AAL PROGRAMME

TSBank

Time and Skill Bank for Active Aging

D2.2- Ethical and Legal Report

ANA ASLAN INTERNATIONAL FOUNDATION

INCREASETIME® Technology for better life

Scuola universitaria professionale della Svizzera italiana

SUPSI

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Executive Summary

The objectives to be achieved within WP2 will provide to technical partners a set of user requirements guidelines that will serve as the foundations of the solution. It will use a guideline of end-users' recruitment and enrolment, the methodologies to enable the collection of data from user focus groups, expert groups, and advisory groups. In addition, this WP will profile the pilot settings scenarios to plan the pilot deployment strategy and system definition.

The task 2.2 (Definition of ethical and legal issues) will describe the ethical and legal issues related to working with human voluntary end-users in general and within the specific context of AAL projects. These refer to a large array of topics, from recruitment and testing-related ethical aspects to exit rights, to information and data management and personal data protection requirements.

This task will address both the issues related to the implementation of the project and the issues related to the solutions developed during the project.

Moreover, task 2.2 will tackle the ethical and legal aspects both from local (national regulations in the piloting countries) and European perspectives.

Document Context

Role of the Deliverable

The purpose of D 2.2 is to define the ethical and legal issues related to working with human voluntary end users within the TSBank project. It will refer to two distinct categories: issues related to the implementation of the project and issues related to the solutions adopted in the project. Both must apply the national and international ethical rules specific for end-users and to society in general, from the concept phase to test installations and eventually launching in the market.
It is pointed out that the nature of AAL projects raises a broad range of ethical concerns, most of them related to the technology involved that is often unfamiliar to the end-users and being sufficiently complex to not allow a full transparency for end-users and other stakeholders (privacy, control of personal data, confidentiality, autonomy and dignity).
In generally the ethical rules in AAL concerns refers to:

- end-user's recruitment,
- end-user's participation to project development,
- the informed consent as a standard procedure,
- the protocol of participation in prototypes testing and validation,
- information on how the end users can withdraw from the project at any time,
- the possible compensations provided for participating (expenses or fees paid, etc.),
- the possibility to contact a person in their own country for ethical issues and related questions.

The exit rights for individual end-users (withdrawal from the project at any time, without giving a reason and without incurring costs or penalties) must be clearly specified and carefully managed because termination of the project may create problems in the terms of losing a help they got accustomed with. Other important issues that require ethical awareness are information and data management, the storage and transmission of personally identifiable information, the application of the national rules of the involved partners, the statement or permission by national and partner institution ethical committees, and the macro level distributive ethics (justice, equality of access, choice etc.). Of a great importance and help in the ethical management is the permanent communication with the National Contact Point.

Relationship to other project deliverables

Deliverable	Relation
D 2.3	Title: Specification of users needs and preferences. *The definition of the ethical and legal issues related to working with human voluntary end users within the TSBank project (D 2.2) contributes in drafting* *the methodology of Focus Group trial.*
D 2.4	Title: Scenarios and use cases *The definition of the ethical and legal issues related to working with human voluntary end users within the TSBank project (D 2.2)is the second step in contouring a set of use cases for all end user profiles integrated in a set of scenarios, according with the data from D 2.3.*
D 4.1	Title: Pilot plan development. *The definition of the ethical and legal issues related to working with human voluntary end users within the TSBank project (D 2.2) contributes in drafting* *the methodology of pilot trial.*
D 4.4	Title: Analysis and evaluation. *The definition of the ethical and legal issues related to working with human voluntary end users within the TSBank project (D 2.2) manages the collection and analysis of the pilots' result.*

Document Structure

This document presents on section 2, after a short description of the project and the proposed system, a detailed information about the ethical and legal issues related to the implementation of the project: European and international laws, rules and regulations; ethical aspects regarding advanced technology for people in Europe, ethical perspective in smart assistive technologies development and access to technology principles. Sections 3 describes ethical and legal issues related to the solutions adopted in the project: ethical issues related to the information data management, regulations on protection of individuals and handling personal data, rules regarding data protection, management of possible users' complaints and withdrawal request, ethics principles for research. Section 4 concludes the report.

1. Project Description

1.1 General Description

The core concept of the TSBank is to give the elderly a way to use their time and skills in a way that is useful to society, enabling them to be active and feel needed, which will greatly contribute to their well-being and reduce their dependence on the caregiving infrastructure. The matching process follows a series of steps to ensure a correct match is made:

1. The elderly register with the online tool via a simple interface and inserts the tasks they are willing to help on, thus ensuring they are adapted to their capabilities.
2. People looking for a specific service looks in the platform, and the system matches their request with the available elderly support work, putting both in contact.
3. Once the support is done both parties are requested to vote/comment on each other, creating a "trust rating" that enables future help requesters to make a better selection.

The TSBank project is built upon the concept of helping the elderly help others, in the process improving their self-esteem and social engagement, which in turn improves their wellbeing.

While existing social networks can also be used to provide the proposed matching of volunteer work/needed service, such solutions are too generic and difficult to use for the suggested target demographic. The TSBank solution differs from them in that it is focused on the elderly and their volunteer work, allowing to have a greatly simplified interface and more efficient match-making capabilities.

1.2 System Description

TSBank will develop, validate, and deploy an online platform – silverskills - that allows the elderly to volunteer their skills and time to perform work on a set of areas. People looking for support can then consult the platform for volunteer elderly that match the sought needs, and the platform puts both parties in contact.

The TSBank platform will be built on a modular system, where there's a single base core of features on top of which there are a series of modules dedicated to specific volunteer work areas. The platform can be expanded to include virtually any area for the elderly to volunteer on, while the TSBank project will implement three areas to serve as the start points for the system: Tourism, Pet Sitting and Consultancy. With these three modules, TSBank contributes for an increase of the quality of life, autonomy and participation in social life of elderly people. At the same time, it serves as a starting point for self-confidence in the use of ICT tools through the use of perception of knowledge and experience transfer by making skills and competencies visible in local communities, boosting elderly acceptance and perceived value of ICT solutions. Other important aspects of the system will be the usability and design, which will have to be developed according to the limitations of the elderly users.

2. Ethical and legal issues related to the implementation of the project

2.1 European and international laws, rules and regulations

The Universal Declaration of Human Rights adopted by the general Assembly of the United Nations in 1948 and The European Union Charter of Fundamental Rights, adopted in 2000 regulates the right of elderly to dignity, independence, privacy, non-discrimination (insertion in the social and cultural life, access to medical preventive, treatment, and recovery care) and personal (data) protection.

The European Convention on Human Rights and Biomedicine also mentions and support the primacy of the human being (of its interest and welfare that must prevail over the sole interest of society or science) (Article 2), the need of equitable access to health care of appropriate quality and the concern for specific measure to be taken (Article 3), adopted the professional standards (Article 4) and the right of private life right and right to information.

The European directive on clinical trials (2001) established and requires Member States to elaborate a system of ethical provisions and the implementation of good clinical practice. "Good clinical practice-a set of internationally recognized ethical and scientific quality requirements which must be observed for designing, conducting, recording and reporting clinical trials. Also established the rights, safety and well-being of trial subjects are protected, and that the results of the clinical trials are credible. In the same manner elaborated the exit strategy.

2.2 Ethical aspects regarding advanced technology for people in Europe

The common aspects in these cases are to do the right thing for all categories of users. They should guarantee the end-user autonomy and consent, safety and independence. The balance between avoiding harm and respecting decisions is an important key point together with privacy protection, dignity, integrity and preferences. Treating the individuals fairly and equally and "human-centred-design-approach" - end users must be involved in the technological research process and design.

Other operative issues should refer to the user's feel of ownership, acceptance (human-machine compliance), to guarantee the choice and freedom to "opt out" at his/her own convenience, equal economical accessibility of old but active people and the need of developing specific socioeconomic studies.

2.3 Ethical perspective in smart assistive technologies development

The Utilitarian perspective refers to the utility: "ethically good" = provided benefit, "ethically bad" = harming, to equality (treating everyone equally) and affordability of ICT applications.
The Aristotelian perspective discusses some topics such as:

- In order to promote self-determination, how all citizens are involved in the development of e-services that promote social inclusion?
- Is it defensible that those people who, for whatever reason, have no or limited access to on-line services are disadvantaged?

- To what extent do disaffected groups perceive online government services as untrustworthy?
- What is the balance between sustaining individual privacy and promoting e-inclusion?

The Kantian perspectives also raise important issues that should be analysed and replied. Some of these are:

- How can public access points to online government be de-stigmatised?
- How can government online services be implemented in a way that respects the EU as a heterogeneous population in terms of culture, economic prosperity and age?
- In order to promote ICT acceptance and effectiveness, how can respect for cultural diversity be realised in generalised ICT products and services?
- In order to treat people with dignity, how can e-inclusion initiatives cater for changing requirements and preferences, as people get older?
- What is important about an individual's autonomy and dignity when planning e-inclusion initiatives?"

2.4 Access to technology principles

Amsterdam Treaty regulates the equal opportunity, no discrimination by religion, age, disability, sexual orientation and universal accessibility - equal access to goods and services.

3. Ethical and legal issues related to the solutions adopted in the project

Protection of personal data is regulated at the European level by Directive 95/46/EC. The Directive applies to data processed automatically (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 aiming 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).

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.

Personal data is defined 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 specific elements, characteristics of his physical, physiological, mental, economic, cultural or social identity and attributes special protection to health data.

The European Directive on the protection of personal data contains a number of key principles, which must be strictly followed. Anyone processing personal data must comply with the eight principles of good practice providing that data is:

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.

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 are already enjoyed at a

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.

3.1 Ethical issues related to the information data management

This aspect is important in TSBank project because the database platform collects a lot of personal data and personal information. This includes the:

- storage and transmission of personally identifiable information;
- application of the national rules of the involved partners;
- statement or permission by national and partner institution ethical committees;
- macro level distributive ethics (justice, equality of access, choice etc.).

3.2 Regulations on protection of individuals and handling personal data

At European level

- The Directive of the European Parliament and of the Council of 24 October 1995 on the protection of individuals regarding the processing of personal data and on the free movement of such data (Directive 95/46/EC) - valid until 25th of May 2018
- The new Directive of the European Parliament and of the Council from 27 April 2016 (Regulation 2016/679 and Directive 2016/680), which sets up the new **General Data Protection Regulation** that will become effective form 25th of May 2018, when the previous directive will be cancelled.

Key differences between Directive 95/46/EC and the new GDPR

- *Geographic reach and scope:* The previous European Data Protection Directive utilized much more of a light-touch approach than GDPR, setting out aims and requirements for data protection standards that were then implemented through national legislation. By contrast, GDPR is a binding piece of regulation, which will be legally enforceable as soon as it comes into effect on May 25th and will apply to all EU nations and every company holding data on EU citizens.
- *Definition of personal data:* GDPR will expand the definition of "personal data" to include a much wider range of consumer information. Whereas the Data Protection Act only pertains to information used to identify an individual or their personal details, GDPR broadens that scope to include online identification markers, location data, genetic information and more.
- *Consent policies:* This is one of the defining differences between GDPR and the Data Protection Act. Under the old rules, data collection does not necessarily require an opt-in, but under GDPR clear privacy notices must be provided to consumers, allowing them to make an informed decision on whether they consent to allow their data to be stored and used. This consent can then be withdrawn at any time.
- *Data breach policies:* With the current rules in place, businesses are under no obligation to report when data breaches occur, although they are encouraged to do so. This will change with the advent of GDPR, with any future breaches having to be reported to the relevant authorities within 72 hours of the incident.
- *Accountability:* GDPR will place a much greater focus on explicit accountability for data

protection, placing a direct responsibility on companies to prove they comply with the principles of the regulation, rather than the hands-off approach of the Data Protection Act. This means firms will need to commit to mandatory activities such as staff training, internal data audits and keeping detailed documentation if they wish to avoid falling foul of the GDPR rules.

- *Data protection governance:* The Data Protection Act does not stipulate how the governance of data security functions should be allocated, requiring only a basic commitment to the concept from management. GDPR will change this, as any company employing more than 250 people will be mandated to appoint a dedicated data protection officer, as will any firm processing more than 5,000 subject profiles annually.
- *Penalties and compensation:* Currently, non-compliance with the Data Protection Act can see companies fined up to £500,000, or one per cent of annual turnover. Under GDPR, these limits will rise significantly to €20 million, or four per cent of annual turnover, whichever is higher. It's also worth remembering that GDPR will allow individuals to claim compensation for material and non-material damage resulting from data security lapses, whereas the current rules only cover material damage.

At National level in piloting countries

In Romania

All the organizations involved in research are under the jurisdiction of National Authority for the Supervision of Personal Data Processing and the legal framework is represented by:

- Law no. 226/2009 on the organization and functioning of the official statistics in Romania;
- Law no. 677/2001 on the protection of persons regarding the processing of personal data and on the free movement of such data;
- Law no. 682/2001 on the ratification of the Convention for the Protection Individuals related to Automatic Processing of personal data, adopted in Strasbourg on 28.01.1981, as amended subsequent;
- Confidentiality rules of statistical data - National Statistics Institute.

However, all the national rules and regulations in Romania regarding data protection will have to be harmonized and comply with the requirements of the new GDRP, as per 25th of May 2018.

In Switzerland

Data protection is mainly regulated by the Swiss Federal Data Protection Act (DPA) and the Data Protection Ordinance (DPO). The DPA contains:

- General rules on data protection.
- Specific regulations on data processing by private persons and federal authorities.
- Provisions on the Federal Data Protection and Information Commissioner (Commissioner), which is the main supervisory authority in this field.

The DPO was adopted to clarify certain aspects of the DPA provisions. In particular, the DPO contains more details on the:

- Measures that must be taken for the cross-border disclosure of data.
- Functions and duties of data protection officers and the Commissioner.

To prepare for the entry into force of the EU General Data Protection Regulation, the Swiss Government has issued a draft of a new Data Protection Act (Draft-DPA) that aims to:

- Modernise Swiss data protection law.
- Maintain its adequacy status granted by the European Commission, to ensure the free flow of personal data between the EU and Switzerland.

3.3 Rules regarding data protection

- Transparency- the right of the person to be informed: that a category of its personal data is under processing, also the purpose of processing and the recipients of the data.
- Person's right to access all his data under processing.
- The right to demand rectification, blocking or deletion of incomplete, inaccurate data
- Person's consent about his/her data processing.
- Data have to be processed in the interest of their owner, for accomplishing a task of public interest or for the fulfilment of a contract. Also, data have to be processed in an adequate and not extensive way and will not be further processed beyond the initially specified, explicit and legitimate purposes.
- Data keeping must permit identification of their owner only on the period necessary to accomplish the purpose for which they are collected.
- Special attention regarding sensitive personal data of racial, political, philosophical religious.

3.4 Management of possible users' complaints and withdrawal request

The end-user volunteer is entirely free to withdraw the study at any time.
He is informed that the explanation of withdraw is important for the project management and the research, so is up to the end-user volunteer to provide it at his/her convenience
Possible complaints of the end user will be addressed to the project team members, who has the task to solve them and specify these situations in a report.
Researchers involved in the preparation of evaluation trials and end-user feedback collection and analysis should comply with the ethical and legal framework detailed even after the cessation of the activity in the respective organization.

3.5 Ethics principles for research

The ethical principles for research should be applied in the TSBank project. These refers to discuss intellectual property, follow informed-consent rules and inform participants about: the purpose of the research, the expected duration and procedures, the participants' rights to withdraw, the potential risks, discomfort or adverse effects.
Should be mentioned any prospective research benefits, the limits of confidentiality, such as data coding, disposal, sharing and archiving, and when confidentiality must be broken.
Incentives for participation and who can participants contact with questions must be mentioned.
Respect confidentiality and privacy: discuss the limits of confidentiality. Give participants information about how their data will be used, what will be done with case materials, photos and audio and video recordings, and secure their consent.

It is important to know specific country legislation and take practical security measures regarding data protection.
Confidential records should be stored in a secure area with limited access.
Safe data sharing and code data to hide identities whenever possible is an issue that must be applied as much as understanding the limits of the internet data sharing is a reality.

4. Conclusion

The methodology of approaching the ethical and data protection related aspects within the projects have been summarized in the TSBank Ethics Manual (Annex 1).
In particular, the informed consent (Annex 3) will be accompanied by a short introductory, descriptive letter, with all the most relevant aspects for a volunteer; this will be handed to all the senior volunteers together with the consent (Annex 2).

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Annexes

Annex 1: TSBank Ethics Manual

According to the described project objectives, TSBank will target elderly people, a segment of the population that is not very familiar with new technologies and their fundamental rights could become unprotected. For this reason, TSBank will carefully consider the ethical aspects of the project with the aim to ensure the adequate protection of the privacy and the personal rights of the users at every moment and in every situation. 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 organizations 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 TSBank project will be conducted in Portugal, Switzerland and Romania. In addition, field-testing and evaluation will be performed in Switzerland and Romania.

A summary of the plans and actions foreseen to handle the ethical aspects of the project will be presented in 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.

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, will also be a subject of protection.
- Personal information on marital, living status, level of independence
- Personal preferences: with regards to media usage, entertainment, information, cultural events
- User location information: when relevant, it could also be the subject of ethical concerns.

Over the course of the project, when the system will be more developed, and we can observe more specifically the possible ethical problems, the consortium will specify the necessary technological measures to protect the privacy of people interacting with the system.

1. Ethical issues and Personal Data collected during the focus groups and questionnaire-

based surveys

WP2 - Needs analysis

This Work Package has as its main objective to gather and define, through a careful analysis, the functional requirements for the TSBank system — which is the input for the design to be produced by WP3.

The input of the end-users (voluntary subjects) will be extremely important in this work package in order to identify their preferences for the existing formal and informal care services, to profile the typical TSBank end users' profile and to determine end-users need with regard to the product to be developed.

This objective will be achieved by the consultations of end-user representatives through focus groups with the end users and questionnaire-based surveys held by the end-user organization in Switzerland and Romania

All researchers are responsible for ensuring that participants:

- are well-informed about the purpose of the research they are being asked to participate in
- understand the risks they may face as a result of being part of the research
- understand the benefits that might accrue to them as a result of participating
- feel free to make an independent decision without fear of negative consequences
- may drop out at any time during the research

1. Information for participants

Informing participants about the project and procedure will form part of the recruitment process. All prospective participants contacted will be provided with one- or half-page flyer describing the research as well as some background information about the project, explaining how the data will be used and whether the information will be kept confidential. The information sheet should be given to participants prior to the focus group and should also be given in hard copy on the day of the focus group.

2. Participant consent - All participants should sign an informed consent form.

Participants should have the opportunity to provide informed consent prior to participating in the focus group or survey.

3. Management of possible user's complaints and withdrawal request

The end-user partners manage user complaints and withdrawal requests. Each user has the right to quit the trial at any time without stating reasons. In the informed consent, it was clarified that the rejection of participation or early withdrawal has no adverse consequences for participant.

4. Recruitment

Potential participants are contacted by phone or in writing by post/email. At this point, the research and rationale for selecting them to participate should be properly explained. If the individual agrees to participate, this is known as 'first consent'.

5. During the focus groups

The interviewer should remind the participants of the purpose of the research and why they have been selected. They should confirm the participant's agreement to participate. Confidentiality should also be covered: how will the data be used and stored, and will they be named or identified in the report? Finally, the researcher must make it clear that the participant can stop the interview/leave the focus group at any time and withdraw from the research, even after they have given their consent to participate.

6. Safeguarding and disclosure issues

At the start of each focus group the researcher/interviewer/facilitator as well as in the opening letter for the survey will explain that the data collected will remain confidential.

7. Locations

For focus groups, ideally the location would be somewhere quiet and comfortable where conversations cannot be overheard to protect the confidentiality of the participant.

8. Vulnerable people

The focus groups should respect the principles that apply when conducting qualitative research with vulnerable adults:

- written materials should be printed in large letters and the design of materials should be appropriate for the audience.
- use images or visual aids and simplified language.
- accommodate to the needs of the participant for example, participants who would prefer to write or type their answers instead of talking should be provided with a template with the questions and space for answers - so a printed version of the focus group questions, in form of a questionnaire, should always be available for all participants involved in the focus group.
- in the case of mentally ill or cognitively impaired patients, it is important to measure comprehension and develop valid tools for it, before obtaining informed consent to participate in the research study.

9. Data protection & confidentiality

- All information provided will be securely kept on a password-protected computer. No names or organizations will be identified within the research process.

- Data from any focus group and quantitative survey will be kept securely and fully anonymised.
- Names and other identifying features will not be used in any reports.
- Any demographic information we collect, and use will be used purely for statistical data analysis and profiling.
- Any personal and sensitive data (names, ethnicity, age, gender, marital and living status, level of independence) will not be kept with the data collected from the focus groups/surveys
- In case of video recording of the focus group, all participants' consent for this specific purpose (video- recording and distribution) will be obtained before the focus group.
- Questionnaires will be anonymous and encrypted for data centralization and statistical data analysis purposes.
- PC's used for data storage and analysis will be password protected.
- In case of data sharing among project partners: only anonymous data will be shared and only via secure connections.
- Participants ID data will only be mentioned on the Informed consent forms that will be kept in a locked storage device.

2. Ethical issues within Pilot Testing

WP4 – Pilot Organization and Validation

Through the tasks of this WP the consortium will evaluate with end users the TSBank / Silverskills platform. This evaluation will be carried out at the older adults' homes or in elderly care day-centres, in a real environment. Results from the first cycle will be used for further refinement and development of the system, both from a functional and technical point of view. The output from the second (last) cycle will be crucial for the final Business Plan delivery.

At the beginning of each pilot phase the end-users will be thoroughly informed about the project, the purpose, objectives and methodology of current research to be conducted, what is expected from them and the possibility to drop out at any moment. All volunteer end users participating in research activities have to sign an informed Consent form.

The field trials with voluntary end-users will take into account the aforementioned national legislation and local regulations. In every project that supposes the involvement of human subjects, the recruitment of old voluntary end-users will be made based on previously established inclusion-exclusion criteria. If a new end-user recruiting becomes necessary for replacing someone who withdrew his/her participation, then the entire procedure of end-users' recruitment, including Consent Form and the other ethical matters is performed. Each investigator should be trained about the legal and

ethical rules to be pursued during the work sessions with the end-users.

Information procedure

Before participants give their consent, they should be properly informed about the project, and the pilot phase. They will be informed about:

1. What they will be asked to do
2. The expected duration of their participation
3. Who will be conducting the study, whether anyone else will be present
4. Whether they will be audio- or video- recorded and what exactly will be recorded
5. A reasonable estimation of whether it will be boring, difficult, stressful etc.
6. What they should do if they wish to withdraw, with information that this is their right and won't have negative consequences, particularly on their reimbursement (if reimbursed)
7. Who will have access to their data, where and how long it will be stored, with appropriate information about anonymity and confidentiality
8. How will the results of the study be disseminated?

To facilitate understanding of the research methodology and concept, several actions will be undertaken. All information about the study (not only during the recruitment process, but at all stages of the study) will be provided in formats suitable for the particular participants.

It is compulsory that all the researchers working on the pilots have previous relevant experience in working with elderly and in implementing and developing tailored conduct and strategies.

Data protection

1. Treatment of data is governed not only by professional ethics, but by the data protection legal requirements. Data protection refers to all stages of data management: collection (design of data collection methodological instruments), processing, storage, transfer.
2. Over all stages of the pilot testing and beyond, confidentiality and anonymity of participants' data must be strictly preserved. In all computer files, participants will be referred to by a code that cannot identify them.
3. All computer files should be stored only on secure equipment.
4. Particular care should be taken on security issues if files are transferred between partners for analysis. This should be undertaken using secure means and the transferred data should not include any ID.
5. Audio and video files should not be shown beyond the immediate research team unless a written agreement from the participants has been obtained prior to

the registration.

6. Only anonymous data can be reported in project deliverables or in public documents. Reports should mainly include aggregate data. Should individual information be necessary (like comments from individual participants) it must be reported such as to not embarrass the individual and preserve his/her anonymity.

3. Management of possible user's complaints and withdrawal request

As specified including in the Informed Consent procedure, the end-user volunteer is entirely free to withdraw the study at any time, at its convenience and with no penalty. However, he is informed that the explanation of withdraw is important for the investigators and the study, so it is up to the end-user volunteer to provide it at his/her convenience.

Any complaints made by the end-users will be addressed to the principal investigator of each of the end-user organizations, whose task will be to properly address them and specify them in the study report.

The researchers involved in the preparation of evaluation trials and end-user feedback collection and analysis within each pilot site have the obligation to comply with the ethical and legal framework detailed in this document, even after the cessation of the activity in the respective organization.

4. The Exit Strategy

A special attention will be paid to the exit strategy.

It is intended that the commercial and technical partner will offer TSBank as an operational service beyond the lifetime of the project, ***and to offer the possibility for the volunteers to use the platform for one year, for free, both as a provider of services and as a beneficiary from other volunteers.***

However, we need to keep in mind that TSBank is a research project, which means that there is always a certain risk involved, that the idea fails (due to various reasons). Therefore, at the beginning of the project the participants who volunteer to test and validate the service will be informed that, after the project ends, it may be possible that they face some discomfort because of service discontinuation.

A special set of measures will be applied in order to manage the possible discomfort experienced by the end-user when s/he must give up the services s/he already learned to use. This set of measures will include:

- Clear information about the role, of the end-user, i.e. the expectations for him as voluntary contributor to the accomplishment of TSBank project goals, phases and activities. During the project running, this task will be accomplished in the introductory presentation of each field trial with the end-users.
- During initial training session s/he will be informed about the measures that project's team adopted for minimizing the possible discomfort experienced by him when the project testing ends:
    - The possibility to keep using the service for at least one year after project ends at no cost, both as a supplier of services or as a beneficiary of such services from other volunteers
    - The possibility to withdraw his/her participation at any time during the trial phase without any repercussion,
    - The possibility to solve any unwanted situation or complaint by calling or e-mailing the responsible investigator of the pilot site, whose contact details will be entrusted to him/her during the initial training session.

  The last two items will be specified in the Informed Consent form.

A closing seminar will be arranged at the end of the project at each piloting site, with the end-users and their relatives or friends being invited to attend. Participants will receive a diploma of participation.

Annex 2: Introductory letter to the senior volunteers

What are the aims of the TSBank project?

TSBank is a multinational and multidisciplinary project funded by the AAL Joint Program of The European Commission that aims to give the senior persons a possibility to use their time and skills in a way that is beneficial to the society, enabling them to remain active and feel appreciated, which will greatly contribute to their well-being and reduce their dependency on the care giving infrastructure.

For doing that, the project's medico-social and technical researchers will create a modern technology-based online platform, entitled ***silverskills***, that will allow the elderly to volunteer their skills and time to perform work on a set of areas. People looking for support can then consult the platform for volunteer elderly that match the sought needs, and the platform puts both parties in contact.

What would be your role and contribution expected in the TSBank project?

You will voluntarily participate in all the activities of the project for which your opinions and recommendations as end-user are highly needed for detecting your needs, opinions and preferences for the services to be created and offered by the silverskills platform, thus contributing to the progressive improvement of the prototype, as well as to its testing and validation at your own home.

The investigators of the ANA / SUPSI project team will explain your role in each working session, and how to use the ***silverskills*** platform components, or the documents used for collecting your opinions and suggestions about platform's usability and usefulness.

You will receive individual training at home two times during the testing period for creation of a Gmail account and for the use of the platform. Also, it will be demonstrated to you how to do the collection of the feedback of usability in an autonomous way.

It is desired that you access the platform once per day (in the 1st pilot) / four times a week (during the 2nd pilot). You will be asked to fill in at certain intervals the questionnaires provided to you for helping us with your feedback. Also, you will be contacted for short interviews, which will also help us improve the platform's performance.

Please note that any testing session during the project running doesn't mean at all that your capacities or skills will be tested, but only the functioning of the prototype and the usability and usefulness of the services it will provide.

How many people will take part in the study?

About 60 / 30 voluntary end-users are expected to take part in this study in Romania / Swiss

All the end-users will be involved in the project's activities by the ANA's/SUPSI's network, in

Are there benefits for you to take part as voluntary end-user in the project?

Your contribution to this study will be for research purposes only.

According to the AAL projects financial provisions, you will not be paid for participating in this study.

You should not expect to widely and definitely improve your state as a result of participating in this project and using the services it creates.

However, by participating in this project you will get new information about you and, about the newly created, vanguard virtual methods that may help you improve your quality of life, by remaining active.

Also, we hope that your involvement into a multinational research project aiming at improving the quality of life of seniors at their own home may represent a moral reward for you.

Annex 3: Informed Consent

Organized by .....

Within the project

"Time and Skill Bank for Active Aging "

The present study aims to evaluate T S B a n k platform operability and to identify active senior's preferences regarding..... The study will be conducted by .....specialists, within the project "Time and Skill Bank for Active Aging – .....", financed through AAL 2014 programme.

Your involvement in the study will consist in participating in the pilot – where you will test how the online platform works, then you will fill in a questionnaire. The questionnaire is anonymous. The pilot will be conducted by ....., representative of the company.
.....

Your participation is voluntarily and you can drop out at any time. The training will last about 40 minutes during which you will see a presentation of the projects, you will be instructed on how the system operates, you will test by yourselves and you will fill in a questionnaire. The information you will share with us if you participate in this study will be kept completely confidential to the full extent of the law, according to the Romanian / Swiss legislation. All the collected data will be processed and stored in strict confidentiality and your identity will never be revealed.

If you have any questions about this study, please contact [NAMES OF PIS, PHONE NUMBERS AND EMAIL ADDRESSES].

Your signature on this consent form indicates your agreement to participate in this study.

You will be given a copy of this form to keep, whether you agree to participate or not.

The second signed consent form will be kept by the researcher.

Thank you very much!

Name: _____

Signature: _____

Date: _____