ALT solutions*
- Business case
  - Can businesses gain from ALT?
    - ✓ *Market and welfare goals combined in innovation policy*
- Ethical issues
  - Will the decline in costs also lead to decline in quality?
  - Will everyone receive equal treatment?
- Un-conducive reimbursement and incentives systems
  - How can ALT get into publicly funded health care?
    - ✓ *Conducive reimbursement approaches*
- Fragmentation of systems and services
  - How can ALT systems be integrated?
    - ✓ *Interoperability and flexibility as key components in ALT solutions*
- Un-receptive or underdeveloped regulatory regimes
  - How can the legal and administrative system based on personal contact transform to fit ALT?
  - How can the different levels and structures of care be integrated through ALT?
    - ✓ *Regulatory and policy changes to make a more favorable environment*
- Resistance to change and lack of capacity to innovate
  - How can health professionals embrace ALT?
    - ✓ *Fostering market deployment by active involvement of end users*
    - ✓ *Market deployment promotion thanks to a partnership with other stakeholders (Boresella, Mantovani and Porcari (2015, 26–27; 31)*

Boresella, Mantovani and Porcari (2015) suggest a division of stakeholders of ICT solutions for the elderly according to four levels

Categories	Type of Stakeholders
Primary Stakeholders	Private users: <ul style="list-style-type: none"> <li>• Senior and impaired citizens</li> <li>• Private caregivers; family members and relatives</li> </ul>
Secondary Stakeholders	Professional users: <ul style="list-style-type: none"> <li>• Medical professionals e. g. operating a tele-medicine center</li> <li>• Professional care providers; care homes</li> <li>• Housing Associations</li> <li>• Mobility Providers e. g. Public Transport</li> </ul> <p><i>Members of this group have a B2C14-relation to the Primary Stakeholders i. e. they “sell” ICT for ageing solutions to clients and have a B2B15-relation to tertiary stakeholders, i. e. they “buy” ICT for ageing solutions from suppliers.</i></p>
Tertiary Stakeholders	Suppliers: <ul style="list-style-type: none"> <li>• Research Organizations : public and private</li> <li>• Enterprises <ul style="list-style-type: none"> <li>• Large enterprises with a business in telemedicine and/or telecare</li> <li>• Providers of ICT infrastructures: networks and databases</li> <li>• Small and Medium size enterprises : hardware, software and/or services provisions</li> </ul> </li> </ul>
Quaternary Stakeholders	Supporters: <ul style="list-style-type: none"> <li>• Policy Makers</li> <li>• Social and Private Insurance companies</li> <li>• Employers</li> <li>• Public Administration</li> <li>• Standardization Organizations</li> <li>• Civil Society Organizations</li> <li>• Media</li> </ul>

Table 1. Categories of Stakeholders in the area of ICT solutions for an ageing society. From Boresella, Mantovani and Porcari (2015, 28)<sup>4</sup>

The case studies from Responsible Industry on ALT were found through a competition. The project announced prizes for best descriptions of RRI with “focus on the grand challenge of health, demographic change and wellbeing” (Schroeder 2015, 65). The judging criteria were:

- Relevance of the case study to the field of RRI
- Clear industry focus (preferably ICT, better ICT and Health, even better ICT, Health, Ageing)

<sup>4</sup> This division could well be used in the Assisted Living project. However, I have to concerns regarding this division. The first concern is, and this is common to most of the reviewed literature, that the governmental (or public) institutions – here “public administration” – that are likely to pay or cover the costs for parts or the whole of these system seem to be invisible. The second concern is to place the media in the same category as employers. If a person is employed and is using ALT, then of course the employer will have a much more direct stake than the media. These two points just illustrate the usefulness of such a table since it starts reflections in the reader.

- Originality of the issues raised
- Transferable relevance to other applications, technologies etc.
- Engaging writing style
- Justification of the use of resources (Schroeder 2015, 66).

It would be reasonable to suggest that the collection of case studies from Responsible Industry consist in a form of best practice of RRI connected to health and ageing. Based on these cases, that took place from between 2008 and 2014; there are some common elements that stand out:

Dialogues between developer and outsiders, such as

- Users
- Care givers
- Academics
- Citizens

The dialogues can take the form of

- Interviews
- Focus groups
- Workshops
- Online consultation

At different stages of the project, such as

- Preliminary background
- Before trial
- During the testing
- During assessment
- Before second trial
- Before and during design phase

For solutions that aim at

- General ageing public
- Patients with dementia
- Patients with other chronic, somatic disease
- Improving the way innovators work in order to find solutions

What is particular from the case studies that aim at aids for people with cognitive loss is that they highlight the needs for interaction together with caregivers in a well-known setting using methods adapted to the users, but without making presumptions about their relations to and understandings of technology.

## **ETICA & FRRICT**

In the 2013 anthology on RRI, Stahl, Eden and Jirotko (2013) present findings from the research projects “Ethical Issues of Emerging ICT Applications” (ETICA)<sup>5</sup> and the “Framework for Responsible

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<sup>5</sup> [www.etica-project.eu](http://www.etica-project.eu)

Research and Innovation in Information and Communication technology” (FRIICT)<sup>6</sup>. They hold responsibility in this context to be a prospective exercise, and see RRI as more of a meta-responsibility that must be aligned with specific (and potentially conflicting) professional responsibilities: “RRI can aim to align responsibilities, to ensure they move in a particular way. RRI can define socially desirable consequences that existing responsibilities can work toward and develop responsibility relationships that ensure that the achievement of such desired aims is possible” (Stahl, Eden and Jirotko 2013, 202).

In the field of ICT, Stahl, Eden and Jirotko propose to analyze RRI according to the four p’s “product, process, purpose and people” (2013, 203). All these four aspects of ICT will entail different considerations, and together they can be used in the work towards a framework for RRI in ICT. From the ETICA project, the authors present a list of the shared features of prospective ICT products:

- Natural interaction (use of ICTs becomes similar to interaction with humans)
  - Invisibility (as a result of miniaturization or embedding of artefacts)
  - Direct link (either physical implant, direct contact (e.g., wearable ICT) or through sensors)
  - Detailed understanding of the user (emerging ICTs will require a highly detailed model of the user to fulfil their tasks)
  - Pervasiveness (ubiquitous embedding of ICTs in the human and natural environment)
  - Autonomy (ability of ICT to act without direct user input)
  - Power over the user (ability to structure the space of action of the user)
  - Market driven (allocation decisions are reached through commercial exchange mechanisms)
- (Stahl, Eden and Jirotko 2013, 205).

They underline that the importance of this documentation is a discussion in the present on how one can act in order to improve the possible ethical and social consequences of ICT solutions containing such features. Central to the task was then the conceptualization of what the “categorisation is meant to represent, namely a view of current discourses on emerging technologies. These discourses are important in that they shape perceptions but also infrastructures and funding that will be used to promote the futures implied in them” (Stahl 2011, 23).

The ETICA project also mapped the main ethical issues in the literature for emerging ICTs, and found these to be privacy, security, trust, liabilities, and digital divides. However, also other more invisible issues were found, such as changes in human identity, new forms of relationships between humans and technologies, novel relationships between individuals or collectives.

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<sup>6</sup> [www.oerc.ox.ac.uk/projects/friict](http://www.oerc.ox.ac.uk/projects/friict)

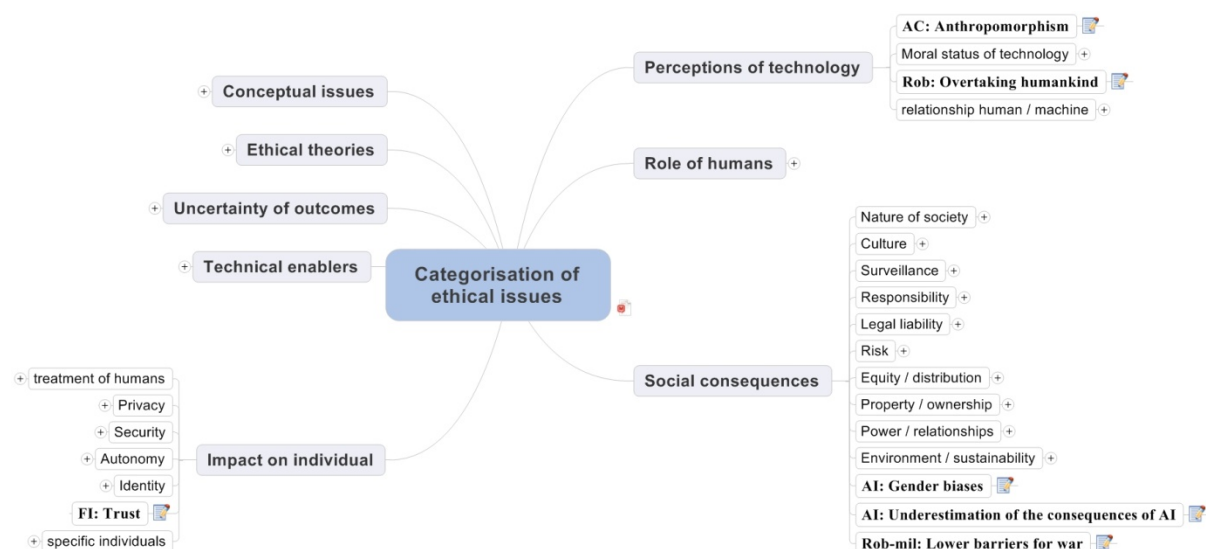


Figure 8 The ETICA method illustrated (Stahl 2011, 27).

They further used a triangulation, or rather quadrangulation method, of evaluating emerging ICTs from the perspective of law, ethics, gender and technology assessments in order to make a prioritized list over which technologies, or aspects of ICT, one should address first – and here ambient intelligence came out on top of the list.

FRRRICT conducted a landscape study through interviews with researchers and research funders in order to see how they articulated their professional responsibilities. They tended to see responsibility as connected to how close to societal use a technology actually was. Further the context of use is deemed to be important by the researchers: if they develop generic functions, they do not see themselves as connected to a public, but if they make concrete applications, this societal use is connected to their professional responsibility. The researchers held that possible negative impacts needed to be clearly identified before one should intervene in their research, and they tended towards seeing the use of products as separate from the production of a device. They are negative to societal debate and oversight of research agendas and priorities, and lack faith in the use of foresight methodologies.

The FRRRICT found that the researchers preferred to discuss issues and potential outcomes during the process and not reflect in advance. They thus suggest to facilitate discussions between the researchers “in an informal and non-binding manner where Chatham House Rule applies, ensuring free and open discussion” (Stahl, Eden and Jirotko 2013, 211). They also see it as fitting that research funders start to investigate how more reflective mechanisms can be included in ICT funding programmes.

The ETICA project proposed to facilitate for ethical impact assessment in ICT, to establish an ICT Ethics Observatory, and establish a forum for stakeholder involvement, on the institutional scale. For researchers and industry, they suggest inclusion of ethics into ICT R&D and project developments.

When it comes to the realization of RRI in ICT, the authors suggest that the activities of RRI will encompass the following aspects:

- Description of subjects of responsibility in ICT (e.g., researchers, professional bodies, funders, policy makers)
- Attribution of objects to subjects (e.g., sustainability, usability, privacy, transparency)
- Facilitation of discourses on norms, values, and ethical foundations
- Design of sanction and incentive structures
- Reflection on preconditions for successful responsibility relationships (Stahl, Eden and Jirotko 2013, 215).

Stahl holds that policy makers are responsible to create conditions for “specific responsibility ascriptions during the technology research and development process” (2011, 29).

The added value of RRI will then consist in being able to align these aspects that already are part of different dimensions of the assessments of ICT processes and products. Stahl, Eden and Jirotko signals that there are needs for future research in

- How to practically preform RRI in ICT
- To align personal and institutional responsibility
- Analysis of the socio-economic environment of ICT applications
- How to incorporate profit thinking (business ethics) into RRI
- The role of policy makers and research funders play as responsibility subjects
- The role civil society can play in RRI for ICT
- The democratic legitimation of publicly funded research

### **PRISE and EuroPriSe**

Privacy enhancing shaping of security research and technology (PRISE)<sup>7</sup> and European Privacy Seal (EuroPriSe)<sup>8</sup> aimed at including data protection and privacy in the fundamental design of ICT systems (Peissel 2011).

PRISE used a mix of expert Technology Assessment and document analysis in combination with participative approaches where they held stakeholder workshops with industry, science and security technology as well as hosted debates in European countries on development scenarios. The outcome was

a high level of consensus among the non-specialist groups in all countries. Among the key statements made, for example, was that a threat from terrorism does not justify an infringement of privacy, that technologies invading the very private (intimate) sphere are unacceptable, and that the abuse of security technologies ought to be prevented (Peissel 2011, 40).

Also the PRISE project found the principle of proportionality to be among the most important ethical issues in ICT. The PRISE project suggested an evaluation of expectation of outcomes of projects in three stages:

1. baseline of personal life (data that should not be gathered and/or stored)
2. data protection compliance (how data presently are stored and protected)
3. context-sensitive trade-offs (areas where security technologies might conflict with privacy, but create security gains). (Peissel 2011)

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<sup>7</sup> [prise.oeaw.ac.at](http://prise.oeaw.ac.at)

<sup>8</sup> [www.european-privacy-seal.eu](http://www.european-privacy-seal.eu)



The PRISE project concluded in its statement paper that

- i) An inviolable *baseline of privacy* needs to be established.
- ii) There is no linear, interchangeable relationship between privacy and security, and the relationship between them is *not a zero-sum game*.
- iii) Minimising the processing of personal data is an important principle of data protection.
- iv) *The consolidation of databases* in order to analyse the behaviour of the entire population breaches the principle of the presumption of innocence and the principle of proportionality.
- v) The protection of privacy is the shared responsibility of all involved, and observance of *privacy should be a key non-functional requirement* of security technologies.
- vi) In addition, the *criteria* for evaluating security technologies must be *continuously developed* and regulations should be introduced for a limited time and continuously reassessed (Peissel 2011, 41)

The EuroPriSe investigated the possible introduction of a quality seal for privacy among European ICT entities. The project developed a model whereby an ICT entity and an independent security expert as well as a lawyer agree on a “Target of Evaluation”. The experts notifies the accrediting body.

From the PRISE and the EuroPriSe project, there are not expressed direct research needs, but rather challenges for research projects:

- Design security in order to enhance privacy
- Expand the exploration into societal and technological developments in the understanding of privacy and the protection of privacy
- How can legislation be enforced in a specific project
- Apply and test existing tools and concept – specifically self-regulation of companies.

### Technolife

Rommetveit (2011) presents how technologies and responsibilities are co-created by drawing on the notion of “socio-technical imaginaries” in the findings of Technolife<sup>9</sup> project. There are two main imaginaries identified by the project, according to Rommetveit there are two opposing views of the Internet where the one is

“flexible, de-centralised, open and evades regulation ... bottom-up, highlights complexity and unpredictability, and so is easier associated with open and horizontal societies” (Rommetveit 2011, 73),

and the other

“top-down and seeks to impose regulation on the ungovernable ... centralised and imposes standardisation and control, and is associated with governmental hierarchies and large corporations” (Rommetveit 2011, 73)

The framing of ICT projects and the consequent views on responsibility, justice, ethics, and society depends on whether one sees them as flexible or controlling. Technolife holds then that a view where privacy and security can be balanced against each other accepts an understanding of information as being based on the control imaginary, and not as a part of the sharing and flexible

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<sup>9</sup> [www.technolife.no](http://www.technolife.no)

imaginary. The public has more advanced and nuanced views on the role of ICT in their lives than a simple trade-off understanding.

The Technolife projects then sets out the task for future research:

- to better understand the public's situated understandings of ICT technologies in relation to underlying concerns, values, preferences, sociability etc.

## **PRESCIENT**

The Privacy and Emerging Sciences and Technologies (PRESICENT)<sup>10</sup> had as aim to develop a Privacy Impact Assessment (PIA). Wright et al. define PIA as

a process of engaging stakeholders in order to consider how privacy might be impacted by the development of a new technology, product, service, project or policy and what measures could be taken to avoid or mitigate unwanted effects. (2011, 84)

PIA takes as a point of departure the precautionary principle. This principle, Wright et al. suggest, demands action to counteract undesirable potential outcomes. They include participatory approaches in order to include “all points of view, even the views of a minority, in order to have as complete a picture of the situation as possible” (Wright et al. 2011, 88). A PIA should, according to the UK Information Commissioner's Office have the following aims:

- identify a project's privacy impacts,
- understand and benefit from the perspectives of all stakeholders,
- understand the acceptability of the project and how people might be affected by it,
- identify and assess less privacy-invasive alternatives,
- identify ways of avoiding or mitigating negative impacts on privacy,
- document and publish the outcomes of the process. (Wright et al. 2011, 91)

The PIA comprises a full set of phases similar to other process tools that include issues of balancing concerns, and ends with a final audit. However, it seems that the inclusion phases of the PRESICENT are limited to the preparatory phase and the analysis phase, and without any such engagement in the final phase, see illustration:

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<sup>10</sup> [www.prescient-project.eu](http://www.prescient-project.eu)

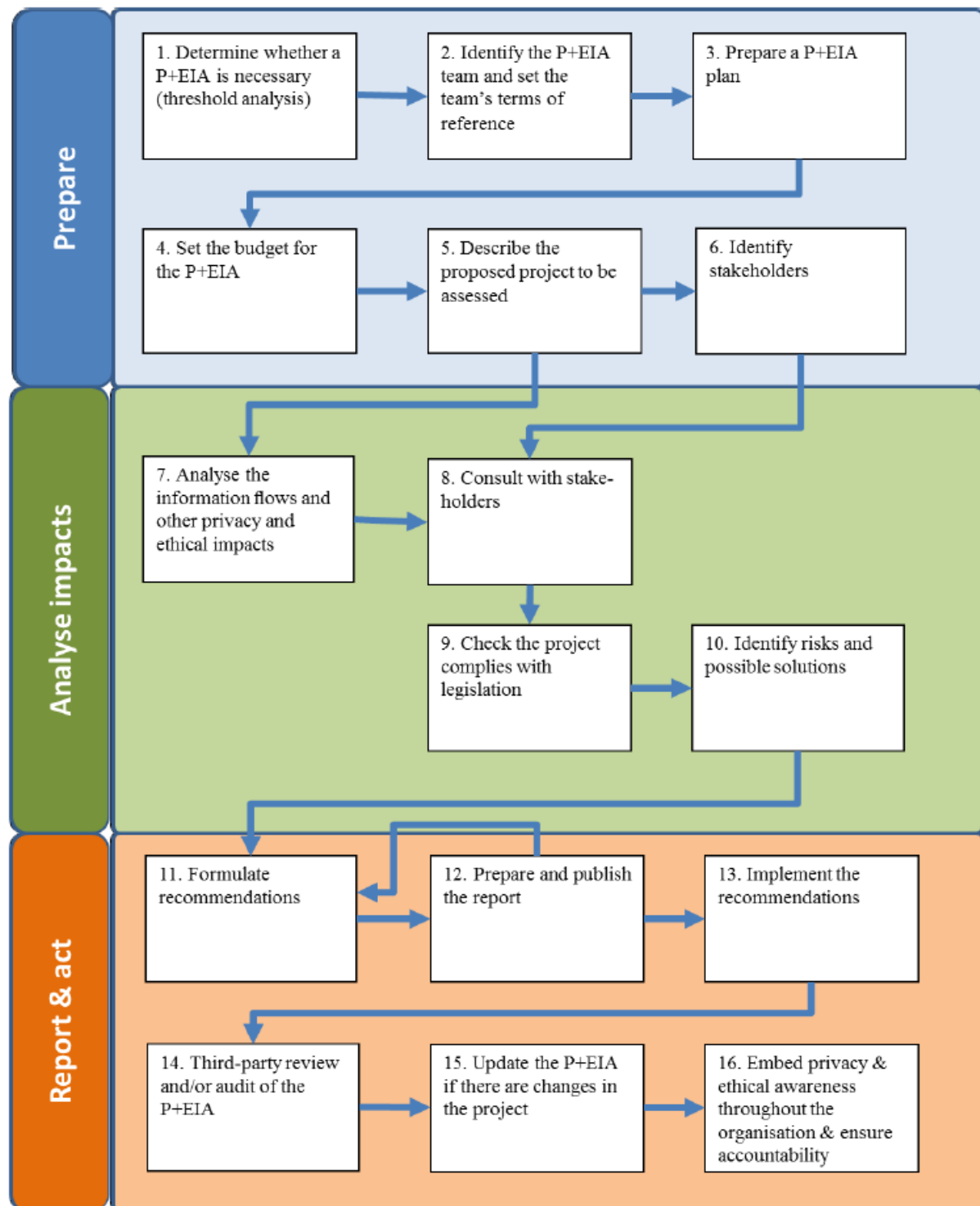


Figure 9 Integration of EIA with PIA (Venier et al. 2013, 92).

The illustration above presents the 16 step PIA suggested by the PRESCIENT, as a tool for organization that wish to engage in risk management. What they highlight as remaining issues are

- how best to balance competing values,
- how best to implement such instruments at all pertinent levels and sectors of the society,
- how to integrate stakeholders in the best participatory mode remain (Wright et al. 2011, 97)

## PATS project

In the project Privacy Awareness through Security Organisation Branding (PATS)<sup>11</sup>, they identified a “gap between data protection regulations and privacy practices – practices often do not follow the written rules. There is thus a need for measures to guide the transformation of existing rules into practices” (Guagnin, Hempel and Ilten 2011, 100).

The PATS project found that their studied organizations perceived privacy as being the citizens’ responsibility. They suggest that a system of self-regulations can assist security organizations to align their practice with the legal regulations.

Their research found that data protection is linked to and framed as data security in the interviewed organizations, and not connected to linking of data sets and power arising from the ownership of data. Privacy concerns were mainly communicated rather than implemented, and the concern is to avoid conflicts with the authorities. Privacy is further understood as a technological issue or a legal issue, as a fixated and unchanging concept.

The PATS project raises the issue of choice: How much choice can a person be said to have in a situation that is societally streamlined into being monitored? And what further privacy demands might a citizen claim towards the monitoring agent when the citizen has agreed to data sharing and storage? The organizations seemed to shift the accountability towards the end-user if she/he had agreed to take part in an ICT-based activity that involved storage of personal data.

The PATS report on a grass root lay panel that oversees municipal CCTV practice as one example of end-user involvement, and open source software as another.

The authors suggest that a concept of accountability – “*who is accountable for what and to whom*” (Guagnin, Hempel and Ilten 2011, 108) – as more encompassing than mere responsibility because of its three dimensions. Consequently, the authors suggest a type of evaluation and possible remediation process.

The authors highlight that

- there is a need to develop a form of “bridge between the concept of privacy and the practice of data protection” (Guagnin, Hempel and Ilten 2011, 112) through and by self-regulation based on accountability thinking.

## ETHICAL

The Ethical<sup>12</sup> project studied the “[e]thical implications of data collection, use and retention” (Menevidis, Swartzman and Stylianidis 2011, 118) in medical and/or biometric data with the aim to provide a practical toolkit for researchers.

They suggested to include a deliverable on risk management, and in addition a set of guidelines expressed in a code of conduct, based on structure of the code of conduct for responsible nanosciences and nanotechnologies research.

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<sup>11</sup> pats-project.eu

<sup>12</sup> www.ethical-fp7.eu

The code might not be of direct relevance to the Assisted Living project, but it draws upon general guidelines for data gathering, and it calls for a further validation through empirical cases and use.

### EFORTT

The Ethical Frameworks for Telecare Technologies (EFORTT)<sup>13</sup> was an ethnographic project aiming at documenting how telecare affects and is understood by those receiving care. Mort, Roberts and Milligan (2011) see care as being split into three different domains monitoring, physical care, and social-emotional care through the installation of telecare systems. They conclude that only monitoring can be achieved with some degree of efficiency by telecare systems.

As was mentioned in the general part of the review, telecare systems ignore the actual contribution and bonds between call center operatives and the elderly. Further, it neglects that the physical aspects can create novel risks such as anxiety through the introduction of devices or false positives in the case of pill dispensers that are empty, but without indicating if the medication was actually taken. The physical aspect in telecare arrangements might well be placed into the responsibility of unpaid (female) relatives and/or low-paid (female) workers. Notions like “unnecessary visits” to see if an elderly is well, ignores the socio-emotional aspects of care, and suggests a pure instrumentality.

Telecare’s logic is then presented as involving

- a) monitoring or checking is reduced to a ‘purely technical’ procedure that can largely be done by machines, backed up by monitoring centre staff when alerts are triggered;
- b) ‘physical’ care is seen as basic labour and is left in the hands of poorly paid women, often migrants; and
- c) ‘social and emotional’ care is performed by loving, but busy, family members. (Mort, Roberts and Milligan 2011, 160)

The authors conclude with the challenge for a Responsible Innovation approach to telecare:

- To give attention to the potential of telecare to reorder social relations,
- To rethink care as a relational practice, and apply this in the design of care technologies
- To imagine substantive improvements in the lives of older people, and their carers (Mort, Roberts and Milligan 2011, 162)

This can be achieved through:

- inclusive design,
- ongoing engagement with older people as users of new care technologies and
- public involvement (Mort, Roberts and Milligan 2011, 162)

so that policies might be aligned to the inherent aspiration of care work and to the changing content of care practices itself

### ALwEN

Ambient Living with Embedded Networks (ALwEN)<sup>14</sup> worked on developing “an in-house monitoring application for people with COPD [Chronic obstructive pulmonary disease] based on ambient

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13 [www.lancaster.ac.uk/efortt/](http://www.lancaster.ac.uk/efortt/)

14 [www.almende.com/alwen](http://www.almende.com/alwen)

intelligence technology” Doorn 2014, 307). Doorn identified hesitation between technologists and clinicians as to who should take the initiative in the work, and bring it forward: “The technical partners seemed to be waiting for instructions ‘how to establish social acceptance,’ whereas the clinical partners seemed to be unaware of the possibilities of WSN technology” (Doorn 2014, 311). The technologists wanted to keep the options open for as long as possible, but the social acceptance and views depend on applications. Doorn suggest that ethicist and social scientists in RRI projects do not limit themselves to a neutral view on technologies, but consider actual (existing) applications at all stages in a project. She advises that engineers are trained in moral, ethical and social issues in order for them recognize such potential issues and invite in experts in these fields when they encounter issues that hesitate dealing with.

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