DELIVERABLE 2.5
Actual and perceived privacy considerations and ethical requirements II

<table>
<thead>
<tr>
<th>Dissemination Level</th>
<th>Public</th>
</tr>
</thead>
<tbody>
<tr>
<td>Due Date of Deliverable</td>
<td>Project Month 18, 30 September 2016</td>
</tr>
<tr>
<td>Actual Submission Date</td>
<td>30 September 2016</td>
</tr>
<tr>
<td>Work Package</td>
<td>WP2, Early detection of emerging functional impairments</td>
</tr>
<tr>
<td>Task</td>
<td>Task 2.2, Review of sociological, ethical, and gender issues</td>
</tr>
<tr>
<td>Lead Beneficiary</td>
<td>FZ</td>
</tr>
<tr>
<td>Contributing beneficiaries</td>
<td>FSL and FHAG</td>
</tr>
<tr>
<td>Type</td>
<td>Report</td>
</tr>
<tr>
<td>Status</td>
<td>Submitted</td>
</tr>
<tr>
<td>Version</td>
<td>Final</td>
</tr>
</tbody>
</table>
Abstract

This report includes an updated literature review containing the sociological, ethical and gender-related projections on medical data collection.

History and Contributors

<table>
<thead>
<tr>
<th>Ver</th>
<th>Date</th>
<th>Description</th>
<th>Contributors</th>
</tr>
</thead>
<tbody>
<tr>
<td>00</td>
<td>14 Jun 2016</td>
<td>First draft, establishing document structure.</td>
<td>NCSR-D</td>
</tr>
<tr>
<td>01</td>
<td>11 Jul 2016</td>
<td>Input added in Section 3</td>
<td>FZ</td>
</tr>
<tr>
<td>02</td>
<td>18 Aug 2016</td>
<td>Content added by FZ (to all sections)</td>
<td>FZ, FHAG</td>
</tr>
<tr>
<td>03</td>
<td>19 Sept 2016</td>
<td>Commented by FHAG</td>
<td>FHAG</td>
</tr>
<tr>
<td>04</td>
<td>27 Sep 2016</td>
<td>Section 2 added. Content added to Section 4. List of requirements updated.</td>
<td>FZ</td>
</tr>
<tr>
<td>05</td>
<td>28 Sep 2016</td>
<td>Internal review</td>
<td>FHAG/NCSR-D</td>
</tr>
<tr>
<td>Fin</td>
<td>30 Sep 2016</td>
<td>Final document preparation and submission</td>
<td>NCSR-D</td>
</tr>
</tbody>
</table>
## Abbreviations and Acronyms

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
</tr>
<tr>
<td>ASQ</td>
<td>After-Scenario Questionnaire</td>
</tr>
<tr>
<td>IADL</td>
<td>Instrumental Activities of Daily Living</td>
</tr>
<tr>
<td>interRAI HC</td>
<td>The <em>interRAI</em> Home Care Assessment System</td>
</tr>
<tr>
<td>interRAI LTCF</td>
<td>The <em>interRAI</em> Long-Term Care Facilities Assessment System</td>
</tr>
<tr>
<td>MMSE</td>
<td>Mini Mental State Examination</td>
</tr>
<tr>
<td>PIADS</td>
<td>Psychosocial Impact of Assistive Devices Scale</td>
</tr>
<tr>
<td>SUS</td>
<td>System Usability Scale</td>
</tr>
<tr>
<td>HTMS</td>
<td>Home Telecare Management System</td>
</tr>
<tr>
<td>AT</td>
<td>Assistive technologies</td>
</tr>
<tr>
<td>ICT</td>
<td>Information communication technologies</td>
</tr>
</tbody>
</table>
CONTENTS

Contents ...................................................................................................................................................... iii
List of Figures ................................................................................................................................................... iv
List of Tables ................................................................................................................................................... v
1 Introduction .................................................................................................................................................. 1
  1.1 Purpose and Scope .................................................................................................................................. 1
  1.2 Approach ............................................................................................................................................... 1
  1.3 Relation to other Work Packages and Deliverables .............................................................................. 2
2 Ethics and Assistive Technologies ............................................................................................................. 3
3 Individual perception of obtrusiveness ....................................................................................................... 4
  3.1 Physical dimension ................................................................................................................................. 4
  3.2 Usability ................................................................................................................................................. 5
  3.3 Privacy .................................................................................................................................................. 7
  3.4 Function dimension ............................................................................................................................... 8
  3.5 Human interaction ................................................................................................................................ 9
  3.6 Self-concept ......................................................................................................................................... 10
  3.7 Routine dimension ............................................................................................................................... 11
  3.8 Sustainability dimension ...................................................................................................................... 11
  3.9 Trade-offs between obtrusiveness dimensions ...................................................................................... 12
4 Notifications to caregivers and perceived obtrusiveness ......................................................................... 14
5 Requirements ........................................................................................................................................... 15
6 Conclusions ................................................................................................................................................ 16
References .................................................................................................................................................... 17
LIST OF FIGURES

Figure 1: Dependencies between this deliverable and other deliverables........................................2
LIST OF TABLES

Table 1: RADIO ethical requirements ................................................................................................. 15
1 INTRODUCTION

1.1 Purpose and Scope

This report reviews current studies of sociological, ethical, and gender issues associated with collecting information for medical purposes and investigates the impact of such sociological, ethical, and gender issues to the RADIO system’s design. This work includes (a) studying how RADIO can alleviate an elderly person’s insecurity when living alone; (b) setting privacy requirements on the information transmitted to medical personnel and to informal care-givers as well as to the actions that the platform may effect; (c) conditioning and customizing the above to end-users of different gender and social, cultural, and ethical background.

1.2 Approach

D2.4 Actual and perceived considerations and ethical requirements I, the predecessor of the present report, discussed issues related to actual and perceived privacy. Actual privacy considerations were considered from the perspective of data protection. Specifically, D2.4 listed the relevant data protection directives and outlined the parameters RADIO must take into account to assess the data protection impact. User’s perception of privacy was also treated considering: the dynamically evolving capabilities of monitoring, public perception of privacy in the health context, human-robot interaction issues, and gender issues. Finally, the report set a number of requirements related to both data protection and preservation of user’s privacy and sense of control over the system. Moreover, D2.6 further analyzed, among others, the multidimensional construct of obtrusiveness and how it is perceived by each individual.

In this report, we take as a starting point the various considerations related to perceived obtrusiveness (as discussed in D2.4 and D2.6) and we examine if and to what extend the various dimensions of obtrusiveness are related to: the characteristics of our target group, the social and cultural background and the gender.

Moreover, we look into more details issues concerning to what extend the various notifications that the formal and informal caregivers receive are considered obtrusive by the primary users.

The final and main product of this deliverable is a final list of considerations/ requirements for the RADIO system.
1.3 Relation to other Work Packages and Deliverables

D2.5 sets the actual and perceived privacy considerations and ethical requirements for the RADIO system considering the details of the target group.

This deliverable is a successor of D2.4: *Actual and perceived privacy considerations and ethical requirements I*.

D2.3 and D2.5 together will be used to set the trade-off between medical requirements and the obtrusiveness of the RADIO System (D2.7).
2 ETHICS AND ASSISTIVE TECHNOLOGIES

Mordini et al., (2009), in their report “Senior citizens and the ethics of e-inclusions”, have analyzed the ethical principles that the European Union imposes when it comes to senior citizens and their access to digital and information technology. The basic ethical values that have to be preserved are privacy and data protection, quality of life, autonomy and safety. Also, according to them, Assistive Technologies (AT) are aimed at compensating for frailty, and for protecting and enhancing quality of life and promoting independent living.

Ethics refer to moral principles that relate societal values to actions. The EU Charter of Fundamental Rights is the key document for understanding the fundamental ethical principles of the EU. It sets out what can be viewed as the core values of the EU: human dignity, freedom, democracy, equality, the rule of law and the respect for human rights. It recognises both the right to private life (Article 7) and the right to the protection of personal data (Article 8) and therefore applicable to ICT research. Article 25 provides for the recognition and respect of the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life.

The discourse around assisted living technologies, particularly when used to support the care for vulnerable persons in their home and the ethical issues raised around privacy, dignity, autonomy and respect have been ongoing for some time.

The framework, originally developed by Beauchamp and Childress (1994), has been widely used in health and social care and it is specifically relevant that it has been used by a number of authors to discuss the ethical issues associated with the use of assisted living technologies to support people with dementia.

The four principles are: autonomy, beneficence, non-maleficence and justice; each of them is described briefly below.

**Autonomy** — the ability of an individual to make choices — promotes independence and choice in everyday life. In the case of elderly people being monitored, the introduction of assisted living tools can drastically influence their level of autonomy.

**Beneficence** — the principle of working for the benefit of the individual. Assisted living technology has the potential to benefit people, and when materialized under human centered design, can provide assurance and confidence and a much better quality of life in everyday terms.

**Non-maleficence** — the principle of doing no harm. While AT is capable of providing various kind of services to the beneficiaries, it also has the potential to expose people to risk, so a balance must be achieved between ensuring safety and invading privacy, adding a cautionary note that the potentially stigmatising effect of monitoring should be recognised and minimised.

**Justice** - Justice relates to a moral obligation to act on a fair adjudication between conflicting claims, so in this context, ‘justice’ refers to fairness in access to support services. The essence of justice focuses on the allocation of assisted living technologies in a way that balances the needs of the individual with the development of the preconditions for accessibility for all.

---

3 INDIVIDUAL PERCEPTION OF OBRUSIVENESS

As described in details in D2.6, obtrusiveness is a multidimensional concept associated with the telehealth technology; it is a subjective term; the user is not the only subject but also involves all residents of the home; and finally it is dependent on where the technology (home vs institution) applies [Hensel et al., 2006]. In this report, we examine to what extend the several dimensions of obtrusiveness, such as usability, privacy, function, human interaction, self-concept and routine, depend on the characteristics of our target group (frailty and age).

The characteristics of the RADIO primary users (described in details in D2.1) are individuals older than 64 years old, with some frailty (they are able to walk without human assistance indoors but they need supervision in almost two iADLs)

3.1 Physical dimension

Physical dimension of obtrusiveness is related to functional dependence, discomfort or strain, excessive noise, obstruction or impediment in space, aesthetic incongruence [Hensel et al., 2006]. As discussed in D2.6 ‘Guidelines for balancing between medical requirements and obtrusiveness’, issues related to this dimension concern: the use of environmental (smart home) sensors vs wearable sensors, and the environment itself (institutional vs private). The physical dimension is affected significantly by the morphology of the particular setting where the older persons live, and of course by the presence of the equipment as functioning part of this setting. Moreover, in terms of robot use, excessive noise and proximity to the user during operation must be considered.

Obstruction in space and aesthetic incongruence in one’s own environment can be quite obtrusive for elderly as the aging of the elders and the progressive contraction of their life space makes the immediate environment of their homes even more important. This could perhaps explain the reluctance of older people to make changes in their living environment. In fact, most of them tend to view their environmental situation as comfortable, being eager to psychologically adapt themselves into the environment than altering the physical or social characteristics of their home environment [Wister 1989].

Forlizzi (2005) describes the complex interactions between people, products, activities, and resulting experiences that take place in an elder’s environment as ecology of aging. In fact, while technology intends to cover newfound needs or increase the safety of the beneficiaries as they decline, technological innovations can possibly serve as a source of frustration and even isolation. Many products due to the aging process and possible change of environmental conditions may have some unintended consequences for elders as well [Forlizzi, 2005].

Environmental factors play an important role in the adoption of assistive technologies by elderly. Hirsch and colleagues (2000) conducted a qualitative study focused on identifying and assessing the importance of psychological and social factors in the eldercare experience in the framework of the ELDER (Enhanced Living through Design Research) project. The results of this study suggested that elders will not set usability as a priority compared to social, emotional, and environmental factors. On the contrary, they might reject a device that does not match their environment or makes them feel embarrassed (this is also pertinent to the self-concept dimension of obtrusiveness).

The role physical dimension of the equipment can play in end user’s acceptability is also shown in Demiris (2009) study aiming to evaluate the acceptance of two sensing approaches to smart home design, namely Distributed Direct Sensing (DDS) and Infrastructure Mediated Sensing (IMS) by older adults. Participants stated that using a home’s existing utility infrastructure (IMS) provides important
benefits with regard to privacy when compared to approaches that propose cameras, sensors or microphones within the living space (DDS) as they seem less obvious to visitors and are not clearly visible as constant reminders of one’s own frailty.

According to Courtney et al. (2007) study, perceived invasion of personal information and perceived violations of the physical self and personal space at home are associated with perceptions of obtrusiveness in the privacy domain.

Another important issue of physical obtrusiveness is mainly connected with the location preferences of the older people within the home. Mihailides et al. (2008) studied the willingness of two generational cohorts (current baby boomers and older adults) to accept home monitoring technology. The most important factor influenced by the type of the location was the correlation between the perceived invasion of privacy to the perceived risk of injury. The most evident example in this study was about bedroom and bathroom, areas where highly private yet risky activities take place, where some of the strongest comments were given.

A barrier related to the physical dimension of obtrusiveness is also the capability of the living environment - especially the home environment - to adapt effectively the technological infrastructure.

Edward and colleagues (2001) refer to the "accidentally" smart home, which contains technological components embedded in an environment and has not benefited from a holistic, ground-up approach to design and integration. While current research into domestic technologies has taken an intentional approach in designing the smart home environment from the ground up to support assisted living technologies, the homes of the elderly people cannot be custom designed from the start to accommodate and integrate these technologies.

Oswald et al. (2007) examined the relationship between aspects of objective and perceived housing and aspects of healthy aging, argue that housing solutions should be seen under a multidisciplinary approach to assessment and care planning leading to home modification and relocation as part of the holistic consideration of the personal needs and preferences of the older people.

In terms of people’s perception of assistive robots and smart domotic environments with the use of a robotic mediator in a domestic environment equipped with sensors, Cesta et al. (2007) found that elderly people did not consider robot as a possible source of intrusion/disturbance in personal life. Moreover, the elderly showed more positive reactions and evaluations when having the opportunity to know what a robot can actually do in the domestic environment.

3.2 Usability

The usability dimension of obtrusiveness is related to lack of user friendliness or accessibility, additional demands on time and effort [Hensel et al., 2006]. Moreover, we also consider in this dimension the notion of utility and usefulness. Several parameters should be taken into account when having to do with the process of ageing and subsequent needs, the right justification of the usefulness of the technological equipment in terms of safety and quality of life, and the attitude of older people towards technology.

For this reason, it is an absolute priority that the actual needs of stakeholders including end users, caregivers, and clinical professionals should be the first to be taken under consideration for the design and implementation of sensing technology in smart homes and not the functional capabilities of the technological advancements [Ding et al. 2011]. An important precondition for the acceptance by the elderly people of technology is to be able to recognize and agree with the benefits it promises to provide [Steele et al. 2009].
According to Davis (1989) ‘perceived usefulness’ is a major determinant of ‘intention to use’ and the users will adopt a new IT system if they perceive the system useful, even if they dislike it suggesting that patients’ should be made aware of the useful aspects of the system in order to improve their acceptance. This aspect was also brought forward in more recent studies. Mahoney et al. (2009) concluded in their research on understanding of the elders, families and staff concerns in independent living residencies (ILR), that monitoring technologies need to be customized to the concerns of the key stakeholders in order to promote adoption and buy-in. Key to acceptance was the residents’ perceived need and usefulness of the system to maintain independence and prevent being relocated to a more restrictive environment.

Rahimpour et al. (2008) focused on identifying any major factors that could affect patients’ perceptions of a Home Telecare Management System (HTMS). They found that patients’ concerns were related to “ease of use”, self-efficacy and anxiety. The findings of this study suggest that HTMS self-efficacy and anxiety are likely to be important constructs in patients’ acceptance of home telecare.

Again in the study of [Mihailides et al, 2008] another aspect that should be carefully examined is that usability of a given technological infrastructure for elderly people might well be affected by the lack of perceived need as being a reflection of current health status of the participants.

The lack of exposure of older people to technology infrastructure and monitoring equipment can also become obtrusive in terms of usability. Despite many expressed reservations concerning the capacity and willingness of elderly people to cope with complex technological equipment, the so called technophobia, as it comes out from several relevant researches, is not at all justified [Mihailides et al., 2008; Browsnell et al., 2000; Demiris et al., 2004; Zimmer & Chappell., 1999].

Giuliani et al. (2005) in their research on understanding to what extent elderly people are likely to accept a technological aid in performing everyday activities, they put under dispute the widespread stereotype that elderly people would be hostile to changes, even more when it comes to the introduction of technological devices. They argue that technological devices clearly go unused only when they appear to be unrealistic or in conflict with the main goal of their action.

Similarly, Demiris et al. (2006), in a study aiming to present an evaluation framework for a formative and participatory evaluation of a smart home application for older adults, confirmed the positive attitude of the participants towards technology and their will to accept the installation of sensors and devices in their homes. Lack of any evidence ‘for a positive relationship between age and technophobia’ was also confirmed in an older study that reported a survey of 2500 older people [Collins et al., 1992].

In any case, technology must be compatible with the actual capabilities of the older people and their carers, taking into account the end users perceptions towards technology and the easiness of usage of the technology itself. Researchers and technology developers are responsible for considering how they will address the needs and limitations of older adults with regard to their interface with technology [Mahoney et al. 2007]. Age-related constraints and potential inexperience with technology of the elderly users is one of the biggest challenges that home telecare systems designers need to address in order to increase the system’s functional accessibility and cover the varying needs of the final users [Demiris et al. 2001]. Optimizing the patient’s abilities to accomplish their tasks through system usability and design interfaces will help users to perceive the system as a useful tool.

Users’ acquaintance with ICT is a determining factor in their confidence in handling new technology, according to a study of focusing on a comparison of elderly perceptions of social assistive domestic robots between Italian and Swedish user groups [Cortellessa et al. 2008]. In addition, lack of confidence in their computer skills and slower retrieval of information, especially in regard to processing speed and psychomotor skills [Cheek P. et al. 2005].
According to Hirsch et al., (2000), user perceptions of their own abilities are often out of step with their actual capabilities causing them either to be fearful of attempting relatively safe tasks, or in case of overestimation of their capabilities to undertake risky tasks. The design of assistive technologies is extremely significant as a factor contributing to disparity between perceived and actual capabilities since it can contribute to an inaccurate assessment of one’s functional ability.

In the study of McCreadie et al. (2005), sixty-seven people aged 70 or more years were interviewed in-depth during 2001 to find out about their use and experience of a wide range of assistive technologies. It comes out that the acceptability of assistive technologies depends on the successful balance between the assessments of ‘objective’ needs to the individual’s perception of his or her own needs, the recognition of “product quality” and its availability and cost. They also emphasize that there are not only diverse needs, but also variable interpretations of comparable needs by different individuals.

The ease of use is another parameter affecting usability. Steele et al., (2009) findings from an exploratory study carrying out qualitative research into the perceptions, attitudes and concerns of elderly persons towards wireless sensor network (WSN) suggested that systems with a simple interface that require the least amount of interaction are more likely to be accepted by an elderly person.

Finally, in terms of having an interactive robotic around the house, older adults prefer an assistive technology that can be adaptive to their needs [Heerink M., 2011]. Heerink demonstrated a video of a robot interacting with an elderly to 100 older adults living in apartments close to or within eldercare institutions in the cities of Almere and Amsterdam. He concluded that adults prefer a system that adapts itself, requiring limited or no knowledge on operating it, but still leaving the user in control. In fact when adaptive, a request for approval (suggesting more user control) leads to a higher score on acceptance.

### 3.3 Privacy

The privacy dimension of obtrusiveness is related to invasion of personal information and violation of the personal space of home [Hensel et al., 2006]. Besides the ethical and ontological consideration which was analyzed in detail in D2.4, the notion of privacy is affected by the personal beliefs and perceptions of each individual and his/her current physical, social and mental condition in the location he/she lives. The privacy terms can affect the willingness of people to participate in smart home projects or their acceptance of certain types of smart home IT [Stefanov et al, 2004]. The knowledge of how privacy concerns affect older adults’ willingness to adopt new technologies is one necessary component for identifying which seniors might benefit from the technology.

Before the evolution of the technology, the main concerns around privacy depended fundamentally on the characteristics of the built environment (not allowing to someone to hear or to see us) and the behavioral norms concerning the preservation of interpersonal space [Altman I., 1975]. Preservation of privacy in spatial terms, meaning the avoidance of the violation of the physical space, has to do with the means, the context, and the extent to which privacy can be compromised [Bauer, 2001].

Nowadays, the advancement of technology has substantially modified the end users concerns not only in aspects of space and location, but also and mainly, in aspects concerning the accessibility of information and the obtrusiveness deriving from the constant surveillance.

The relationship between privacy and smart home technology is multidimensional and can be a barrier to adoption of technology by the users despite resident needs [Coughlin et al. 2007]. Under this perspective the design of smart home technology and subsequent interventions need to consider both privacy and self-perception of need [Courtney, 2008]. Privacy management is a dynamic response to circumstances rather than a static enforcement of rules defined by a set of tensions between competing
needs; the way technology disrupts the boundaries between these tensions is how it impacts on privacy [Palen et al. 2003]. Demiris et al. (2006) found that older adult had a positive attitude towards smart home technologies while they seek for a balance between the benefits of monitoring, determined by level of need, and the concomitant perceived intrusion into privacy at home.

Regarding assisted living technology, privacy is defined by the ability to control access to personal information in smart homes, ensuring that elderly people retain the control over the parameters of the applications [Courtney et al., 2008]. In addition, users consider that their privacy is undermined when health information that users believe should be kept private is shared or when the use of monitoring equipment is not well understood by the elders.

In many cases, elderly people place their preference on ensuring that help is readily available over privacy or the confidentiality of their health information [Steele et al, 2009]. Privacy can be a secondary issue if the monitoring is deemed useful with respect to safety, maintaining independence, and health [Mihailides et al, 2008].

In an anticipatory evaluation of an actual “smart home” project implemented in an independent retirement facility [Demiris et al. 2008], participants did not express privacy concerns. Their participation in the smart home project and permission for the installation of the technology in their apartments was based on their belief that the concomitant perceived intrusion of their privacy at home was to be balanced by the benefits of such monitoring. Furthermore, throughout the study, participants stated that they had no privacy concerns and felt that allowing for monitoring of their daily activities was providing ease of mind and/or the sense of contributing to generating of new knowledge by participating in a research study.

On the other hand, in another study [Demiris et al. 2004], 15 older adults participated in three focus group sessions to explore the perceptions and expectations of seniors in regard to ‘smart home’ technology installed and operated in their homes with the purpose of improving their quality of life and/or monitoring their health status. All participants felt that the use of cameras within their homes for the purpose of identifying falls or other accidents was ‘obtrusive’ and would be violating the resident’s privacy. This is verified also by other surveys concerning the concerns of the elderly people on the violation of their privacy by cameras [Brownsell et al. 2000; Courtney et al. 2008; Mihailidis et al. 2008]. Nevertheless, the study confirmed that all participants had a positive attitude towards technology and were willing to accept the installation of sensors and devices in their homes for the sake of safety.

Caine et al. (2006) investigated the effects of different types of visual sensing devices as well as the level of their functioning on the perception of privacy, 25 older adults between the ages of 65 and 80 passed a structured interview expressing differentiated privacy concerns that are related both to image type and a person’s need for support. The complexity of the context of privacy requires the perfect understanding of the variables that influence privacy concerns as well as the degree to which such concerns are mediated by potential benefits.

In another study Essen et al. (2008), conducted in-depth interviews with 17 seniors who participated in a tele-monitoring project and who had experience of being continuously monitored in their own homes. The majority of the seniors considered care surveillance as protecting their safety and indirectly protecting their privacy by enabling them to continue living in their own homes rather than moving to a nursing home.

### 3.4 Function dimension

The function dimension is related to malfunction or suboptimal performance, inaccurate measurement, restriction in distance or time away from home, perception of lack of usefulness [Hensel et al., 2006].
Although concerns regarding the usage and functionality of the assisted living devices as well as system reliability is an important issue for all users, nevertheless the possible frailty and less resilience of an older user makes it more crucial for them [Coughlin et al., 2007].

Moreover, the functional consistency and operational procedures of the assisted living devices in case they fail to respond to the wishes and feelings of older people can subsequently affect the extent of non-acceptance and non-usage of the system [Fisk M., 1998].

### 3.5 Human interaction

The human interaction dimension of obtrusiveness refers to the threat to replace in-person contacts, lack of human response in emergencies and detrimental effects on relationships [Hensel et al., 2006]. Human contacts are particularly valued in supporting the aging process. Technology advancements while searching to satisfy the versatile nature of the older people’s needs, should always leave space for the beneficial contribution of the personal contact either through the physical presence of the caregiver, or even through the human-machine interface. In many articles worries are expressed that the usage of assisted living technology might lead to loss of human contact [Boissy et al., 2007; Demiris et al., 2004; Demiris et al. 2008; Landau et al., 2010; Mihailidis et al., 2008; Robinson et al., 2006; Sixsmith, 2000].

In general, the need to quickly establish human contact on a daily basis was felt to be especially important for elderly people, and caring was seen as an essential factor for enhancing the feeling of security for them [Valkila, Litja, Aalto, & Saari. 2010].

In their comprehensive review of existing health monitoring systems Stefanov et al. (2004) conclude that the future success of “smart houses” will depend in large part on the human-machine interface, where the individual’s needs and expectations will be adequately addressed.

Nevertheless, the meeting point between the need for autonomy - privacy and the need for socialization of the older people is very sensitive and requires a well studied combination of the technology’s capabilities with the beneficial effect of the human presence of the caregiver or the medical person. Important balances have to be struck between human and technical contributions to care, since AT seems not to able to replace human contacts and support [McCreadie et al., 2005].

Technology should be designed with ease of use by older adults, and it should provide opportunities for more social contact. Social contact is a sign of health in older adults and monitoring systems should be designed with this concern in mind and not as a substitute for skilled caregivers [Kang et al. 2010].

Rahimpour et al. (2008) aimed to identify any major factors that could affect patients’ perceptions of a Home Telecare Management System (HTMS) through ten focus group interviews conducted with chronic disease patients. Participants expressed their interest to use the system on their own while emphasising the importance of receiving the benefits of face-to-face visits with the medical doctor (a health care provider) from time to time.

Scopeliti et al. (2005) found that elderly people in comparison with younger ones, are the most fearful at the prospect of having a robot at home, and they try to ward off their anxiety by attributing features to robots like small size, slow motion, or feminine voice. They also show some mistrust towards machines that are likely to be unsafe by preferring to limit the autonomy of the machine, being pre-programmed in a fixed way, and not free to move at will inside the house. The same study argues that the mistrust shown by the elderly people is mostly due to an emotional difficulty with technology and absence of stimulation, rather than on a well-founded assessment of how technology can or cannot improve their life.
Cesta et al. (2007) recognize the deep involvement with the home place elderly people have, and emphasizes on their rather positive attitude towards a robot that may bring a technological modification in the domestic environment. Yet, the inclination of the elderly people to use technological devices is strongly associated to the problem they have to cope with. In addition, according Scopeliti et al. (2005), addressing the issue of human-technology inter-action from a psychological perspective and the potential influence of domestic robotic devices in people’s everyday life, while home modification may improve people’s independence, elderly people often consider difficulties as conditions related with the aging process, rather than perceive them as good reasons for change. Concerning the image of the robot, again [Cesta et al. 2007] reports that elderly people clearly indicated their preference for a faceless robot, hardly resembling a human being, as better integrated in the home setting and more valued as a source of advantages in the management of everyday life. Nevertheless, robot’s image preferences are influenced by the cultural background of the users as well.

In the study of [Cortellessa et al. 2008] the results in the analysis phase, end users perceive the presence of the robot- mediator as an added value, even though its presence adds nothing to the functionality of the system.

### 3.6 Self-concept

The self-concept dimension of obtrusiveness is related to symbols of loss of independence, cause of embarrassment, or stigma. [Hensel et al., 2006].

Many older people have wrong perception of their abilities something that may be a significant barrier to technology adoption. Few adults see themselves as old and even fewer see themselves as frail and smart technologies are considered by many as a “stigma to older people” and as being symbolic of frailty rather than of independence [Coughlin et al., 2007].

Monitoring devices may cause users to feel ashamed and powerless and pose a stigmatizing aesthetic that leads older people to avoid using them outside their homes or in limited environments because of their embarrassment of being relied on assistive devices [Hirsch et al., 2000]. That is why aesthetic considerations such as size and form of the device as well as product function and underlying technology are essential components of the assistive technology design Especially the minimization of the size and visibility is seen as an important aspect for reducing stigmatization [Landau et al., 2010; Robinson et al., 2009].

Other studies indicated that the older adults found it difficult to ask for help and that the move from being independent to becoming a service user was seen as a considerable life changing step to take, because it was strongly associated with the idea of “giving up” or of admitting defeat [Valkila et al. 2010]. Thus, employing technology before it is actually needed and presenting it as a useful and helpful solution that promotes safety, could delay the changes associated with the onset of disability and avoid stigmatizing older persons [Kang et al., 2010].

It is true that as elderly people grow old they constantly assemble and redefine their own attitudes towards ageing. Therefore, the preconceptions of the elderly held by service providers do not correspond to the reality. In reality, fixed conception definitions of the elderly that would embrace all elderly people are impossible [Valkila et al. 2010].

Indeed, in the study of [Wild K. et al. 2008] aiming to identify monitoring needs and expectations of community-residing elderly and their family members through focus groups, older adult’s less enthusiasm compared to the family members/friends about some of the possible monitoring measures, was expressed more as a need for pragmatic justification than as an a priori rejection of the concept. In
fact the theme of maintaining independence was often invoked in this context—if the technology in question can help them to maintain independence, then it is valuable.

Similarly, in the [Courtney et al., 2008] study investigating the factors that influence the willingness of older adults living in independent and assisted living continuing care retirement community (CCRC) to adopt smart home technology, it is concluded that the acceptance of the technology by the elderly participants could be an acknowledgement of their frailty to themselves and others. In this case, older adults who might benefit the most from smart home technology would be the persons least likely to adopt it.

### 3.7 Routine dimension

The routine dimension of obtrusiveness is related to interference with daily activities, acquisition of new rituals [Hensel et al., 2006].

The design and automation of user routine tasks is one of the most important challenges in the development of Ambient Intelligence systems. Assisted living technologies and robotic devices are moving towards the direction of taking decisions when and how they will attract user’s attention for the accomplishment of different tasks. Automation of routine tasks in an unobtrusive manner, includes adjusting the level of obtrusiveness at runtime according to the user attentional resources and context [Gil et al. 2013].

An alarming issue on the development of smart homes is that of viewing users as dependent patients instead of enhancing their engagement, social inclusion and independence [Demiris et al. 2004]. Failing to take the needs of older adults into consideration and instead design systems driven only by the features of current technology risks the adoption of approaches that are related with disempowerment of older people. Automating everyday tasks can result in making some residents less active, physically and possibly even mentally [Demiris et al. 2009].

The trade off between assistance and autonomy lies on allowing older people to use their competence. Otherwise, autonomy might negatively impact their self-efficacy, since too much support may lead to a loss of autonomy or even decline of capability [Mynatt et al. 2006].

### 3.8 Sustainability dimension

The sustainability dimension of obtrusiveness is related to concern about affordability, concern about future needs and abilities [Hensel et al., 2006]. The aging of the population poses significant societal challenges to technology as of its great potential to preserve the autonomy and independence of older adults offering them the best possible quality of life for the remaining of their lives. By ensuring that the views and perspectives of the potential users are present and by keep monitoring the end user’s needs and concerns it will help to ensure that technology responds ethically and most importantly in massive scale.

There is an obvious shift of the elderly care services from the hospitals to homes, where the provision of the services can be provided more efficiently and tailored to the different needs and particularities of each individual. There is a strong belief that the user-centred, home-based system will become the basis of health care in the future. However, assisted living technological innovations tend to be dominated by suppliers providing a technology-push, rather than a demand-pull approach, causing user disappointment resulting from inadequate comprehension of user needs and poor demands for products and services to be used in smart homes [Chan et al. 2009]. Monitoring technologies need to be able to customize to the concerns of the key stakeholders in order to promote adoption and buy-in [Mahoney et al., 2009].
Thus, stakeholder participation is critical to usability and adoption, particularly to accommodate the needs of older adults [Reeder et al. 2013]. Nevertheless, the design method can be a universal design or ‘design for all’ approach to create barrier-free designs for the widest audience possible while the alternative perspective is that the large degree of variability in the overall health, functional status and cognitive status of older adults precludes such an approach.

Despite the different approaches concerning the central idea of the design method for assisted living technologies, it is safe to conclude that the design and implementation of a successful assisted living technology should empower elders, making them active participants in the health care process and in the monitoring of their condition rather than passive recipients of care services [Demiris et al. 2008].

Rahimpour et al. (2008) suggest that cost would be one of the most important factors related to the intention to use the HTMS. Since most target users are elderly people, often with limited incomes, the practical implication is that the HTMS would need to be provided at affordable prices. Therefore, before the marketing phase, conducting a careful study of the average income of the target population is recommended. In addition, support by the government or health insurance companies to overcome the problem of cost is likely to promote the diffusion of HTMS technology.

Similarly, Steele et al. (2009) recognize cost as the most frequently discussed issue in their survey and places affordability or cost offset as a determinant factor in order for a system to be widely accepted and adopted by the older people even if it is deemed useful. Across the same lines, Coughlin et al. (2007) confirm that the cost of the assisted living devices is one serious concern the elderly users have. Moreover, in the case services must be paid by the users themselves, it is questionable whether the benefits of high technology will become available to those on a low income.

Nevertheless, the large scale implementation of Assistive Technology (AT) could contribute to cost reduction, allowing AT to become available for everyone, and by this annihilating any problems of equity related with the financial capabilities of each user, and the phenomenon of stigmatization [Zwijsen et al. 2011]. On the other hand, the massive installation of ATs to the elderly people’s homes could cause problems related to the tailored configuration and the individual approach the system should have for each of the users, so it is apparent the need for finding a balance between both the (economic) advantages of a collective approach and an individual approach.

Finally, when it comes to developing a sustainable robotic-smart home two main challenges lie ahead: (a) the need to create technologically robust, efficient and secure solutions; (b) the adaptation of the robots in terms of user perspective, in order to adhere to user requirements and be acceptable in the long term.

### 3.9 Trade-offs between obtrusiveness dimensions.

Throughout the previous analysis there are several trade-offs that appear between obtrusiveness dimensions. The dimensions of privacy and usability appear to be weighted by each individual’s perception of need and independence. Actually, Mynatt et al. (2004) in their research examining the usability and engineering challenges in designing devices for aging in place, argue that by working directly with older adults and applying a topdown perspective from gerontology, we can better understand the intriguing trade-offs and tensions older adults are facing as they contemplate using these technologies. They might accept a technology with significant privacy implications given its overall value for sustaining a more independent lifestyle. However, they might reject a simple technological aid owing to concerns of overreliance on technology.
Therefore, obtrusiveness—obviously should be examined under the subjective conditions that exist in each patient’s micro environment and in accordance with his/her personal perceptions. The magnitude of the obtrusiveness is heavily affected by the self-perception of need of the patient.

Usability of a given technological infrastructure for elderly people might well be affected by the lack of perceived need as being a reflection of current health status of the participants [Mihailides et al, 2008]. Self-perception of need is mostly related with the claim for autonomy and self-management of the patient and by that the acceptance of the infrastructure depends on how much obtrusive he/she thinks that it is. Under this perspective, it is very important for the assisted living infrastructure to be able to cover such concerns without compromising any of the necessary functions and services.

Compromises in privacy are most likely to happen and to be accepted when there is a clear benefit for the patient, after he/she has come to the position to understand his/hers condition and needs [Coughlin et al. 2007]. The privacy lost from accepting video cameras could only be acceptable if it prevented transfer to a long term care facility which represents the greatest loss in autonomy [Townsend et al. 2011].
4 NOTIFICATIONS TO CAREGIVERS AND PERCEPTED OBFUSCATION

Caregivers are an integral part of the elderly care services not only for implementing very important tasks during the daily routine of the older person in need, but also for preserving the social identity of the beneficiary while allowing him/her to avoid for as long as possible hospitalization.

Under these circumstances, caregivers like beneficiaries do, may have constant or even daily interaction with the assisted living equipment that can significantly influence the way they provide their services (for example reliance on automation, lessened sense of personal responsibility). Furthermore problems could arise when it is needed to interpret the beneficiary’s wishes in vital issues as it is individual freedom, personal autonomy, informed consent, and privacy, since they may have different approach to a situation.

According to [Courtney et al, 2007] perceived invasion of personal information and perceived violations of the physical self and personal space at home are associated with perceptions of obfuscation in the privacy domain; What users regards as an infringement on their privacy sphere occurs when health information that users believe should be kept private is shared or when the use of monitoring equipment is not well understood by the elders.

At this point the level of trust between the caregiver and the beneficiary, and the credibility of the monitoring system to safely handle personal data may define user’s acceptability and cooperation.

From this literature review we also concluded that while elderly people want the human presence of the caregiver which is essential for their socialization and psychological balance, at the same time they want to have their own time and if possible their own control upon their everyday reality.

That is the opportunity for many patients and their families through the information and communication technologies to reduce the number of intrusions into their homes by healthcare workers and thereby protect the intimate sphere of the home. This kind of physical privacy is ethically significant because it enables patients and their families to maintain comfortable routines at a time when much in their lives is out of their control [Keith A. Bauer, 2001].

While patients seek the human contact as a viable factor for retaining their social substance, it is also important to retain their right to be left alone when needed. When assisted living technologies credibly cover fundamental user’s requirements as it is avoidance of stigmatization, protection of personal data, safety and utility, it is then possible for the end users to choose not to have the constant presence of the caregiver around them relishing the so called right to be left alone, at least for a while.

The relationship between the caregiver and the patient, aggravated by the workload of the caregiver, and the ageing and health problems of the care recipient can cause enough friction to disturb the smooth communication between the two parts and to destabilize the care process.
5 REQUIREMENTS

In addition to the requirements set in D2.4, the following list is also added to the ethics requirements.

*Table 1: RADIO ethical requirements*

<table>
<thead>
<tr>
<th>Requirements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Obstruction in space and aesthetic incongruence: not big construction, not human like shape.</td>
</tr>
<tr>
<td>Discreet and least visible monitoring equipment</td>
</tr>
<tr>
<td>Restriction of usage inside sensitive areas (as bedroom or bathroom) if possible</td>
</tr>
<tr>
<td>Easiness of use, clear and concrete handling actions</td>
</tr>
<tr>
<td>Keeping a discreet distance from the patient unless it is required the proximity by the patient or due to specific tasks of the robot.</td>
</tr>
<tr>
<td>Sense of control: request for approval of the user for certain actions</td>
</tr>
<tr>
<td>Credibility of functionality, safety assurance</td>
</tr>
<tr>
<td>Affordable price</td>
</tr>
</tbody>
</table>
6 CONCLUSIONS

Conducting a thorough literature review for the purposes of the present deliverable, we found that there is a lack of empirical studies which address an elderly person’s and caregiver’s perception, attitude and concerns towards assisted living technologies. With the advance of new technological innovations for assisted living, there is still a wide field to investigate older individuals’ perceptions of smart home technologies or other home-based technological applications and how obtrusive they are in any of the above stated dimensions. Furthermore, the psychological implications of human-robot interactions still remain a scarcely explored field.

It is obvious that the effect and obtrusiveness of monitoring technologies have a proportional impact on the end user’s quality of life assessment. The more obtrusive the device is, the greater the technological effectiveness and improvement in quality of life should be. From the other part, quality of life is a broad concept and goes beyond effectiveness and obtrusiveness, having a significant influence on someone’s independence, self-esteem, or daily tasks.

This literature review recommends the further development of a validating instrument focusing on the type and frequency of user’s concerns as they relate to the dimension of the obtrusiveness framework across different settings and to individuals across a range of older adult’s health status. Designing assisted living equipment for elderly people requires the consideration and balanced combination of many different dimensions that are strictly related with obtrusiveness and apparently in central position should be placed the principle of human centered design based on the mapping of the needs of the final users and the particularities of the end user’s surrounding environment.
REFERENCES


D2.5: Actual and perceived privacy considerations and ethical requirements II


Actual and perceived privacy considerations and ethical requirements II


D2.5: Actual and perceived privacy considerations and ethical requirements II


