

NATURE OF THE DELIVERABLE		
R	Report	X
P	Prototype	
D	Demonstrator	

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Dissemination Level		
PU	Public	
PP	Restricted to other programme participants (including AALA)	X
RE	Restricted to a group specified by the consortium (including AALA)	
CO	Confidential, only for members of the consortium (including AALA)	

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Table of Contents

PURPOSE	5
OVERVIEW	5
GENERAL PRESENTATION OF PLA	5
MAIN ETHICAL ISSUES	6
ADDRESSING ETHICAL ISSUES	7
1. Concept phase.....	8
2. Test installations	8
3. User involvement during the project	8
4. Solution testing and market launch	8
USER INVOLVEMENT	9
Informed consent.....	9
NATIONAL LAWS / REGULATIONS IN EACH COUNTRY	10
France.....	10
Portugal.....	11
Hungary.....	12
Poland	14
ANNEX – INFORMED CONSENT FORMS.....	17
France.....	18
Poland	21
Hungary.....	22
Portugal.....	30

Purpose

The purpose of this document is to question and thus clarify the ethical issues that arise in the PaeLife project. Since the objective of the project is to design a communication system to fight elderly social isolation, this approach raises ethical questions at different levels and throughout the different phases of the project. On the one hand, this research project involves participatory methods and data collection procedures. The target users are older adults which raises questions of the respect for their autonomy and dignity. On the other hand, because of the specificities of the communication system that is being designed, the digital data involved also raises ethical and privacy issues.

These questions have been the object of discussions and collective thinking among the project partners. The aim was to collect and consider these ethical issues, both reflecting on our research practices and also complying with the regulatory framework of each partner country. These important questions have helped to organize the structure of this document.

Overview

This Ethics document starts by presenting the PLA – the communication system designed in the PaeLife project – and the privacy and security issues involved. Furthermore, the document presents the main ethical issues related to the PaeLife project and how the consortium have addressed them in the different Work Packages and throughout the different project phases. The idea is to strictly balance the need we have for relevant information about participants but also respect their privacy and anonymity. Since the research, design approach and considered services are user-centered, there has been a deep reflection on user involvement. The precautions taken to ensure participants' fully informed involvement and to respect participant's dignity and privacy are explained, namely the use of informed consent forms. Finally, we present the privacy laws and regulations linked to digital and personal data for each country. The informed consent forms used in each country (English version) can be found in the annex of this document.

General presentation of PLA

The Personal Life Assistant (PLA) is a desktop, tablet and mobile-based platform, supported by cloud-hosted services that allows senior users easy access to a set of services of fundamental relevance in today's digital society. These services include, but are not limited to email, calendar, social networks (Facebook, Twitter and YouTube), audio/video call and instant messaging services through Skype and Lync, through the use of a simplified and natural user interface. The platform allows users to easily interact with technology through multiple input modalities, such as touch, gesture and speech (ASR), besides the traditional keyboard and mouse. The output can be displayed on-screen or through speech output (TTS). These modalities are integrated in a seamless way, increasing the overall platform usability.

As far as privacy is concerned, the PLA will only store a minimal amount of information to ensure correct and secure operation of all supported services: locally the PLA stores the user's platform authentication credentials and time-limited tokens that expire after a specific period of time, all of which is stored in a secure, encrypted local storage offered by the platform, to ensure that none of this information leaks. To ensure minimal user-interaction with authentication processes that might require additional user-input, the platform will also store authentication tokens used to access a user's social network services from the cloud backend. All this information is also securely stored in an encrypted database on the cloud service, and is only accessible by the PaeLife services that run on the cloud. All information exchanged between the PLA application and the cloud service is encrypted using a secure HTTPS connection. Minimal face recognition features will also be stored securely and locally only, and to be used exclusively as the basis of one of PaeLife's privacy features, namely detecting people other than the primary user to prevent potentially sensitive information from inadvertently displaying at that time.

All user-stored information can and will be deleted if so requested by the user, be it through the PLA application, or by explicit user request (ex: account termination).

All user data that might be collected must be explicitly noted in the application's Terms of Use and/or Privacy Terms, all of which will be validated by legal counseling, and the user must also explicitly consent to the capture of higher impact user data such as location data.

To ensure that all necessary precautions are taken into account, both privacy and security wise, a standard process has been adopted as standard practice on all releases of the PLA platform, called the Security Development Lifecycle. This process, based on an internal process adopted at Microsoft for the release management of all Microsoft applications is described in further detail on the project's quality manual. This process included several privacy validations (including several contacts with privacy experts and the establishment of privacy terms and/or terms of use with legal and privacy advisors), definition of an entire security validation and patching process (identifying contacts, procedures and timeframes for security fixes), and running automated tools to test for security flaws in all components included in the platform (clients and services).

Main ethical issues

Since PaeLife does not involve biomedical testing or handling of health data, but web services and communication, the main ethical issues are digital ones, namely:

- Privacy;
- Management of personal data;
- Confidentiality;
- Autonomy and dignity.

To ensure the respect of these issues when involving participants in our research, all data collection and processing will be done at our own local level. There is no subcontracting involved for research purposes or when participants' personal data are involved. The only type of subcontracting done is for voice data collection, where several proctors are involved, because of the amount of voice data needed in order to meet the objectives. However, no personal data allowing people identification is involved in voice data collection, which is strictly framed by the privacy terms and Terms of Use on the data collection website, which has been validated with a privacy expert. Furthermore:

- Neither PII (Personable Identifiable Information) or sensitive data will be stored in the local computers;
- Neither PII or sensitive data will be shared by email;
- All online digital data transfers will occur under a secure and encrypted communication channel.

In France, the proctors are employed by UTT, and the work contract includes confidentiality clauses to which the proctors are bound by law. In Poland, the proctors were employed by SSW. The contracts included clauses with the obligation to follow the general Polish legislation. We also gathered formal consent from seniors about participation in data collection.

In Hungary and Portugal, proctors are employed through subcontractors. Every proctor has to take part in a proctor training before starting the speech collection. The training is about privacy and confidentiality, autonomy and dignity of the elders, methodology and "how to do" recordings. Proctors are not allowed to start working in the project without taking part in this training and accepting the privacy terms, by explicit contractual formal acceptance.

For all the tasks where user participation is needed, every precaution is taken to ensure the security, well-being and respect of the elder participant. The research team either goes to the elder's place with prior explicit and voluntary consent, or ensures that the participant can come to our premises safely and comfortably, by planning the appointments well in advance. The usability tests or interviews, are done in a private place with the door closed, to ensure the privacy of the information given by the elder.

The qualitative data collected are stored on secure server, whose security is ensured by the IT service of the different institutions.

Addressing ethical issues

Ethical issues are at the heart of PaeLife's user-centered approach. Indeed, elder participants are involved in the project at different levels and in different tasks:

- User needs analysis (WP1);
- Voice data collection (WP2);
- Adaptation of multimodal interfaces for the elderly (WP3);
- Evaluation of PaeLife prototypes and technologies (WP6).

Throughout these tasks, we ensure participants' privacy, confidentiality, autonomy and dignity, as explained above. These principles are at the basis of how we conceive of the different activities of the tasks. This implies that ethical issues have been / are / will be addressed at different phases in the project:

1. Concept phase

The ethical issues have been addressed following the NCP guidelines in the proposal, under the title "Legal and ethical issues". In the Ethical Issues Table, the main issues are addressed, including, among the issues relevant for PaeLife: Informed consent and Privacy. The PaeLife project was accepted on the basis that only adult volunteers giving their informed consent were involved and that no private/sensitive/health data would be collected, and that participants' privacy would be preserved. Only relevant data for research purposes will be collected in the project framework.

2. Test installations

The first usability testing and evaluation are planned for the second half of the project. An important precision concerning the methodology is the fact that tests concern the device; it is not the participants who are being tested. Therefore participants' identity, background, and any other digital personal information are not relevant and are not used in the tests as such. However, user data, e.g. Gender, Age, literacy, professional activity, might be relevant to explain the collected data and come up with meaningful results. They will be kept confidential; used only for R&D statistical analysis purposes and will be anonymized. Outside the people conducting the actual user studies, no one will know who yielded which data. No names will be used, but generic terms like "User 1", "User 2", etc.

3. User involvement during the project

Coherent with the user-centered approach adopted in PaeLife, senior users are involved at all phases and in many tasks. *Their* perspective is taken into account, *their* needs analyzed, *their* feedback considered to improve the device development, and *they* are the ones validating the final product. As mentioned earlier, their privacy, confidentiality, autonomy and dignity is ensured at all times.

4. Solution testing and market launch

The final testing procedures and the actual market launch will follow the same ethical guidelines as the previous user needs analysis or evaluation, in terms of respect of people's autonomy and privacy.

User involvement

Throughout the tasks where users are involved, the following issues are ensured:

- Correct recruitment;
- Correct involvement of end-users;
- Informed consent;
- Transparency.

Each partner of the consortium has proven experience in user-centered approach, fieldwork and his own domain of research. The tasks have been planned according to precise objectives, therefore requiring user participation at relevant phases and tasks, and selecting participants with representative profiles – gender, age, IT proficiency, personal/marital situation.

At all times, they are explained clearly (in “lay” language, avoiding technical terms) the tasks that they are expected to achieve, and broadly explained the objectives. The aim is to ensure the transparency of our research, to give enough account to make the person at ease, without, however, going into too much detail, which would bias the testing. Before starting any type of testing task, the participant gives his explicit written informed consent, which entails more than obtaining a signature on a form.

Informed consent

The informed consent is a written document, which the participant and the research institution contact person, both sign – in two original copies, one for each party. The informed consent ensures that participants can reach a truly informed decision about whether or not to participate in the research, based on a clear understanding of what their participation involves. Once they have read the consent document and their questions are answered, if they agree to participate in the research, they sign and date the informed consent document. Thus, they give their informed consent freely, without coercion, and can quit at any moment, without financial or other consequences for them.

All the informed consent forms used in the PaeLife project follow these general guidelines. However, they are specific to each partner, depending on the methods mainly used at the evaluation phase of the PLA developed in the project: video ethnography (France) or log data analysis (Hungary and Poland), and on the incentives. Two versions are provided by each partner: one in English – so as to be sharable among the members of the consortium; one in the local language – French, Hungarian or Polish – to ensure that the participants fully understand the implications.

Apart from the informed consent, each partner has also established a document for voice data collection that presents the PaeLife project and its objectives, and contains the contact information for every country.

The informed consent form for each country can be seen in the annex, at the end of this section.

National laws / regulations in each country

France

As mentioned at the beginning of this section on Ethics, the main ethical issues that are relevant to the PaeLife project are digital ones. Technology has impact in all aspects of our life, particularly in the way we grow older. The advent of ICTs in the daily life of the elderly and care practices makes the debate on ethical issues crucial. While ICTs enable the creation of new opportunities and forms of social interaction, instant information access, constant availability and higher control of the surrounding environment, there is also the risk that this highly impending technological pressure could severely harm the freedom (to accept or refuse the use of any device) or to human dignity (loss of private space). Therefore, there is the need to ensure that Information Technology respects human identity, human rights, privacy and liberties, especially in the case of elders in the situation of loss of autonomy.

The issue of ethics related to technologies for ageing people staying at home is currently debated in Europe. In France, the work of Vincent Rialle (2005, 2007-b) examines the types of problems/issues related to technologies assisting health or the loss of autonomy: privacy, responsibility, dependence.

Ethics is at the basis for the creation of laws. Germany (1971), Sweden (1973), and France (1978) were the first three States to adopt a "Computers and Liberty" law. Section 1 of the French law "computer and freedom" states: "IT must be at the service of every citizen. Its development should take place within the framework of an international cooperation. It shall not prejudice to human identity, human rights, privacy, individual or public liberties". This law is ensured by an independent control authority, the "Commission nationale de l'informatique et des libertés" (CNIL).

CNIL's mission is to ensure that the data privacy law is applied to the collection, storage, and use of personal data. State financed, the CNIL's power is limited and defined by law but its administrative authority status is totally independent for selecting the actions that it will undertake. The CNIL ensures that the methods used to implement an individual's statutory right to access his/her data on files do not impair the free exercising of that right. It holds the specific competence to access State security, defense and public security files, on behalf of citizens.

CNIL responds to all the requests for advice it receives; it adopts recommendations for a correct implementation of the law, and promotes the adoption of professional rules of good conduct or codes of deontology in various professional sectors (direct marketing, call centers, mass marketing).

Sensitive data processing is subject to CNIL's authorization. Data controllers that fail to comply with those formal requirements may be liable to administrative or criminal sanctions. CNIL keeps itself informed of the evolution of technical processes; it draws up reports which are submitted to public consultation. It advises the French government on all the necessary legislative or regulatory measures for adapting the protection of rights and Liberties regarding the evolution of technologies. CNIL also monitors the security of information systems by checking that all precautions are taken to prevent the data from being distorted or disclosed to unauthorized parties.

Portugal

In Portugal there are two major entities that deal with data privacy concerns:

1. [CNPD – “Comissão Nacional de Proteção de Dados”](#);
2. [CNECV – “Conselho Nacional de Ética para as Ciências da Vida”](#).

1. CNPD – “Comissão Nacional de Proteção de Dados” is the Portuguese Data Protection Authority. CNPD is an independent body, with powers of authority throughout national territory. It is endowed with the power to supervise and monitor compliance with the laws and regulations in the area of personal data protection, with strict respect for human rights and the fundamental freedoms and guarantees enshrined in the Constitution and the law.

The following deliberations and initiatives are relevant to the PaeLife Project:

- New technologies
 - [Radio frequency identification \(9/2004\)](#) (only available in Portuguese).
- Health
 - [Principles applicable to personal data treatments carried out in the framework of the national pharmacovigilance System of medicinal products for human use- Pharmacovigilance \(219/2009\)](#) (only available in Portuguese);
 - [Principles applicable to treatment of personal data, in the context of clinical trials on medicinal products for human use \(333/2007\)](#) (only available in Portuguese);
 - [Principles applicable to personal data treatments carried out in the framework of scientific research studies in the field of health \(227/2007\)](#) (only available in Portuguese).
- Access to third-party data
 - [Decision regarding interpretative Resolution 51/2001, as regards to access health data of deceased persons \(72/2006\)](#) (only available in Portuguese);
 - [Access to health data by a third party \(51/2001\)](#) (only available in Portuguese);
 - [Access to voter registration data \(22 /2001\)](#) (only available in Portuguese).
- [Data privacy Work group](#)
 - This group meets in Brussels every two months with the following goals:
 - Give advice to the EU about the level of protection in the community;
 - Advise the EC on measures to be taken for the protection of the rights and freedoms of individuals;
 - Give an opinion on codes of conduct drawn up at Community level;
 - Make recommendations on any matters of personal data protection.

2. CNECV – “Conselho Nacional de Ética para as Ciências da Vida” is an independent body created in 1990 by Law no. 14/90 of the 9th of June for the purpose of "analyzing systematically the moral problems which arise out of scientific progress in the fields of biology, medicine or general health care". The CNECV defines itself as national, independent, pluralist and consultative.

The following deliberations are relevant to the PaeLife Project:

- [Ethical Reflexions on Human Dignity \(26/CNECV/99\)](#): CNECV considered that it was important, within its sphere of competence, to reflect on the concepts that serve as guidelines or ethical grounds to the opinions it elaborates. Thus, CNECV decided on its own initiative to reflect on the concept of human dignity, both in terms of its philosophical, biological and psychological components and of its ethical implications.
- [Patient Rights to Information and Informed Consent \(57/CNECV/09\)](#): the CNECV considered that it was also important to address the constitutional rights to information and informed consent. These are described in this document (only available in Portuguese).

At a more local level the following ethical board can also be consulted:

- “Unidade de Ética e Educação do Serviço de Bioética e Ética Médica da Faculdade de Medicina da Universidade do Porto”.

Hungary

Data Protection

When examining information technology data protection, the interaction between several areas need to be considered. Data protection regulation consists of levels based on and interacting with International Agreements, Regulations, International Recommendations, International Directives, National Regulation and with Organizational Regulation.

The Data Protection Act (Act LXIII of 1992 on the protection of personal data and the disclosure of data of public interest) came into existence in order to ensure the fundamental right declared in the Constitution of the Republic of Hungary and to establish an act that meets the requirements of the related decision of the Hungarian Constitutional Court that came into effect on 1st January, 1993. This act declared the general principles and guarantees related to the protection of personal data. From the point of view of medical data, probably one of the most important elements of this act, was the definition of the concept of “special data”. According to this act, special data means any personal data related to racial, or national or ethnic minority origin, political opinion or party affiliation, religious or ideological belief, or membership in any interest representing organization; and state of health, pathological addictions, sexual life or personal data pertaining to criminal records. In the spirit of this act, these extremely sensitive data should be processed in a special way. Therefore additional particular regulations were declared as well.

The creation of the new data protection act is justified by the new Fundamental Law of Hungary came into effect in 2012; the new data protection regulations enhanced that the Hungarian Government and the Parliament are committed to effectively ensure fundamental rights, the Government considers the protection of constitutional fundamental rights of citizens as a fundamental element guaranteed. The Fundamental Law of Hungary guarantees the independent

authority control of the right of protection of personal data and the disclosure of data of public interest on constitutional level. The Hungarian Authority is independent, inferior only to the Act, is not allowed to be instructed regarding to its mission, it is not part of the hierarchic public administration organization system. On 11th July 2011, the Hungarian Parliament adopted the cardinal act regarding to information self-determination and freedom of information that determines the contents of information rights in order to ensure effective prevalence of fundamental rights. By adopting the act Data Protection Ombudsman was decided to be succeeded by the Hungarian National Authority for Data Protection and Freedom of Information.

Hungarian Laws Regulating the Collection and Use of Personal Data

1. General Laws

As mentioned above in 2011, the Hungarian Parliament adopted a new act on data protection, Act CXII of 2011 on the Right to Informational Self-determination and Freedom of Information (DPA), which came into effect on 1st January 2012 and implements Directive 95/46/EC on data protection (Data Protection Directive). The DPA aims to guarantee the rights of individuals to exercise control over their privacy and to have access to data of public interest and public data on the grounds of public interest. The DPA is regarded as background legislation for specific statutes regulating the collection and processing of personal data.

2. Sectorial Laws

In addition to the DPA, the following statutes are particularly relevant for data protection purposes in Hungary:

- Act XLVII of 1997 on Processing and Protection of Medical and Other Related Personal Data (Medical Data Act) that regulates the conditions and purposes of processing sensitive data concerning an individual's state of health and related personal data.
- Act LXVI of 1992 on Personal Data and Address Records of Citizens that provides detailed rules on the use of records containing individuals' personal data, including their address.
- Act C of 2003 on Electronic Communications (Electronic Communications Act) that regulates the processing of subscribers' personal data by communication service providers, including the obligation to retain data.
- Act CXIX of 1995 on Processing of Name and Address Data for Research and Direct Marketing Purposes that contains regulations on the processing of name and address data for the purposes of research and paper-based direct marketing.
- Act XXII of 1992 on the Labor Code that regulates employers' processing of employees' personal data. This is due to be replaced by Act I of 2012 on the Labor Code, which will come into effect on 1st July, 2012.
- Act LX of 2003 on Insurance Companies and Insurance Activity (Insurance Act) that provides detailed rules on the processing activities of clients' personal data that qualifies as an insurance secret.

- Act CXII of 1996 on Credit Institutions and Financial Undertakings (Credit Institutions Act) that regulates the processing activities of clients' personal data that qualifies as a bank secret.
- Act XLVIII of 2008 on the basic conditions of and certain restrictions on business advertising activity (Advertising Act) that regulates the processing activities of personal data for direct marketing purposes.
- Act CVIII of 2001 on electronic commercial services and services related to information society (Electronic Commerce Act) that provides rules on sending unsolicited electronic commercial communications.

Data Control

The DPA draws a distinction between data control and data processing from the point of view if the individual possesses decision making competence, has definitive say in decision regarding data or not, or he/she only executes instructions. A data controller determines the purpose of data processing and makes decisions on data processing, a technical data processor can only perform technical tasks related to data processing operations, and technically process personal data on the basis of the data controller's instructions. The technical data processor is not entitled to make any decision on the merits concerning data processing. Whilst a technical data processor is any individual or legal person or organization without legal personality that on the basis of a contract concluded with the data controller (including conclusion of a contract on the basis of legislation) performs technical processing of data. A data subject is any specified individual who is, or can be, directly or indirectly identified by any personal data (DPA).

A data controller is any individual or legal person or any organization without legal personality that (DPA): determines the purpose of data processing (alone or together with others), makes decisions on data processing (including concerning the means of processing), implements these decisions or has them implemented by a technical data processor.

Data control activities must strictly comply with the following rules:

- Purpose Limitation Principle;
- Legal ground of data control;
- Providing unambiguous information;
- Data protecting register.

Poland

In Poland, the right to privacy and data protection is guaranteed in the Constitution of the Republic of Poland. The principles of data processing and the rights of natural persons whose personal data are or may be processed in data filing systems are specified in the Act on the Protection of Personal Data of 29 August 1997 and in secondary legislation: the Regulations of the Minister of Interior and Administration:

1. The Regulation of 29 April 2004 on personal data processing documentation and technical and organisational conditions which should be fulfilled by devices and computer systems used for personal data processing
2. The Regulation of 11 December 2008 on specimen of notification of a data filing system for registration by the Inspector General for Personal Data Protection.
3. The Regulation of 22 April 2004 of the Minister of Interior and Administration on the specimen of personal authorisations and service identity cards of the inspectors employed in the Bureau of the Inspector General for Personal Data Protection.

In Poland, the authority responsible for oversight of compliance of data processing with the provisions on the protection of personal data is the Inspector General for Personal Data Protection (<http://giodo.gov.pl/>).

In the Polish Act, the catalogue of sensitive data is more precise than in EU Directive and covers information on political parties' membership, genetic code, addictions, convictions, decisions imposing penalty, fines and other decisions issued in court or administrative proceedings.

The processing of data is permitted only if:

1. The data subject has given his/her consent, unless the processing involves erasing personal data;
2. The processing is necessary for the purposes of exercising the rights and duties arising from a legislative provision;
3. The processing is necessary in order to perform a contract to which the data subject is a party or to take measures, at the request of the data subject, before signing a contract;
4. The processing is necessary in order to perform tasks provided for by law and carried out in the public interest;
5. The processing is necessary for the purposes of legitimate interests pursued by the controllers or data recipients, provided it does not violate the rights and freedoms of the data subject. Here, legitimate interests are considered to be: direct marketing of one's own products or services provided by the controller, or assertion of claims resulting from economic activity.

These prerequisites are separable. In order to consider the use of data to be legitimate, it is sufficient to meet one of them, and not all of them jointly. Therefore, if rights and duties resulting from a legal provision cannot be exercised without the use of data, then no additional consent for their use is required. Neither is it necessary to justify that the processing is carried out in the public interest or for the purpose of legitimate interests pursued by the controllers. Consent for the use of data to exercise a legal norm is confusing, because it suggests that it may be withdrawn if the transfer of data is required for the purposes of data collection.

The use of sensitive data is, as a rule, prohibited under Article 27 (1) of the Act. However, such data can be used by a controller, provided he proves that it is one of those exceptional situations referred to in Article 27 (2) of the Act.

The processing of sensitive data inter alia is permitted in the event that the data subject has given his/her written consent or specific provisions of other enacted laws allow it, providing for adequate safeguards. The processing of sensitive data is also allowed when it is necessary to protect the vital interests of the data subject or of another person; when the data subject is physically or legally incapable of giving his/her consent until a guardian or a curator is appointed; when it is necessary to carry out the duties of a controller relating to the employment of his/her employees and other persons, and the scope of data is provided by the law; when it is required for the purposes of preventive medicine, the provision of care or treatment, when the data are processed by a health professional engaged in treatment, other health care services, or the management of health care services and subject to providing appropriate safeguards.

Annex – Informed consent forms

France



INFORMED CONSENT – PAELIFE PROJECT

PaeLife is a European research project, coordinated by Microsoft Portugal, bringing together a consortium of partners from four European countries - Poland, Hungary, Portugal and France. The project's objective is to develop an application to enable older people to access the Internet easily and communicate with their relatives and friends through technologies. In this process of simplification, the "natural" modes of interaction are preferred, such as voice control. Being innovative, these modes of interaction must be tested and improved, through user involvement in

- workshops
- testing of the prototype
- qualitative interviews aiming at understanding seniors' lifestyle and use of technology
- Field trials
For a period of one month, the participant will be asked to test the device, which will be left at his/her home..

In France, these studies will be coordinated by Université de Technologie de Troyes.

Data collection

In order to evaluate and improve the developed application, data will be collected at several phases in the project through observations and interviews. The data will be used only within the PaeLife project framework: it will not be made accessible to any third party and will not be stored beyond the time allowed by law. Participants' anonymity will be ensured: The data do not contain the names or addresses of participants and will be edited for full anonymity before being processed (e.g. in project reports or research papers).

Audiovisual material

Video and audio recordings will be collected as qualitative data. Participants will be informed of recordings or photographing in every situation where these are used. These videos and pictures may be used for dissemination and research activities, in public forums, on websites or in conferences. The participant allows Université de Technologie de Troyes to use the said materials; they consent and agree that Université de Technologie de Troyes and the PaeLife consortium members have the right to take photographs, videotape or digital recordings of them, and eventually people interacting with them (who have been informed and given their verbal consent), and use these for the purposes mentioned above. The participant may demand removal of photographs or videos from public forums and websites by simple request, and according to the law "computer and freedom".

Participation and code of conduct

The participant may end his or her participation in the project at any time, without having to justify him/herself or incurring any responsibility. Should the participant leave the project, any hardware or software provided by PaeLife is to be returned to the project. The participant agrees to take care of the equipment, use it

regularly and provide feedback, and not use it for illegal activities. All participants' conduct towards other users should always be appropriate and never offensive or depreciating.

Consent

After having stated these general conditions and rules, we would like to thank you in advance for your participation in the PaeLife project and collaboration with UTT.

Both parties receive a copy of this declaration of consent.

I, undersigned, certify that I have given my consent to participate in the PaeLife project. I voluntarily agree to participate in this project based on my full understanding of what my participation implies and of my rights.

Date :

Participant's name :

Participant's signature :

Researcher's name :

Contact information :

Researcher's signature :



CERTIFICATE – EUROPEAN RESEARCH PROJECT PAELIFE

I, undersigned David Hewson, Professor, certify that Mr. XXXX, student at UTT, participates in the European research project PaeLife. His mission is to collect voices of people over 60 years.

PaeLife is a European project coordinated by Microsoft Portugal, bringing together a consortium of partners from four European countries - Poland, Hungary, Portugal and France. The project's objective is to develop simplified technologies to enable older adults to access the Internet easily and communicate with their relatives and friends. In this process of simplification, "natural" modes of interaction are preferred, such as voice control. Accordingly, a wide campaign to collect voices of people aged 60+ is organized in each country. In France, the University of Technology of Troyes is responsible for this task.

Each recording lasts between 45 minutes and 1h30. The student brings all the necessary equipment, as well as a 3G key for internet connection if necessary. The older adult has to read predefined sentences on the laptop screen, wearing a headset. The voice recording does not commit the volunteers, whose mission is completed once their voice is recorded. Each participant will receive a Carrefour voucher worth 7€.

Pauline HOURSEAU (details below) will be your contact person for this project..

Troyes, Monday 11th of March2013

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Poland

Information on the PaeLife speech recording project:

Dear Sir or Madam,

We are looking for seniors (age 60+) who will be willing to have their voices recorded for an international research project. These voices will be included in the development of a Personal Assistant, a device dedicated to elderly citizens that aims to facilitate the use of computers and new technologies.

In order to make this device work efficiently, to read and “understand” human requests, we need to collect and recorded a certain number of different voices in several different languages, including Polish.

We invite you to cooperate with our representatives who will discuss the course of the recording and provide you with all the details. It should not take more than an hour. The survey is completely anonymous.

Thank you for your time,
Artur Kolesinski

Hungary

RESEARCH INFORMED CONSENT FORM

Prospective Research Subject: Read this consent form carefully and ask as many questions as you like before you decide whether you want to participate in this research study. You are free to ask questions at any time before, during, or after your participation in this research, you are also free to abandon participation at any time, without any consequences or penalty.

3.1 PROJECT INFORMATION

Project Title: PaeLife

Organization:

Location:

Main Researcher:

Other Researcher: <In case of need>

Phone:

Brief Description of PaeLife

PaeLife joins a consortium of 8 partners, located in Portugal, France, Hungary and Poland and focuses on individuals who are recently retired and who are used to some level of technology usage and who wants to keep themselves active, productive and socially engaged. The project's main objective is to fight isolation and exclusion and to allow the elderly to be more productive, independent and to live more social and fulfilling life by empowering these elderly users with Personal (Virtual) Life Assistant (PLA); a virtual presence that supports social communication, learning and entertainment. Personal Life Assistant will mediate and facilitate interaction of these senior citizens with technological devices, such as standard computers, game consoles, mobile devices (smartphone) and home automation modules. Moreover it will be specially oriented to increase the level of productivity, information and service consumption by the elderly by improving the accessibility to existing services on the web, such as interactive online courses acting as a student or as a teacher; and social and entertainment networks. All this will be made possible at people's homes, since elderly people have sometimes some level of impairments caused by age, which reduces their mobility.

3.2 PURPOSE OF THIS RESEARCH STUDY

This study is designed to achieve and evaluate the effectiveness, usability and userfriendliness of PaeLife service.

3.3 PROCEDURES

As end user if you agree to be involved in the PaeLife project you can be involved in

- testing of the prototype
- qualitative interviews aiming at understanding seniors' lifestyle and use of technology
- field trials: for a period of one month, participants will be asked to test the device operated at his/her home...

Test results will only be used in connection with PaeLife project.

3.4 POSSIBLE RISKS OR DISCOMFORT

- There have not been described risks in the use of the service.
- Any new information developed during the study that may affect your willingness to continue participation will be communicated to you.

3.5 POSSIBLE BENEFITS

- Benefits are related to development of a service that will enable to improve capability of seniors to plan, manage and execute communication projects at their own discretion.
- To solve problems that are approached are mainly related to having communication with others or to the access to information, associated health, local limitations.

3.6 FINANCIAL CONSIDERATIONS

There is no financial compensation for your participation in this research, and it will not involve any additional cost for the user.

3.7 CONFIDENTIALITY

Your identity in this study will be treated as confidential. The results of the study, including laboratory or any other data, may be known by the researchers involving this project, but will not be given them your name or included any identifiable references.

You are informed of the inclusion of your personal data to a file owned by(Entity) registered in the(Portugese, French, Hungarian and Polish) Agency of Data Protection in compliance

with national laws and European data protection and in particular Directive 95/46/EC and Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and the free movement of such data.

The research controller is responsible for a file for the purposes of Article 3 of Organic Law 15/1999 of Data Protection December 13, (LOPD) and is committed to fulfilling its obligations as such.

The research controller undertakes to adopt, update and maintain technical and organizational measures to ensure security and confidentiality of Personal Data, preventing any disruption, loss, treatment, processing or unauthorized access. In particular in its treatment of all personal data security measures, organizational and technical, required by Article 9 of the Data Protection Act and, in particular by the regulation implemented, approved by Royal Decree 1720/2007 of 21 December and the current regulations imposed by data protection at any time.

Also, the research take measures to enforce the same duty of confidentiality to those employees involved at any stage of processing of Personal Data. This obligation extends to both the staff with access to information systems as formal or informal caregivers. Also extends to service providers and authorities in charge of the treatment provided or permitted assigns.

3.8 TERMINATION OF RESEARCH STUDY

You are free to choose whether or not to participate in this study. There will be no penalty or loss of benefits to which you are otherwise entitled if you choose not to participate. You will be provided with any significant new findings developed during the course of this study that may relate to or influence your willingness to continue participation. In the event you decide to discontinue your participation in the study you are free of exercising rights of access, rectification, cancellation and opposition by writing to(Entity) in the following address:
.....

3.9 AVAILABLE SOURCES OF INFORMATION

Any further questions you have about this study will be answered by the main researcher:
.....

3.10 AUTHORIZATION

I have read and understand this consent form, and I volunteer to participate in this research study. I understand that I will receive a copy of this form. I voluntarily choose to participate, I authorize the assignment of the data contained therein to companies and researchers and public administrations in order to serve the research and development of goods and services. The assignment is expressly extended to companies, researchers and governments of the countries concerned with the adequate level of protection provided by the Law 15/1999, such as Member States of the European Union, Iceland, Liechtenstein, Norway and the States that European Commission has declared that ensure

adequate protection in Switzerland, Argentina, Guernsey, Isle of Man, U.S. entities adhering to the principles of "Safe Harbor" and Canada with respect to the entities subject to the scope of Canadian law data protection.

Participant Name

Date:

Signature:

Principal Investigator Name:

Date:

Signature:

Data Management Consent

First name:

Address:

Identity card /passport number:

Last name:

E-mail:

Phone number:

I have read the information sheet, and I am fully informed about the objectives and all relevant circumstances of the project entitled By acknowledging the terms of participation in the project mentioned above, hereby I give my consent to the followings:

The employees of the Bay Zoltán Applied Research Nonprofit Ltd. (Fehérvári 130, Budapest, H-1116, Hungary) or the Budapest University of Technology and Economics (BME-TMIT, Magyar tudósok körútja 2., Budapest, H-1117, Hungary) are entitled to record video footage of me, utilize, upload these recording to public Internet sites and use for related promotional purposes (e.g. to promote this project) for 5 years from the date of recording. Interview and public event associated utilization of the footage is also included and authorized within the 5-year period as above.

I hereby acknowledge that my personal data above are correct, and I agree that my personal information defined by 2 and 3 subsections of Paragraph 3 of the Act CXII of 2011 on Informational Self-determination and Freedom of Information is recorded, managed, stored in database, used and assigned to contributors directly involved in project implementation by the Bay Zoltán Applied Research Nonprofit Ltd and the Budapest University of Technology and Economics. The recorded video footage and personal information given are allowed to be managed by the Bay Zoltán Applied Research Nonprofit Ltd. and the Budapest University of Technology and Economics exclusively for the above purposes.

Hereby I acknowledge that this consent is voluntary in nature on the basis of 7 subsection of the Act CXII of 2011 on Informational Self-determination and Freedom of Information data TV 3 § on the basis of.

In case I intend to withdraw my consent in the future, or request rectification of my data, this can be performed by sending it in writing (Bay Zoltán Applied Research Nonprofit Ltd.; Fehérvári 130, Budapest, H-1116, Hungary or the Budapest University of Technology and Economics, BME-TMIT, Magyar tudósok körútja 2., Budapest, H-1117, Hungary) at any time; and on the basis of a), b), c) points of Paragraph 14 of the Act mentioned above I can request data correction or deletion.

Place, date

Signature

.....

.....

In the presence of witnesses:

.....

.....

Name:

Name:

Address:

Address:

Introductory information for Voice Collection



Personal Assistant to Enhance the Social Life of the Seniors

The summary of the PaeLife project

In our daily life, we find ourselves surrounded by technology, which enable the creation of new opportunities and forms of social interaction, instant information access, constant availability and higher control of the surrounding environment. By 2050, the number of elderly people (aged over 65) across the EU is estimated to increase from 16.4% in 2004 to 29.9% (Eurostat 2005). Although today's elderly people over 65 may show some resistance to the adoption of technology (only 10% of people over 65 use the Internet), tomorrow's elderly (middle-aged people, who are now in their 50s and 60s) will have used technology in the last one or two decades of their lives, and due to their healthy lifestyles, they are likely to be kept physically, socially and cognitively active until their seventies or eighties.

PaeLife is a European project started in 2012 and coordinated by Microsoft Portugal, bringing together a consortium of partners from four European countries - Poland, Hungary, Portugal and France and focuses on individuals who are recently retired and who are used to some level of technology usage and who want to keep themselves active, productive and socially engaged. The project's main goal is to fight isolation and exclusion and to allow the elderly to be more productive, independent and to have a more social and fulfilling life, by empowering these elderly users with a Personal (Virtual) Life Assistant (PLA), a virtual presence who supports social communication, learning and entertainment.

One of the main interaction modes of the PLA (next to the touch) would be the voice control which gives an easier usability for the elderlies. In the PaeLife project we develop a voice control working with three different European languages. For that we are collecting voices from 1200 good speaking people over 60 years. In Hungary The Bay Zoltán Nonprofit Ltd. for Applied Research is responsible for this task and the Budapest University of Technology and Economics Dept. of Telecommunications and Media Informatics conducts and control the collection of it.

The mission is to have a data collection with 130 hours Hungarian speech to have this service working with the Hungarian language.

The record should be done with software by a proctor who brings a laptop with 3G key for internet connection and a headset. The older adult reads 60 read and 20 spontaneous sentences on the laptop screen, wearing a headset. Each recording lasts around 45 minutes. During the records there isn't any cost for the elderlies or for the institute where the records take place.

The voice recordings are anonym, we just ask the sex, the age and the region were the elderly grew up. Any other contact (e.g. telephone number) will be asked just if the voice and speech of the elderly is highly prominent because in this case the BME would ask with the consent of the elderly to participate in other projects (e.g. tale recordings).

The voice data collection reached during the project would be a very unique for what we highly appreciate your help!

Bay Zoltán Nonprofit Ltd. for Applied
and
Budapest University of Technology and Economics

Certification for Voice Collection



Bay Zoltán Alkalmazott Kutatási Közhasznú Nonprofit Kft.
Infokommunikációs Technológiai Intézet

Bay Zoltán Nonprofit Ltd. for Applied Research
Institute for Infocommunication Technologies

CERTIFICATION

I, undersigned Peter Pach PhD, certify that participates in the "Personal Assistant to Enhance the Social Life of the Seniors" (www.paelife.eu) project (project number at BZN: K1048) to collect voices. The mission is to have data collection with 130 hours speech from 1200 good speaking people over 60 years to develop the voice control of the PLA.

The Hungarian partners of the consortium are the Budapest University of Technology and Economics Dept. of Telecommunications and Media Informatics (coordinator: Géza Németh PhD) and the Bay Zoltán Nonprofit Ltd. for Applied Research.

We would really appreciate if you were able to support her/his work in order to provide a personal life assistant to enhance the social life of the seniors with better quality of life and the improvement of their independent living!

Budapest, 29th of May 2013

Sincerely,

Dr. Pach Ferenc Péter
Head of Department
Bay Zoltán Nonprofit Ltd. for Applied Research
Institute for Infocommunication Technologies (BAY-IKT)
Department of Information Management

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E-mail: bay-ikt@bayzoltan.hu
Web: www.bayzoltan.hu



Portugal

Consent Form Example

First of all thank you for participating in this study. Your collaboration is essential to the success of our project.

This study falls within the PAELIFE project, whose aim is to study new ways of interacting with devices and ITs, using multimodal interfaces (which include various modes of interaction such as speech, touch and gesture). The project is mainly focused on facilitating access to different services concerning the elderly population. Examples include social media services, like Facebook and YouTube, and other entertainment, organizational and communication services, such calendar, email and audio / video conferencing. In the end we intend to develop a working prototype to test the results of the study.

During this session we will ask you to perform some simple tasks with which you should be comfortable, and also try some devices. At the end of the session we will gather your observations.

This session will be filmed and audio recorded. All data in video and audio collected is confidential and accessible only to people involved in this study. However, for illustrative purposes only, do you allow some images / videos collected here, to be published in scientific conference papers or journals? [] Yes [] No

We request that you fill in the following data (the data provided is strictly confidential and is intended only for future contact and for statistical analysis):

- Name: _____
- Age: _____
- Former Career: _____
- Known health problems: _____
- Phone: _____

[] Check the box if you want to receive updates on this study in the future? (If yes, please provide us your email: _____)

I have read and understood the objectives of this session, participating willingly in it.

Signature: _____

The researcher: _____