



ROBOTS IN ASSISTED LIVING ENVIRONMENTS

UNOBTRUSIVE, EFFICIENT, RELIABLE AND MODULAR
SOLUTIONS FOR INDEPENDENT AGEING

Research Innovation Action

Project Number: 643892

Start Date of Project: 01/04/2015

Duration: 36 months

DELIVERABLE 2.4

Actual and perceived privacy considerations and ethical requirements I

Dissemination Level	Public
Due Date of Deliverable	June 2015, Project Month 3
Actual Submission Date	15 July 2015
Work Package	WP2, <i>Early detection of emerging functional impairments</i>
Task	Task 2.2, <i>Review of sociological, ethical, and gender issues</i>
Lead Beneficiary	FZ
Contributing beneficiaries	NCSR-D, FSL and FHAG
Type	Report
Status	Submitted
Version	Final



Abstract

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

History and Contributors

Ver	Date	Description	Contributors
01	4 June 2015	First draft, establishing document structure.	NCSR-D
04	29 June 2015	Almost complete draft	FZ, FSL, FHAG
05	10 July 2015	Additions on privacy considerations and technical aspects of	FZ and NCSR-D
05	13 July 2015	Internal review	FHAG
Fin	15 July 2015	Final document preparation and submission	NCSR-D

Abbreviations and Acronyms

ADL	Activities of Daily Living
ASQ	After-Scenario Questionnaire
IADL	Instrumental Activities of Daily Living
interRAI	International collaborative to improve the quality of life of vulnerable persons through a seamless comprehensive assessment system. Cf. http://www.interrai.org
interRAI HC	The <i>interRAI</i> Home Care Assessment System
interRAI LTCF	The <i>interRAI</i> Long-Term Care Facilities Assessment System
MMSE	Mini Mental State Examination
PIADS	Psychosocial Impact of Assistive Devices Scale
SUS	System Usability Scale

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1 INTRODUCTION

1.1 Purpose and Scope

This deliverable 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

This deliverable is prepared within Task 2.2 *Review of early detection methods and necessary system actuation* and forms the basis for defining the aspects of the RADIO system that will guarantee acceptance and unobtrusiveness. This deliverable 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.

1.3 Relation to other Work Packages and Deliverables

D2.4 sets the actual and perceived privacy considerations and ethical requirements for the RADIO system. This deliverable is a precursor to *D2.5: Actual and perceived privacy considerations and ethical requirements II*, to *D2.6 Guidelines for balancing between medical requirements and obtrusiveness I* and *D3.1 Conceptual architecture for sensing methods and sensor data sharing*.

D2.2 and D2.4 will form the basis upon which Task 3.1 (M4-M6) will establish the recognition methods required in order to extract the required information. Moreover, D2.2 and D2.4 together set the trade-off between medical requirements and the obtrusiveness off the RADIO System.

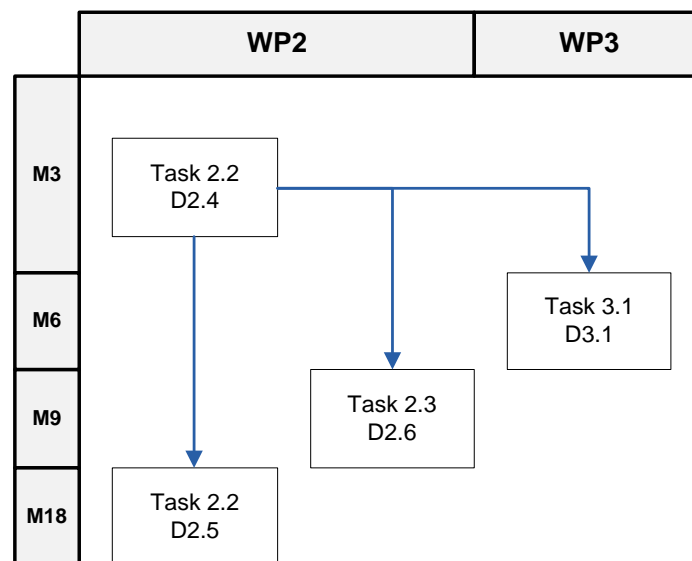


Figure 1: Dependencies between this deliverable and other deliverables

2 PRIVACY CONSIDERATIONS

2.1 Actual Privacy Considerations: Data Protection

In the information age, determining practical ways of collecting, storing and managing of valuable medical data has become a major asset to improve the quality of health care provided. In addition, due to the fact that medical information can be very personal and sensitive, ethical aspects with respect to privacy related to medical records should be taken into considerations. The issues of obtaining patient informed consent, patient information sheet and consent forms will be included as part of RADIO formal ethical approval process by the different research ethics committees and will be dealt with in more detail in deliverables D2.5, D6.1, and D6.5.

In terms of data protection, RADIO will strictly adhere to the Data Protection Directive (1995/46/EC) and the Privacy and Electronic Communications Directive (2002/58/EC) which currently address data protection, privacy and to a certain extent, security. Also, there is the recent (25-1-2012) proposal for a comprehensive reform of the EU's 1995 data protection rules in the adopted regulatory framework.

These directives regulate the processing of personal data, and stipulate among others that:

- The data subject has the right to be informed when his personal data are being processed and
- data may be processed only under the following circumstances (art. 7 1995/46/EC):
 - when the data subject has given his consent
 - when the processing is necessary for the performance of or the entering into a contract
 - when processing is necessary for compliance with a legal obligation
 - when processing is necessary in order to protect the vital interests of the data subject
 - when processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller or in a third party to whom the data are disclosed
 - when processing is necessary for the purposes of the legitimate interests pursued by the controller or by the third party or parties to whom the data are disclosed, except where such interests are overridden by the interests for fundamental rights and freedoms of the data subject
- The data subject has the right to access all data processed about him. The data subject even has the right to demand the rectification, deletion or blocking of data that is incomplete, inaccurate or isn't being processed in compliance with the data protection rules. (art. 12 1995/46/EC)
- When sensitive data are being processed, extra restrictions apply. (art. 8 1995/46/EC)

In this context, RADIO will perform a data protection impact assessment covering the whole range of data protection topics and producing relevant functional and subsequently technical requirements to be reported in corresponding RADIO deliverables:

- *Uses of the System and the Information*: define the scope of the information collected, as well as the reasons for its collection as part of the program being developed
- *Retention*: outline how long information will be retained after the initial collection and the specific protocol for removing data from the records
- *Internal Sharing and Disclosure*: describe the scope of sharing within
- *External Sharing*: define the content, scope, and authority for information sharing externally, as well as the measures taken for data anonymization
- *Notice*: clear notice provided about the collection, uses, sharing, or retention of the data
- *Individual Access, Redress and Correction*: options provided to study individuals for access, redress and correction of own collected data, relevant request procedures and provisioning
- *Technical Access and Security*: clarify the technical aspects of access to the data, technical access control and security (technical and physical), e.g. any data used will be stored and held

securely as per (i.e. in secure office with closed access. Databases used would be password protected and separation of patient identifiable master list held separate from research database which would use numbered subject codes)

- *Technology*: selection process for any technologies used in RADIO, opting for privacy-enhancing technologies and privacy-by-design solutions

2.2 User perception of privacy and obtrusiveness

In the field of health and independent living the present era is characterized by the ability of new technologies to offer more and more monitoring and assistance services in the medical and social care fields. This opportunity creates new challenges and often tests the limits of endurance of acquired human rights, often the same which aims to safeguard. Especially when it comes to handling personal and medical data is fully justified and obvious the reluctance of beneficiaries to share this data and to be persuaded to accept technological innovations that aims to improve their health and quality of life. Under these circumstances new conditions arise that require meticulous and frequent revision based on the advance of technology and the increased demands created on issues such as privacy and obtrusiveness.

With the accelerated pace of technological evolution in contemporary society, and the major impact that technology has on people's lives, early identification and evaluation of uprising ethical issues is an important aim. Yet, so far very little research has been directed at developing sound approaches and methods for ethical analysis of emerging technologies. It is only in recent years that such research has seriously gotten underway¹.

2.2.1 Perceptions of privacy for the individual

Privacy is considered inherent to the human nature and for this has been thoroughly analyzed from legal ethical and philosophical point of view. According to Schoeman (1984)²: "A person has privacy to the extent that others have limited access to information about him, the intimacies of his life, or his thoughts or his body." In addition, most of the experts do agree with the three dimensions of the privacy as given by Fabrice Rochelandet (2010)³.

The first dimension defined as the *secret* is the individual's capacity to control collection and usage of his/her personal data. The second dimension regards the *tranquillity* or «*the right to be left alone*» and therefore does concern the accessibility to a person. The third dimension concerns the *autonomy*, that is the individual capacity to take the decisions for and on him/herself.

Nevertheless privacy is not a constant but rather a dynamically evolving notion, based on the profile of the society, the needs of the people and the technological advancement. For most of experts, problems raised by emerging technologies to the privacy are mostly related to their complexity. Especially in our modern era there is an imperative need to customize privacy as any other preference service on the basis of the context of AmI environments or the features of people. In other words privacy should be influenced by the context in which it is adopted⁴. We cannot seek for a universal application of privacy rules since we have a versatile context defined by the different needs and different environments of the human machine interaction. The need of the privacy continuously to be adapted and redefined to the different existing settings is also described by Solove⁵ stating that privacy is a family of interrelated yet distinct things and for this reason similar activities could have different privacy implications. In our modern era there is a need for constant rearrangement and control of the privacy issues concerning emerging technologies and robotics, since the rapidly evolving capacities of the technology to monitor, interfere, and lately decide on behalf of the human person is a crucial issue that impacts on the integrity and privacy of the individuals and balances the benefits that brings to them.

We must not forget also that data protection is abruptly connected with privacy. Concerning ambient assistive technologies while continuous monitoring of homes and human activity can offer a safer

environment for older people, many are wary of constant surveillance and the lack of control over data collected.

Solutions proved to overcome these concerns include collecting and processing data on a local level, with the data being shared only if an emergency situation is detected, at which point the information could be released to health- care workers and/or carers⁶.

Although it refers mainly to on-line services, the results from a recent Eurobarometer survey reported to a European press release⁷, explicitly show us the concern EU citizens have for a possible access to their personal information and data. 70% of Europeans are concerned that their personal data may be misused. They are worried that companies may be passing on their data to other companies without their permission. 74% of Europeans think that disclosing personal data is increasingly part of modern life, but at the same time, 72% of Internet users are worried that they give away too much personal data, according to the Eurobarometer survey. They feel they are not in complete control of their data. This erodes their trust in online and other services and holds back the growth of the digital economy in general.

Concerning the type of data people regard as personal, according to the special Euro barometer 359⁸ around three-quarters of the European interviewees think that the following are personal: financial information, such as salary, bank details and credit record (75%), while medical information such as patient records and health information follows with 74%. It is obvious the gravity health and medical information has for the interviewees, and this also depicts the necessity for the right measures to be taken in order to safeguard the privacy rights of the participants in RADIO study.

2.2.2 Perceived Privacy Considerations in the Health context

The public perception of privacy as well as the trust and acceptance of connected technologies and institutions have been the subject of extensive societal and anthropological studies and research. E.g. empirical research results published by PACT⁹ project were based in a pan-European study among all EU member states analyzed a variety of factors affecting the attitude and perception in various contexts. In particular to the Health context, preferences and choice main findings can be found as an example in Table 1.

Similar to PACT studies include those provided by PRISMS¹⁰ and SURPRISE¹¹ project. All concluded that simplistic trade-off models used in the past and still in wide use among policy makers and stakeholders (i.e. privacy vs. more security/functionality trade-off) do not represent the reality of perceived privacy and security, which is in fact a far more complex and multi-factor problem.

Table 1: PACT main findings for health context choice exercises¹²

Style Name	Health Context
Amount of personal information	<u>Prefer</u> devices/systems which store data on identification in addition to basic health data
Geographic access to data	<u>Prefer</u> access across the EU rather than in home country only
Personnel	<u>Dislike</u> that their health information is viewed by groups other than medical practitioners <u>Prefer</u> access to devices/systems storing data by paramedics in addition to doctors and nurses <u>Dislike</u> access by fire and rescue services in addition to the above
Amount of personal information	<u>Prefer</u> devices/systems which store data on identification in addition to basic health data

RADIO use cases will be analyzed in the context of perceived privacy, taking into account socio-economic factors and relevant past empirical research. Special emphasis will be placed in the principles of proportionality, justifying properly the use of technology and mitigating the risks of fear or distrust on behalf of the public.

2.2.3 Robots

Robotics belongs to such kind of technologies that are still emergent: they are still largely, or fully, at the research and development (R&D) stage, meaning that they are still at the stage of research into basic techniques, or at an early stage of development mostly resulted in lab prototypes and experimental applications but with little or no serious products that are being used by ordinary users. These technologies are called emerging technologies.

For technologies at the R&D stage, ethical issues relating to their use in society cannot be known reliably, as their impact on society lies in the uncertain future¹³. We must not forget that with the advance of the robotics technology the human robots interaction is now developing and so privacy issues naturally affect the design and level of access robots should have in the home and care environment.

Nevertheless there are some surveys whose results can give a clear perception concerning the attitude of future users on privacy and obtrusiveness while using RADIO platform.

EU citizens¹⁴ express a utilitarian view in that the majority agree that “robots are necessary as they can do jobs that are too hard or too dangerous for people” (88%) and that “robots are a good thing for society because they help people” (76%). On the other hand, the broad consensus with the statement that ‘robots are a form of technology that requires careful management’ suggests that robots are seen to pose a potential threat: 52% of respondents ‘strongly agree’ and 39% ‘tend to agree’ with this statement, while only 6% disagree and 3% ‘don’t know’.

For example, introducing robots into the home and other social settings raises privacy risks similar to those posed by surveillance cameras. Robots will have both sensors and large hard drives that can record all the data they collect. This data offers a benefit, in that it can be analyzed if anything goes wrong. But it will also be a record of all private activity within range of the sensors. Data stored on robots that are connected to the Internet, as most are likely to be, may be accessible for a variety of criminal purposes¹⁵.

Similarly in a survey of EU project Giraff¹⁶, elderly people recognized the potential usefulness of the Giraff assisting robot and its necessity in some cases, but on the other hand, they pointed out concerns, in particular, with respect to the monitoring issue and privacy. Concerns about continuous monitoring and access to the data were raised. To compensate such concerns the design of physically assistive robots must, therefore, take into consideration the privacy rights of clients, as with, perhaps, the deactivation of video monitors during intimate procedures.¹⁷

Yet increasing the power to observe is just one of ways in which robots may implicate privacy within the next decade. According to another study¹⁸ the effects of robots on privacy fall into three categories—direct surveillance, increased access, and social meaning. Increased access (the home robot in particular presents a novel opportunity for government, private litigants, and hackers to access information about the interior of a living space) also justifies increased concerns for privacy breach.

Intimacy of robots also does create issues of privacy. An elderly person might not like the distant monitoring of an operator through a robot while in bedroom changing, or when they are taking a bath. They might prefer to have the choice of allowing or not such an action. Moreover, issues concerning who should have access to the information and for how long are essential for an elderly person to feel safe. With the massive memory hard drives available today, it would be possible to record the entire remainder of an elderly person’s life.

Meanwhile, robots are increasingly designed to interact more socially¹⁹. The social nature of robots may lead to new types of highly sensitive personal information—implicating what might be called “setting privacy.”

Because of the capacity of the assistive robots to store information acquired from sensors and capacities to communicate through wireless connections to servers, privacy of people entering the field of action of the robot’s sensors is at stake. Privacy issues in assistive robotics are further emphasized since these assistive robots are most of the time mobile and moving in the environment. These capacities make assistive robots, vectors of huge intrusion in private life of patients, of care takers, and of people entering the field of perception of the machine²⁰.

2.2.4 Gender and cultural issues

Attitude towards new technologies and especially towards a robot can be influenced up to an extent, among others, by the gender of the user. Due to the fact that robot’s functionalities are rapidly evolving, recent research focuses on the human-robot interaction and communication as important aspects of users’ acceptance of assistive robots. For this reason, the approach of designing robots to fit particular roles in human environments should also take under consideration the particularities of the gender as well as cultural and ethnic differences. Except from the gender of the user that might influence his/hers attitude towards the robot, it is important to underline that the attributed by the users gender to the robot (due to the users own perceptions or due to specific robot’s characteristics like voice, anthropomorphism) is equally important and might influence critically the human-robot interaction. A research made by the University of Bielefeld²¹ shows that “people apply gender stereotypes that typically characterize human–human social cognitive processes to robots. Even though the trait attributions may be interpreted in terms of anthropomorphism (Epley, Waytz, & Cacioppo, 2007), our findings also document that gender stereotypes seem to be so deeply ingrained that people even applied them to machines with a male or a female appearance”.

The tendency humans have to anthropomorphism of robots is discussed by Heather Knight²² in her report, where she argues “that people rapidly assess machine capabilities and personas instinctively, perhaps because machines have physical embodiments and frequently readable objectives. Sociability is our natural interface, to each other and to living creatures in general. As part of that innate behavior, we quickly seek to identify objects from agents. In fact, as social creatures, it is often our default behavior to anthropomorphize moving robots”. In the same report it is analyzed the cultural underpinnings that influence the acceptability of robotics, with religion being a dominant factor in people’s perception and attitude towards robots.

It is obvious that gender either as a characteristic of the users or as a characteristic that is attributed by people to robots, plays an essential role in social facilitation between human and robots. In a research made in 2009 at the University of Washington²³, 19 students were asked to watch videos of two robots, one that was modeled after an adult woman and another that looked like a taller Wall-E with arms. The questions were about how humanlike and friendly the robots seemed, and the results showed that there was a clear preference for the female robot.

In another survey²⁴ gender appeared to have greater effects on attitudes towards healthcare robots than age. Using blood pressure monitoring as the service scenario, a user study was conducted to investigate the differences between two age groups (40 to 65 years and over 65 years) in attitudes and reactions before and after their interactions with the robot. A significant gender effect was found, with males having a more positive attitude toward robots in healthcare than females. This study reveals the importance of considering gender issues in the design of healthcare robots for older people.

Another survey²⁵ investigating people’s perceptions of social presence in robots during (relatively) short interactions, found “various behavioral and attitudinal differences in this study between females and males with regard to robots point to important possible distinctions in how males and females think about, react to, and possibly coexist with robotic entities”.

In Horizon 2020²⁶ Gender is a cross-cutting issue and is mainstreamed in each of the different parts of the Work Programme, ensuring a more integrated approach to research and innovation.

Three objectives underpin the strategy on gender equality in Horizon 2020:

- Fostering gender balance in research teams, in order to close the gaps in the participation of women.
- Ensuring gender balance in decision-making, in order to reach the target of 40% of the under-represented sex in panels and groups and of 50% in advisory groups.
- Integrating the gender dimension in research and innovation (R&I) content, helps improve the scientific quality and societal relevance of the produced knowledge, technology and/or innovation.

In many topics across the work program, it is explicitly requested that applicants take into account women as well as men's needs and behaviors. In addition grant beneficiaries commit to promoting equal opportunities and a balanced participation of women and men at all levels in research and innovation teams and in management structures.

3 ETHICAL REQUIREMENTS

As stated in Horizon 2020 guidelines, ethical research conduct implies the application of fundamental ethical principles and legislation to scientific research in all possible domains of research.

The most common ethical issues include:

- the involvement of children, patients, vulnerable populations,
- the use of human embryonic stem cells,
- privacy and data protection issues,
- research on animals and non-human primates.

In order to deal with obtrusiveness properly from an ethics point of view, some considerations need to be done.

The autonomy of a person is directly correlated with the obtrusiveness, as the right of someone to define how much and for which reasons he will compromise elements of his freedom and privacy for his own good and safety. It is crucial for the users to be able to have the control over the assistive robots. Unless someone is cognitively impaired all users should make their own decisions, including exercising the right to make their own mistakes and take the consequences. Having control over the assisted living environments and robots preserves the notion of free will and self-determination for the patients and users, something that cultivates the smooth human machine interaction. As long as control is on the hands of the user, apparently issues of obtrusiveness can be discussed up to the level where the user consents on the determination of its specific characteristics (type, environment, time, nature, necessity).

It is obvious that from the patient's point of view²⁷, "the most important aspect is the human-machine interface of the robotic device, where the intrusiveness can be a barrier".

At the same page, according to the Accompany project study²⁸ autonomy is regarded as a very significant factor of the person into whose home and for whose benefit the robot is introduced, and consequently some participants of the study commented (unprompted) that having a robot in a home could lead to intrusive monitoring.

"The concern of the users towards assistive devices and robots as intruders into their personal life is completely natural and requires transparent and clear information upon the function of the system. The current complexity of the technology makes more and more difficult for people to understand what happens with their data and therefore decreases the transparency of the processes and the processors"²⁹.

Obtrusiveness is also very much related with the distance a robotic device should keep from the users.

The technological development of monitoring devices is rather advanced. However, especially autonomous ubiquitous robotic devices that move around in the house are still in a developmental stage. Besides, robotic devices have different degrees of contact with people and/or different levels of autonomy³⁰.

The results of a relevant user study³¹ show that the distance range of the personal space in the case of the Nao robot is larger than the distance range of the personal space in human-human interaction context. A main reason for this has to do with the fact that "robots are technological artefacts for which reliability is unknown. So people may be inclined to keep a safe distance".

Table 2 summarizes the ethical requirements of the RADIO system.

Table 2: RADIO ethical requirements

Style Name	Usage
Safety	<p>Authentication procedure as a protection of the access to be included for both family caregivers and professionals.</p> <p>Possibility of external and non authorized intruders to be avoided by a robustness security system</p> <p>Avoid possibility of access to the system without explicit consent of the elderly, including non authorized access of authorized remote operators</p> <p>Unintentional, not authorized disclosure of information related to the life of the users has to be prevented by restricting access to the information stored in the system.</p> <p>Storage and management of personal information related to behaviors and preferences of the users have to be done in safe, restricted databases</p> <p>Storage of personal information related to behaviors and preferences of the users will be limited to that information relevant for the functionalities of the system. Non relevant information processed if not necessary</p>
Obtrusiveness	<p>User to have the control over the human-machine interaction</p> <p>No robot movement should happen without initial confirmation by the user who is in direct physical contact with the robot ?</p> <p>User to have the control over the human-machine interaction</p> <p>Although people at risk accept cameras and monitoring by humans even in sensitive areas (such as the bathroom), it will be a positive development if this can be avoided.</p> <p>Processing before transmitting even inside the house or in sensitive areas.</p> <p>ON/OFF mode to be implemented in order to protect privacy in very personal moments. The access to the —on/off mode could be adaptable attending to the specific frailty of the elderly user.</p> <p>Keeping a discreet distance from the patient unless it is required the proximity by the patient or due to specific tasks of the robot .</p> <p>Clear and understandable signals to the patient for every action of the robot.</p>

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