



Project no.:  
**AAL-2009-2-137**

## **PeerAssist**

**A P2P platform supporting virtual communities to  
assist independent living of senior citizens**

### **Deliverable 1.3 “Ethical issues and Data Protection Plan”**

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# 1. Introduction

## 1.1. *Background: European Directives and Guidelines*

The involvement of ethical conduct in modern scientific research can be described as its cornerstone and main characteristic. Because scientific research often consults human subjects directly and/ or indirectly in its inquiries, it is of implicit necessity to pay special attention to this kind of scientific research.

On the other hand, the European Commission is increasingly addressing the topic of how to introduce the ethical perspective into the working structure of a research consortium, by defining three major directions of ethics in scientific and industrial research. For that purpose, ethics are defined as:

- **An academic discipline.** Ethics is the critical study of the norms that guide our actions.
- **Practical skills.** Ethics is the practical art of knowing how to apply moral principles in concrete situations.
- **Value systems.** Ethics deals with the core values that guide a person or an organisation on the way to its shared vision.

The European Commission defines the principles of European research ethics through the following points [1]:

- **The principle of respect for human dignity**
- **The principle of utility**
- **The principle of precaution**
- **The principle of justice**

Data privacy refers to the evolving relationship between technology and the legal right to, and public expectation of privacy in the collection and sharing of data. Privacy problems exist wherever uniquely identifiable data relating to a person or persons are collected and stored, in digital form or otherwise. Improper or non-existent disclosure control can be the root cause for privacy issues.

The most common sources of data that are affected by data privacy issues are:

- **Health information**
- **Criminal justice**
- **Financial information**
- **Genetic information**
- **Location information**
- **Cultural information**

The challenge in data privacy is to share data while protecting the personal identity from the information [2].

### ***1.2. Scope of this manual***

Privacy is a major problem, particularly for some spoken-word collections when individuals do not have an expectation that their statements will be archived, although they have spoken in a public forum such as a company board meeting or a political rally. It may not be possible to offer a comprehensive solution to the privacy problem, particularly for materials where contact with the original collector or subject has long since been lost, but research in this area can accomplish some practical goals. Future collectors must be armed with reasonable policies to obtain clearances and document applicable rights.

Privacy is important to participants, since they expect the right to control and inspect personal information, and they expect that their personal information maintained by colleagues and centres will be accurate. Today's participants also expect information about their personal activities to be kept private.

Directive [95/46/EC](#) [3] is the reference text, at European level, on the protection of personal data. It applies to data processed by automated means (e.g. a computer database of customers) and data contained in or intended to be part of non automated filing systems (traditional paper files). It sets up a regulatory framework which seeks to strike a balance between a high level of protection for the privacy of individuals and the free movement of personal data within the European Union (EU). To do so, the directive sets strict limits on the collection and use of personal data and demands that each member state set up an independent national body responsible for the protection of these data.

This directive defines personal data as “all information on an identified or identifiable person”, considering an identifiable person as anyone whose identity might be determined, directly or indirectly, in particular by means of an identification number or one to several spe-

cific elements, characteristics of his physical, physiological, mental, economic, cultural or social identity and attributes special protection to health data [4]

On the other hand, the Charter of Fundamental Rights of the European Union (2000/C 364/01) aims to make more visible to the Union's citizens the fundamental rights that they already enjoyed at the European level. It includes, the protection of personal data, as well as rights in the field of bio-ethics, required by advances in information technologies and genetic engineering. Finally, by expressing rights that were at times buried in the abundant jurisprudence of the Court of Justice of the European Communities, it responds to legitimate demands for transparency and impartiality in the functioning of community administration.

The Charter of Fundamental Rights of the European Union [5] states:

*Art 3: Right to the integrity of the person*

1. *Everyone has the right to respect for his or her physical and mental integrity.*
2. *In the fields of medicine and biology, the following must be respected in particular.*
  - a. *The free and informed consent of the person concerned, according to the persons.*
  - b. *The prohibition of eugenic practices, in particular those aiming at the selection of persons.*
  - c. *The prohibition on making the human body and its parts as such a source of financial gain.*
  - d. *The prohibition of the reproductive cloning of human beings.*

*Art. 8: Protection of personal data*

1. *Everyone has the right to the protection of personal data concerning him or her.*
2. *Such data must be processed fairly for specified purposes and on the basis of law. Everyone has the right of access to data which has been collected concerning him or her, and the right to have it rectified.*
3. *Compliance with these rules shall be subject to control by an independent authority.*

*Art. 13: Freedom of the arts and sciences.*

1. *The arts and scientific research shall be free of constraint. Academic freedom shall be respected.*

The European Directive on the protection of personal data contains a number of key principles which must be complied with. Anyone processing personal data must comply with the eight enforceable principles of good practice. They say that data must be:

1. *Fairly and lawfully processed.*
2. *Processed for limited purposes.*
3. *Adequate, relevant and not excessive.*
4. *Accurate.*
5. *Not kept longer than necessary.*
6. *Processed in accordance with the data subject's rights.*
7. *Secure.*
8. *Not transferred to countries without adequate protection.*

### **1.3. PeerAssist Project and its Ethical Implications**

The goal of PeerAssist project will be to develop a flexible platform will facilitate establishing on demand ad-hoc communities with friends, family, neighbours, caregivers, etc., based on shared interests and communication needs. The main objective of the project is to design a platform which allow elderly people to build virtual communities, to increase their relationships and improve their quality of life

According to the described project objectives, PeerAssist will be targeted to elderly people, a sector of the population who is not very familiar with new technologies and their fundamental rights could become unprotected. For that reason PeerAssist will carefully consider the **ethical aspects** of the project with the aim to ensure at every moment and in every situation the adequate protection of the privacy and the personal rights of the users. This aim will not only affect the end-users participating in the project, but will also consider the ethical aspects relevant for the persons and organisations participating in the project and in general the limitations and regulations that must be applied to every project activity: research, development, testing, evaluation and dissemination.

Research and development in the PeerAssist project will be conducted in Spain, Greece and Austria. In addition field testing and evaluation will be performed in Donostia-San Sebastián (Spain), and Athens (Greece). No research or transfer of knowledge to non-European countries is planned within the project.

A summary of the plans and actions foreseen to handle the ethical aspects of the project will be presented this document. By the term *ethical* we mean all these issues that concern questions about life and death, about revealing personal data, revealing diagnosis, about

daily life activities, care and guidance, or about the application of protective or liberty-restraining measures.

The project will explore methods for monitoring its own activities and study possible compromises of ethical concern. An ethical code supervised by an ethical committee will be elaborated for that purpose with the participation of the members of the consortium as well as an independent evaluator, an ethical advisor defined at the beginning of the project (Dr. Elena Urdaneta, from INGEMA). This critical evaluation will be performed during the whole duration of the project, with a special emphasis during the phases of specification, design, testing and evaluation of the prototypes.

The ethical aspects that do affect the project are:

- **Personal contact details:** such as photographs, name, address, phone number, email, etc., video and audio information, in case of needing there information for evaluation purposes, will also be a subject of protection.
- **Personal preferences:** with regards to information, cultural events, entertainment.
- **User location information:** when relevant, it could also be the subject of ethical concerns.
- **Management of sensitive medical information:** This point refers to the way in which PeerAssist will keep the safety and privacy of the users interact with the system. PeerAssist consortium expect to have conflicts in the medical scenarios, for that reason we present in the following table ("Risk and solution table") the possible conflictive ethical issues as well as their possible solution. Nevertheless, and taking into account the initial phase in which the system is still be, the Peer Assist consortium will work to guarantee that this table will be continuously re-adapted along the project.

In the next ethical deliverable (*D1.4 Ethical Issues Report*), when the system will be more developed and we can observe more specifically the possible ethical problems, the PeerAssist consortium will specify the necessary technological measures to protect the privacy of people interacting with the system in the medical scenario.

Moreover, to guarantee that we fulfil with laws and legislations related to the management of this type of information, the PeerAssist project and the measures taken for the medical scenarios will be presented again to the Ethical Committee of Matia/Ingema/Hurkoa. The presentation of these technological solutions to the Ethics Committee, who has extensive experience in similar projects and monitoring the correct implementation of medical scenarios, allow for proper execution of the medical scenario.

**Risk and solution table**

Risk	Description of the risk	Solution
<b>Project refusal from the Ethical Committee</b>	The Ethical Committee could not accept the medical scenario	The Peerassist platform incorporates a complete security architecture that satisfies all the security and privacy requirements of the system (functional & non functional).
<b>Privacy of the conversation</b>	During and after the medical consultation the conversation between the doctor and the user could be stolen from the Peerassist repository	The conversation between the user and the doctor is encrypted; therefore, no one can disclose it. Moreover, as the communication takes part using P2P and a closed group that requires authentication, no discussion data are stored within the PeerAssist platform. Only the two peers (user & doctor) have copies of the carried discussion.
<b>Privacy of the recording</b>	During and after the medical consultation the video-consultation between the doctor and the user could be stolen from the Peerassist repository	The video consultation between the user and the doctor is encrypted; therefore, no one can disclose it. Moreover, as the communication takes place using P2P and a closed group that requires authentication, no data are stored within the PeerAssist platform. Only the two peers (user & doctor) may have copies of the carried video consultation.



<b>Access to the diagnosis of the user</b>	Someone outside the system or other users of the PeerAssist platform could access to the medical information (medical history and medical record) of the users	The medical records of the users are connected to the PeerAssist platform.  The medical discussion between a user and a doctor takes place encrypted, in a P2P fashion using a closed group that requires authentication.
<b>Identity theft of the user</b>	Someone outside the system or other users of the PeerAssist platform could impersonate the identity of the PeerAssist users	The system shall provide authentication and anonymity mechanisms ensuring users' privacy and protecting from impersonation attacks.
<b>Identity theft of the doctor</b>	Someone outside the system could impersonate the identity of the doctors that participate in the PeerAssist project	The system shall provide authentication and anonymity mechanisms ensuring doctors' privacy and protecting from impersonation attacks.
<b>Dignity of the user</b>	Repeated reminders to attend to the medical consultation can be very annoying for some users. The same risk can exist with the reminders after the medical consultation with the general information that the doctor offered to the user.	The user is able to configure his profile according to his preferences.
<b>Privacy of the other person that appear in the recording</b>	During the medical consultation, the relatives or friends of the PeerAssist user could appear in the conversation or in the recording	The system can apply different security policies to each case according the users privacy preferences. Moreover, the conversation between the user and the doctor is encrypted; therefore, no one can

		disclose it. Finally, as the communication takes part using P2P and a closed group that requires authentication, no discussion data are stored within the PeerAssist platform.
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## 2. Data Storing Legislations

### 2.1. Spanish Legislation

INGEMA will fulfil all the requirements stated by the *Spanish Organic Law 15/1999 of 13<sup>th</sup> December on the Protection of Personal Data (LOPD 15/1999)* [6] that intends to guarantee and protect the public liberties and fundamental rights of natural persons, and in particular their personal and family privacy, with regard to the processing of personal data.

This Organic Law shall apply to personal data recorded on a physical support which makes them capable of processing and to any type of subsequent use of such data by the public and private sectors.

With personal data, the Organic Law means “any information concerning identified or identifiable natural persons”. Some important information regarding the LOPD 15/1999 that applies to PeerAssist:

#### *Art. 4: Quality of the data*

1. Personal data may be collected for processing, and undergo such processing, only if they are adequate, relevant and not excessive in relation to the scope and the specified, explicit and legitimate purposes for which they were obtained.
2. Personal data shall be erased when they have ceased to be necessary or relevant for the purpose for which they were obtained or recorded.
3. They shall not be kept in a form which permits identification of the data subject for longer than necessary for the purposes for which they were obtained or recorded.

4. Personal data shall be stored in a way which permits the right of access to be exercised, unless lawfully erased.

*Art. 5: Right of information in the collection of data*

1. Data subjects from who personal data are requested must previously be informed explicitly, precisely and unequivocally of the following:
  - The existence of a file of personal data processing operation, the purpose of collecting the data, and the recipients of the information.
  - The obligatory or voluntary nature of the reply to the questions put to them.
  - The consequences of obtaining the data or of refusing to provide them.
  - The possibility of exercising rights of access, rectification, erasure and objection
  - The identity and address of the controller or of his representative, if any.

*Art. 9: Data security*

1. *The controller or, where applicable, the processor shall adopt the technical and organisational measures necessary to ensure the security of the personal data and prevent their alteration, loss, unauthorised processing or access, having regard to the state of the art, the nature of the data stored and the risks to which they are exposed by virtue of human action or the physical or natural environment.*
2. *No personal data shall be recorded in files which do not meet the conditions laid down by rules regarding their integrity and security, as well as the rules governing the processing centres, premises, equipment, systems and programs.*

*Art 10: Duty of secrecy*

1. *The controller and any persons involved in any stage of processing personal data shall be subject to professional secrecy as regards such data and to the duty to keep them. These obligations shall continue even after the end of the relations with the owner of the file, or, where applicable, the person responsible for it.*

*Art. 15: Right of access*

1. *The data subject shall have the right to request and obtain free of charge information on his personal data subjected to processing, on the origin of such data and on their communication or intended communication.*
2. *The information may be obtained by simply displaying the data for consultation or by indicating the data subjected to processing in writing, or in a copy, fax or photocopy, whether certified a true copy or not, in legible and intelligible form, and without using keys or codes which require the use of specific devices.*

*Art. 16: Right of rectification or cancellation*

1. *The controller shall be obliged to implement the right of rectification or cancellation of the data subject within a period of ten days.*

INGEMA as a part of the MATIA group has, according to the Spanish law [223/2004], a Research Ethics Committee that has to approve all research projects involving human participants. This Ethic Committee was accredited by Resolution of the Basque Health Department (BOVP 18th July 1997). This Committee guarantees the best quality of social, psychological and public health attention to elderly people and the fundamental ethical principles that a Clinical Research on human beings has to have. This Committee respects the criteria of Good Clinical Practice in Investigation and Helsinki and Oviedo Agreements. Also the studies involving humans are supervised by Ethics Committee of Donostia Hospital.

## **2.2. Greek Legislation**

In order to guide the handling of personal data we will follow the “2472/1997 Greek law” [7].

The Law of “Individual Protection from Processing Data of Personal Character” 2472/1997 of Greece: The law of 2472/1997 dedicates several articles to the protection of personal data. The parameters that make processing of personal data legal are defined at its second chapter (4<sup>th</sup> article), which is entitled “Processing Data of Personal Character”. More specific:

In order to perform legal processing on personal data:

- Data should be collected with acceptable and legal methods for predefined, clear and legal purposes.
- Data should be coherent, convenient and no more than that the application demands.

- Data should be stored in a way that the definition of the subjects' identity should be possible, only during the period that this is necessary for the completion the scope that they have been collected. After the termination of this period only the Hellenic Data Protection Authority could allow further preservation of personal data for historical, scientific or statistical purposes given that no right of the subjects is offended.

The observance of the above devolves the responsible of the data processing. All data collected contrary to what has been mentioned above should be destroyed by the responsible of data collection and processing.

The 5th article, mentions that the process of personal data is only allowed provided the subject's assent. The responsible for data collection and processing is indebted to inform the Authority for the existence and operation of the database or the processing of its data.

According to 2472/1997/GR (article 7) processing of personal data is illegal unless:

- The subject has already given a written assent (provided that it has been legally constructed).
- The process of data concerns issues of personal health and it is carried out by someone that his profession is related to health services and he is subject to confidence obligation and relevant deontology code.
- The process is held for research and scientific purposes under the condition that anonymity is observed and all necessary measures for protecting individual's rights are obtained.

The 10th article describes the Confidentiality and Security of Processing Personal Data. More precisely:

- The procedure of processing personal data should be confidential. This means that processing can only be conducted by those that are controlled by the responsible of process.
- The responsible of processing the data has to obtain all appropriate organizing and technical measures for data security and their protection from incident or unwanted corruption, loss, or illegal distribution. The measures have to provide a level of protection proportional to the risks that emerge from illegal processing.

Articles 11 and 12 cover the rights of the subject person to be informed and to access his personal data. More specifically:

- The responsible for data collection and processing has to inform the subjects about his identity, the scope of the process, the recipients of the data.

- The subject of personal data has the right to receive information about all his personal data and their source.
- The reasoning behind the process.
- Subject has the right to correct, delete, or block his data.

### **2.3. Internal Recommendations for Proceedings to Handle Ethical Issues and Personal Data within PeerAssist Project**

As can be seen from the previous sections, data protection legislations at a national level share a lot of common contents that need to be addressed and observed in the PeerAssist project. Below, we present the most relevant common specifications to different national legislations, together with some recommendations to guarantee those rights and proper procedures within the project:

<b>Right / Procedure</b>	<b>Ways to protect this right or to guarantee a good development of the procedure</b>
<b>Right to access to information, purpose of data collection, process and purposes of data use, right to rectification and cancellation</b>	Develop an informative and appropriate consent form which is as much self-explanatory as possible and according to established legislations and directives.
<b>Use of data</b>	<p>Develop a user information collection protocol (i.e. questionnaire) which gathers as much information as required, but with a clear definition of purposes to avoid the collection of personal non-needed information. In this sense:</p> <ul style="list-style-type: none"> <li>- No video or audio information from the users is expected to be taken.</li> <li>- No medical information is expected to be taken.</li> </ul> <p>If the collection of any kind of information of this type were required, additional consent forms would be required, and (where needed) respective national ethical</p>

	committees should be informed to ask about the nature of this information collection, its necessity and its use.
<b>Data protection</b>	<p>Develop procedures within the data exchange within the consortium to protect those data:</p> <ul style="list-style-type: none"> <li>- Personal data dissociated from the rest of information for example via alphanumeric codes</li> <li>- Presentation of user profiles with simulated or changed personal data to avoid identification of both users themselves and sensitive information from them</li> </ul>
<b>Transfer of data to third parties</b>	<p>Exchange of files which are encrypted.</p> <p>For those files containing personal information, it will be kept by one institution (example: SPSS matrix on user requirements is kept by INGEMA) and, in case anybody requires that information, sensitive data that may identify users will be excluded from the matrix.</p>
<b>Dissemination of data</b>	<p>Data from the users will be presented as a group, not on an individual basis.</p> <p>No information directly pointing to the identification of any user will be published without his/her explicit and clear approval.</p> <p>If this will be the case, it would require an additional consent form stating that the user accepts to be presented as a “case report” in any dissemination activity or context.</p>
<b>Destruction of data</b>	Sensitive data, not necessary for dissemination after the project ends and whose utilization was restricted to the

	duration of the project (according to the specificities of the consent form), need to be destroyed. Electronic data will be erased and paper/documentation related to that information will be destroyed after a period of 48 months (4 years).
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### 3. Data protection plan at PeerAssist

For PeerAssist purposes, the way of collecting data to be carried out will be the collection of personal data (social demographical data, health general status, emotional status, leisure activities, and use of technologies). We have therefore analyzed these aspects of data collection, studying the legislation in Europe as well as specifically in each involved country (mainly Spain and Greece), and proposing a data protection plan that aims to cover all the cited aspects. This plan is presented below.

#### 3.1. General issues concerning data protection plan

**Purpose of the data protection plan:** The data protection plan becomes part of the signed agreement between PeerAssist consortium and the investigator(s) participants in the project. If the agreement is executed, all members of the research team with access to the data are contractually obligated to follow all aspects of the data protection plan. The fundamental goal of the protections outlined in this plan is to prevent persons who are not signatories to the restricted data use agreement or the supplemental agreement with research staff from gaining access to the data.

**What should be covered by the plan:** The data protection plan applies to both the raw data file received from PeerAssist consortium as well as any copies made by the research team, and any new data derived solely or in part from the raw data file. The plan also should address how computer output derived from the data will be kept secure. This applies to all computer output, not only direct data listings of the file.

**Components of the plan:** PeerAssist data protection plan should contain the components listed from section 3.1.1. to 3.1.5.

##### 3.1.1. Informed Consent

Informed consent is the process by which a participant will be fully informed about the research in which he/she is going to participate. It originates from the legal and ethical right



the participant has to direct what happens to his/her personal data and from the ethical duty of the investigator to involve the participant in research.

Respect for persons requires that participants, to the degree they are capable, be given the opportunity to choose what shall or shall not happen to them. This opportunity is provided, when adequate standards for informed consent are satisfied. In order to involve a human being as a participant in research, the investigator will obtain the legally effective informed consent of the participant or the participant's legally authorized representative.

All investigators within AsTeRICS will seek such consent only under circumstances that provide the prospective participant or the representative sufficient opportunity to consider whether or not to participate and that minimize the possibility of coercion or undue influence.

The information given to the participant or the representative will be in language understandable to the participant or the representative. No informed consent, whether oral or written, may include any exculpatory language through which the participant or the representative is made to waive or appear to waive any of the participant's legal rights, or releases or appears to release the investigator, the sponsor, the institution or its agents from liability for negligence.

### ***3.1.2. Data Storage and Handling Processes***

Much research revolves around information about people –their age, lifestyle, health– drawn from records, scientific tests, surveys and interviews. Sometimes, the information also reveals facts about relatives and relationships. These types of information are sensitive and private for many people, although attitudes and expectations vary widely.

The protection of the privacy of participants is a responsibility of all people involved in research with human participants. Privacy means that the participant can control the access to personal information; he/she decides who has access to the collected data in the future.

Due to the principle of autonomy the participants have to be asked for their agreement (informed consent) before private information can be collected. It should be also ensured that all the persons involved in research work, understand and respect the requirement for confidentiality. The participants should be informed about the confidentiality policy that is used in the research.

The privacy plays a role at different levels:

- Hints to or specific personal information of any participant in publications.

- It should be prevented to reveal the identity of participants in research deliberately or inadvertently, without the expressed permission of the participants.
- Dissemination of data among partners.
- Access to data method of access, data formats, method of archiving (electronic and paper), including data handling, data analyses, and research communications. Offer restricted access to privacy sensitive information within the organization of the partner.
- Protection of the privacy within the organization of volunteers (employers, etc.) throughout the whole process like, communications, data exchange, presentation of findings, etc.
- Destruction of data once the purposes for which the data were obtained (and for which the consent form was signed) is over.

Furthermore, the participants have to be able to control the dissemination of the collected data. The investigator is not allowed to circulate information without anonymization. This means that only relevant attributes, i.e. gender, age, etc. are retained. Another possibility is to keep the identity of the participants, but only with prior consent of those.

As already mentioned, protection of confidentiality implies informing the participants about what may be done with their data (i.e. data sharing). As databases are developed, confidentiality will become increasingly hard to maintain. Simple stripping of the participants name and its replacement with a code is no guarantee of complete confidentiality.

### **3.1.3. Process of Encoding and Anonymization**

Information should be anonymized so that individual identities cannot be revealed. Anonymization provides a safeguard against accidental or mischievous release of confidential information.

There are different ways in which personal data can be modified to conceal identities:

- Coded information contains information, which could readily identify people, but their identity is concealed by coding, the key to which is held by members of the research team using the information.
- Anonymized data with links to personal information is anonymized to the research team that holds it, but contains coded information, which could be used to identify people. The key to the code might be held by the custodians of a larger research database.

- Unlinked anonymized data contains nothing that has reasonable potential to be used by anyone to identify individuals.

As a minimum anonymized data must not contain any of the following, or codes for the following:

- Name, address, phone/fax. numbers, e-mail address, full postcode.
- Any identifying reference numbers.
- Photograph or names of relatives.

Researcher and database developer should always consider – when designing studies, before passing information to others, and before publishing information- whether data contain combinations of such information that might lead to identification of individuals or very small groups. Within PeerAssist we will follow the unlinked anonymized data policy, especially since we may include users having rare diseases and other identifiers like age, gender and nationality. Once anonymized, the data will not allow tracing back the participant in any way, and any analysis of the data will be based on group analysis.

Data will be encoded, and anonymized using numerical codes. During the experiments and the development stages, the correspondence with the users list will be saved into a local database, which will be encrypted.

At PeerAssist the computing environment in which the data will be used at each of the sites, is explained below:

From INGEMA, specific measures will be developed and are recommended for the rest of the partners:

- Computing platform (PC, workstation, mainframe platform): PC
- Number of computers on which data will be stored or analyzed: 2
- Whether personal computers used in the research project will be attached to a network or will operate independently (stand-alone): Stand-alone computers for the data collection, computers connected to a LAN for analysis.
- Physical environment in which computer is kept (e.g., in room with public access, in room locked when not in use by research staff): In a room locked when not in use by research staff.

### **3.1.4. Process of Data Destruction**

During the data collection, it needs to be clear that any personal data gathered from the persons participating in the project are relevant and as less as necessary for the successful development of the relevant purposes of the project. However, in this process of data collection, special needs may rise up that require collection of sensitive information when it comes to train or improve a technological device relevant for the project. For example, and this is not related to PeerAssist, in the case that a speech recognizer should be developed, it could be that voices of users may need to be recorded in order to provide the speech recognition system with raw data of users' voices to train the system. In the specific case of Spain, law 15/1999 identifies the "voice" as sensitive personal information in need to be protected in terms of privacy. For this particular sample, all the data gathered to train such a system should be erased and destroyed after the project ends, regardless the interests of the developers of that speech recognizer, since they were collected "only for the purposes and within the scope of the project".

From INGEMA, specific measures will be developed and are recommended for the rest of the partners:

- Dissociation of personal identifiable data as it was specified in section 3.1.3.
- Destruction of paper/documents with a paper destroyer by the time the project ends.
- Erasing of electronic documents containing medical information by the time the project ends.

#### 4. Evaluation Criteria of this Data Protection Plan

These data protection plan evaluation criteria will be followed as guidelines throughout the project and its fulfilment will be supervised, deviations from it will be minimized and appropriately justified. A brief report, describing the fulfilment of these criteria, eventual conflicts, and how these have been solved, will be supervised by INGEMA and sent to the Commission at the end of the project.

The proposed criteria that will be observed to measure the fulfilment of this evaluation plan will be the following:

Criteria	YES	NO	N/A
The users have been informed about the goals of the project			
The users have given their consent to their participa-			

tion.			
All the data collected in the user requirements questionnaire are necessary (but also are the minimum, in order to avoid asking for non relevant, but sensitive, information) for the subsequent development of the PeerAssist platform			
For any data not initially expected or specified in the consent form, a justification for its needs has been reported to the respective ethical committees (if required). This may include: Video information about the users. Audio information about the users.			
For any data not initially expected or specified in the consent form, additional consent forms have been provided to the users.			
Sociodemographic identification data have been dissociated from the rest of information about the users			
Sociodemographic identification data have been encrypted on a separate database			
Risk of identifying users in profiles or scenarios have been minimized			
Any file exchanging personal information from the users have been encrypted.			
The site where the SPSS matrix of PeerAssist users' information is stored is password protected			
Scenarios show conflict with legislations about privacy and security			
For those scenarios showing conflict with legislations about privacy and security, necessary adaptations to fulfil these legislations have been carried out.			
Dissemination activities performed do not allow identification of the users			
Presentation of "case reports" has been done fulfilling the users explicit approval for each individual situation.			

## References

- 1 European Commission: Ethics - Ethical scientific research - Respect of fundamental principles. 2007 [Online]. Available:<http://ec.europa.eu/research/science-society/index.cfm?fuseaction=public.topic&id=366&lang=1> [accessed 24 May 2010]
- 2 European Commission: Ethics for researchers, Facilitating research excellence in FP7.
- 3 Directive 95/46/EC. Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data.
- 4 Directive 95/46/EC. Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data.
- 5 Charter of Fundamental Rights of the European Union. 2000/C364/01. Official Journal of the European Communities 18 December 2000.
- 6 Ley Orgánica 15/1999, de 13 de diciembre, de Protección de Datos de Carácter Personal (BOE núm. 298, 14-12-1999, pp. 43088-43099) [Organic Law, 15/1999, for Protection of Data of Personal Nature, Text in Spanish]
- 7 Greek Law 2472/1997 on the Protection of Individuals with regard to the Processing of Personal Data - as amended by Laws 2819/2000 and 2915/2000

## Annexes

### Annex I: Research Information Form for the Ethical Committees (In English)

**PeerAssist – A P2P platform supporting virtual communities to assist independent living of senior citizens**

**AAL-2009-2**



#### [Project information Sheet]

Partner	Name	Acronym	Country
1 (Project leader)	University of Athens – Communication Networks Laboratory	UoA	Greece
2	Seekda GmbH	Seekda	Austria
3	InAccess Networks	IAN	Greece
4	Warp Networks, S.L.	Warp	Spain
5	Fundación Instituto Gerontológico Matía	Ingema	Spain
6	Municipality of Athens Development Agency	AEDA	Greece
7	Semantic Technology Institute Innsbruck	STI-IBK	Austria

**Title of the project:** PeerAssist (A P2P platform supporting virtual communities to assist independent living of senior citizens)

**Coordinator:** Prof. Lazaros Merakos (UoA, Grecia)

**Principal researcher at local level:**

**Institution:**

**Funding:** AAL Programme (The Ambient Assisted Living Joint Programme)

**Duration:** 2010-2013

## 1. AIM OF THE PROJECT

The main objective of the PeerAssist Project is to develop a platform to help the establishment, as the demands of users, networks of communication with their families, neighbors, friends, assistants, or others with whom to share common interests and needs. So, it could be possible to create ad-hoc communities involving all those who the system detects sharing similar interests and concerns. It will improve the ways of communications of the elderly people as well as their social relationships and quality of life.

## 2. ¿WHO IS THE TARGET GROUP OF THIS PROJECT?

The end users group are adults (60+ years old) without cognitive impairment, in good physical and mental conditions, living independently and be active. On the other hand, it is not necessary that users have been familiarized with new technologies.

The tests will be carried out in:.....

The inclusion criteria are:

- 60+ years old person
- Elderly people participative, communicative and free time
- Person without cognitive impairments

Exclusion criteria are:

- Persons under 60 years old
- Cognitive impairment

## 3. PARTICIPANTS IN THE STUDY

In the PeerAssist project users' participation is required twice. The goal is to collect the initial and final opinion of the users about the platform. The tests will be carried out in 2 parts:

1. - User requirements, interests and needs: an evaluation will be carried out with 20 elderly people using a structured interview. Its objective is to achieve information about their sociodemographics data, social support, physical, psychological and social and skills and interests about new technologies



Complementarily, an assessment of cognitive abilities and quality of life will be conducted to increase the knowledge about the intellectual and social functioning of older people, whose overall results will guide the work of the technologists on how best to adapt the PeerAssist platform to the elderly.

2.- PeerAssist final platform evaluation: An evaluation of the final prototype will be carried out with 20 users. With this aim we will contact again the users and after administering the informed consent, each user will be assessed individually. The test will be focused on usability, acceptability and accessibility criteria.

Two hours is the time estimated to carry out each trial in this prototype evaluation.

#### **4. ESTABLISHING CONTACT WITH THE PARTICIPANTS**

The next process will be established to recruit the participants' recruitment.

1. Contact with the participants will be established by telephone. We will inform them about the aims of the project and, for those interested, the possibility of having a face-to-face meeting will be asked in order to give them more information.

2. Once the participants accept to participate in the project, an individual interview will be carried out. In this interview more information will be given to the users: aim of the research, voluntary participation, procedures, risks and benefits, privacy and confidentiality (fulfilment of the *CORRESPONDING LAWS*), and project contact persons for further information on the project.

3. When they are interested in participating, a written informed consent will be delivered to them. At the same time, a researcher would explain the informed consent in order to do it understandable with no doubt. After that, if the person agrees, both sides will sign the informed consent and the user starts participating in the project.

4. At the beginning an alphanumeric code is assigned to every participant, and at any time a specific user's data are needed, this user is identified by means of this code. As a result, the personal data are dissociated from the project related data in a different database that will not be used for the further analysis. Only one of the (*PARTNER COMPANY NAME*) researchers will manage the database in which the personal data are listed.

In this project, within the work package 1 aimed at the evaluation, a specific ethical issues task is led by INGEMA Foundation. The aim of this task is to assure the ethical validity of the project. Part of this work package's aim is to ensure that the project development and specifically the evaluation is carried out with the necessary ethical correction, and the autonomy, independence, benevolence and justice are respected and guaranteed throughout the project. This work package is linked to all the project activities and specifically with the user related activities.

## **Annex II: Brief Project Information Sheet for users (In English)**

### **PeerAssist – A P2P platform supporting virtual communities to assist independent living of senior citizens**



**AAL-2009-2**

#### **1. PROJECT GOALS**

PeerAssist is a Project funded by the AALProgramme (The Ambient Assisted Living Joint Programme) with an expected duration of 30 months, starting in September of 2010 and ending in February of 2013. The goal is to develop a flexible platform connected to a TV that allows users to increase and improve communication ways through the creation of a virtual community of communication.

The main objective of the project is to develop networks of communication with their families, neighbors, friends, assistants, or others with whom to share common interests and needs, based on user demands. So, it could be possible to create ad-hoc communities involving all those people the system detects sharing similar interests and concerns.

PeerAssist might establish the basis for developing a wide number of applications that may improve the quality of life of the elderly people including: organization of social activities such as going to the movies, exchanging books or organizing social gatherings, soliciting peer help on housekeeping and other daily activities, allowing support organizations to place relevant content to interested elderly users, allowing caregivers, facilitators and family members to receive alerts if certain expected home activities of the elderly people are interrupted or responding to emergency or unexpected situations that may need immediate action.

#### **2. ¿WHO IS THIS PROJECT AIMED AT?**

The end users' group at which this Project aims is: adults (60+ years old) without cognitive impairment, in good physical and mental conditions, living independently and being active. On the other hand, it is not necessary that users have been familiarized with new technologies.

#### **3. PARTICIPANTS IN THE STUDY**

Within PeerAssist Project, it is required the participation of the users throughout the Project in different moments, the first moment will be the initial phase of the Project. In the first phase, the goal will be to gather knowledge about the users' needs and interests, and, in order to collect that

information, we will perform an evaluation to collect data such as: sociodemographic data, quality of life, social support, cognitive abilities, skills, interests and interactions about new technologies, etc....

The main goal of this first evaluation stage is to gain knowledge about users' needs in order to fulfil them (to the extent that is possible) by means of the devices developed throughout the project time.

During the second year of the project, we will develop the final evaluations of the PeerAssist platform. We will observe how the user interacts with the final prototype and its applications, and we will gather their opinions on which aspects that may be improved from the users' perspective.

## Annex III: Consent Form (in English)

### PeerAssist – A P2P platform supporting virtual communities to assist independent living of senior citizens



**AAL-2009-2**

**Title of the project:** PeerAssist (A P2P platform supporting virtual communities to assist independent living of senior citizens)

**Coordinator:** Prof. Lazaros Merakos (UoA, Grecia)

**Principal investigator at local level:**

**Institution:**

**Funding:** AAL Programme (The Ambient Assisted Living Joint Programme)

**Duration:** 2010-2013

**Name of participant:** \_\_\_\_\_

The study described in this text is a part of the research project "PeerAssist – A P2P platform supporting virtual communities to assist independent living of senior citizens, funded by the AAL programme.

#### 1. INTRODUCTION:

You have been invited to participate in a research study. Before you decide to participate, please read this consent report carefully. Please ask all the questions that may come to your mind. In this way, we will be sure that you understand all procedures of the study, including the risks and the benefits.

This consent sheet may include words that you do not understand. If so, please ask the contact researcher or any person included in the study to explain to you any word or information you do not

clearly understand. You can take away a copy of this consent to think about it or to discuss it with your family before making any decision.

## **II. AIM OF THE STUDY:**

The main goal of the PeerAssist Project will be to develop a flexible device to communicate and share information remotely via a platform installed in a TV. This platform will allow elderly people to build up virtual communities of communication based on interests and needs they share.

The goal is to develop a platform which will allow users to contact family, friends and others so they can share common interests, hobbies, etc. The platform will improve the means of communication between people, providing they can maintain contact with other people with common interest, and thereby improving their social relationships and quality of life.

## **III. PARTICIPANTS IN THE STUDY:**

You are being asked to volunteer in a research study. This consent/information form includes information about this study. We want to make sure that you are informed on the purpose of this study and what it means for you to participate in this study.

Please ask us for clarification on any point in the following information sheet. If you do not understand certain contents, please do not sign this form before you feel confident that you are aware of the study and its goals.

The purpose of the study is to identify which are the main needs of the older people, especially those related to the use and interaction of new technologies (computer, phone, touch screen ...) and their levels and satisfaction of social support and their leisure activities.

The participation in the study is totally voluntary. You can quit at any moment without being penalized or losing your benefits.

## **IV. PROCEDURES:**

In the initial phase, your participation will consist of an interview. The goal will be to gather knowledge about: demographic data, quality of life, their physical, psychological and social health, and skills and interests about new technologies. Moreover, after making a brief presentation of the PeerAssist project and its main objectives, it will be develop a focus group to collet their point of view and opinions.

This procedure will last two hours. The main purpose of the evaluation is to achieve information about your daily needs and your opinion about the new technologies in order to improve and to adapt the platform to your needs. In this way, these needs can be taken into account and your actual needs will be achievable by the device developed in the PeerAssist project. At the end of the study, if you want, you can receive information about the results of this evaluation.

## **V. RISK OR INCONVENIENCES:**

No risks or damages are foreseen during the assessment.

**VI. BENEFITS:**

You will probably not receive any personal benefit for your participation in this study. In any case, the data collected in this study might result in a better knowledge of elderly people's needs.

**VII. PRIVACY AND CONFIDENTIALITY:**

We will record your answers to our notes in a way that it will not hold any identification of yourself nor it will not be possible to identify you later on. In other words, when someone agree to participate in the research, they receive a code-number, and since that moment every personal data are under that code, because of that no one could know to whom the data belongs to. The information will be processed during the analysis of the data obtained and will appear in the project deliverables but only in the way that it will not be possible to identify from whom we received the information assuring in every moment the performance of *(NAME AND NUMBER OF SPECIFIC NATIONAL LEGISLATION)*

*“(RELEVANT TEXT CAPTIONS FOR THE SPECIFIC LAW MENTIONED ABOVE)”*.

The results of this research can be published in scientific magazines or be presented in clinical sessions, always guaranteeing the complete anonymity.

The authorization for the use and access of the information for the aim of research is totally voluntary. This authorization will apply to the end of the study unless you cancel it before. In this case we will stop the use of your data.

If you decide to withdraw your consent later on, we ask you contact principal investigator of this study and let him know that you are withdrawing from the study.

The Principal Investigator can be contacted under the following address:

*(NAME AND CONTACT ADDRESS OF PERSONAL INVESTIGATOR)*

Since the moment of your withdrawal, your data will not be processed again in any further phases of the research project. However, it will not be possible to alter already existing published documents or completed project deliverables.

**VIII. CONTACT PERSON**

For further information about your rights as a research participant, or if you are not satisfied with the manner in which this study is being conducted or if you have any questions or suffer any injury during the course of the research or experience any adverse reaction to a study drug or procedure, please contact the Principal Investigator:

*(NAME AND CONTACT ADDRESS OF PERSONAL INVESTIGATOR)*

**IX. CONFIRMATION:**

Your participation in the study is possible only if you sign a stand-alone consent form that will authorize us to use your personal and health information and the information on your health status. If you do not wish to do so, please do not take part in this study.

I have read the information written in this consent report or has been adequately read to me. All my questions about this study and about my participation on it have been met.

Tick one of the following:

I read all the information in this form.

The information in this form was read to me by: .....

All questions I had were answered by: .....

I authorize the use and dissemination of my answers to the aforementioned entities and for the above mentioned purposes. The signing of this consent report does not imply the renunciation to any legal right. I voluntarily agree to participate in this research study carried out by Ingema Foundation and other members of the "PeerAssist" project.

I understand that I am entitled to and will be given a copy of this signed Consent Form.

Name and Surname of participant

Date

Signature of participant

Name and Surname of the researcher

Date

Signature of the researcher

\_\_\_\_\_

