AMBIENT ASSISTED LIVING, AAL

JOINT PROGRAMME

"ICT-BASED SOLUTIONS FOR SUPPORTING OCCUPATION IN LIFE OF OLDER ADULTS"

D1.2 Ethical Guidelines

Final Version

Project acronym:	**ProMe**
Project full title:	**ProMe – Professional Intergenerational Cooperation and Mentoring**
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ProMe

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1. EXECUTIVE SUMMARY

1.1 Link with the objectives of the project

This report is a continuation of D1.2 (version 1) Ethical Guidelines that was submitted in M3 of the project. In the first version the ethical guidelines that are of importance during the user studies in the first phase of the project, such as the focus group sessions and the design sessions were elaborated. The ethical guidelines are defined to ensure the ethical and privacy rights of the end users involved in the initial phase of the research.

This second report presents a continuation of the first version, including the ethical guidelines for the pilot running in the project. It focuses on the deployment ethics: Ethics around relationships between users of ProMe supported and formed by the platform. Deployment ethics refer to the appropriate and effective deployment of the ProMe results into a pilot in a real life setting, and further implementation of results into the market. This guideline will have the main focus on issues regarding primary end users, mainly focused around the relationship between a mentor and a Mentee, but also including the professional environment and the business where end users work.

1.2 Scope of the document

The ethical guidelines are based on European legislations. Also, national legislations from the countries involved in this project are taken into account, especially, from those countries where the user studies are taking place. The guidelines will also be built upon the practical experience of the project partners. Based on the state of the art in ethical regulations and guidelines, this deliverable handles two types of ethics in ProMe: research ethics and deployment ethics.

Research ethics: These ethical issues relate to the research activities in the project. They are the guidelines related to the involvement of end users in focus groups, prototype and usability evaluations. Research ethics attempt to best protect all groups involved in the research: participants, institutions, funders, and researchers throughout the lifetime of the research and into the dissemination process. The partners will have clear, transparent, appropriate, and effective procedures in place for ethics review, approval, and governance whenever it is necessary. In the first version of this deliverable (D1.2) the guidelines are provided so that the research in ProMe is designed in a way that the dignity and autonomy of research participants are protected and respected at all times. It starts with an overview of the corresponding legislation (Section 2) and gives an overview of the ethical guidelines that are deployed in the project (Section 3) related to data protection, privacy and confidentiality, data storage, the Informed Consent, and the relation with the research participant.

In this second version of the deliverable, the information from the first version will be updated. Section 4 and 5 will proceed to give guidelines on the deployment of ProMe in the pilot and beyond.

Deployment ethics: The deployment ethics refer to the appropriate and effective deployment of the ProMe technical results into a pilot in real life setting and further implementation of results into the market. These guidelines will focus on different aspects related to relationships between users, more specifically Mentor and Mentee. It will also focus on the businesses and professional environments where users work and the level of involvement of different actors. Also, important aspects will be privacy issues around sharing of knowledge.

In summary, this second version (M15) will complement the first version and focus on the ethical issues around the pilot and implementation of results in the market.

2. LEGISLATION ON ETHICAL ISSUES

2.1 International Policies and European Union Regulations

The ProMe consortium fully endorses the following guidelines and regulations of the EU and commits to respect them.

2.1.1 The Charter of Fundamental Rights of the EU

The Charter of Fundamental Rights in the course of the respective legal trend dedicates a separate article to the protection of personal data. Article 8 sets out the right to the protection of personal data of an individual and, thus, the protection of personal data has now its own legal basis, beyond the right to respect for an individual's private life and the protection of the human dignity. Article 8 of the Charter sets out the rules for the legitimate processing of personal data, notably that the processing shall be fair and for pre-specified purposes based on the consent of the data subject or other legitimate basis laid down by law. Reference is furthermore made to two rights of the data subject: the right of access to the data and the right to have it rectified. Finally, Article 8 sets out the need for an independent authority, which shall control the compliance with the data protection rules. The charter also describes the political, social, and economic rights for citizens and residents of the European Union (EU). The following articles are specifically important in the ProMe project:

- Article 7, 8, protection of personal data
- Article 10, freedom of thought, conscience and religion
- Article 14, right to education for all
- Article 17, right to (intellectual) property
- Article 20, equality before the law
- Article 21, non-discrimination for all
- Article 22, cultural, religious and linguistic diversity
- Article 23, equality between men and women
- Article 25, the rights of the elderly

2.1.2 Nuremberg Code 1949

The Nuremberg Code is a set of guidelines for research ethics principles regarding human experimentation, set as a result of the Nuremberg Trials at the end of the Second World War. The Nuremberg Code consists of ten points of which the voluntary consent of the research participants is absolutely essential. This means that the person involved should have the legal capacity to give consent and be able to exercise free power of choice. The research participant should have sufficient knowledge and comprehension of the elements of the subject matter involved to enable him or her to make an informed decision. The research participant should be aware of the nature, duration, and purpose of the experiment, the method, and means by which it is to be conducted.

Furthermore, the Nuremberg Code states that the experiment should be for the good of society and not inflict unnecessary physical or mental suffering and injury.

2.1.3 Helsinki Declaration of 1964

All consortium members agree to adhere to the Helsinki Declaration of 1964 (Recommendation for conduct of clinical research), as lastly amended in Edinburgh in October 2000. All national legal and ethical requirements of the member states where the research is performed will be fulfilled. There will be arrangements for protecting the confidentiality of personal data of participants at any time of the research. Potential safety implications of ProMe will be clearly indicated. This means, in detail, that:

- All the test subjects will have the ability to give informed written consent to participate;
- All the subjects will be strictly volunteers and are able to withdraw from the trials at any time without any restraints;
- All personal data collected during the pilots, e.g., the preferences and habits of subjects, will be strictly confidential.

In addition, all test volunteers, following detailed oral information, will receive in their own language:

- A commonly understandable written description of the project;
- The project objectives;
- The planned project progress;
- The related testing procedures;
- Advice on unrestricted disclaimer rights on their agreement;
- Access to a complaints procedure.

The written information, as well as the sought informed consent, corresponds to the revised version of the mentioned Declaration of Helsinki. Participants with legal guardian aids, as well as participants, who cannot rationalize the expected end-user activities and goal based on any impairment of their cognitive abilities, will be excluded from any project study.

2.1.4 Data protection policy

Information relating to individuals, called 'personal data', is collected and used in many aspects of everyday life. These data may subsequently be used for other purposes and/or shared with other parties. Personal data can be any data that identifies an individual, such as a name, a telephone number, or a photo. Advancement in computer technology along with new telecommunications networks is allowing personal data to travel across borders with greater ease. As a result, data concerning the citizens of one member state are sometimes processed in other member states of the EU. Therefore, as personal data is collected and exchanged more frequently, regulation on data transfers becomes necessary. Data controllers are the people or body 'which determines the purposes and the means of the processing', both in the public and in the private sector. Data controllers are required to observe several principles. These principles not only aim to protect the data subjects

but also are a statement of good business practices that contribute to reliable and efficient data processing. Each data controller must adhere to the data processing rules of the member state where s/he is established, even if the data processed belongs to an individual residing in another State. When the data controller is not established in the Community (e.g., a foreign company), s/he has to comply with the laws of the member state(s) if the processing equipment (e.g., a computing centre) is located within the European Community.

2.1.5 Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995

Directive 95/46/EC of the European Parliament and of the Council of 24th October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data. The Directive lays down a series of rights of the data subject, for instance a demented patient. These are:

- The right of access to his/her personal data;
- The right of erasure, blocking, or rectification of the data which do not comply with the provisions of the Directive, are incomplete or inaccurate;
- The right to be informed of all relevant details relating to the data processing and the rights granted to him/her;
- The right to a judicial remedy for any breach of the above mentioned rights.

All these are applicable to ProMe. The first three aforementioned rights may be restricted if this is necessary for reasons relating to the protection of the data subject or the rights and freedoms of others or to prevent a criminal offence or for reasons relating to public security.

At an international level, the ProMe consortium acknowledges heterogeneity in international data protection jurisdiction, starting with the OECD guidelines including the "Guidelines on the Protection of Privacy and Transborder Flows of Personal Data" (1981) and "Guidelines for the security of information systems" (1991/92).

The rules according to the directive are:

- Data must be processed fairly and lawfully.
- They must be collected for explicit and legitimate purposes and used accordingly.
- Data must be relevant and not excessive in relation to the purpose for which they are processed.
- Data must be accurate and where necessary, kept up to date.
- Data controllers are required to provide reasonable measures for data subjects to rectify, erase or block incorrect data about them.
- Data that identifies individuals must not be kept longer than necessary.

The directive states that each member state must provide one or more supervisory authorities to monitor the application of the Directive. One responsibility of the supervisory authority is to maintain an updated public register so that the general public has access to the names of all data controllers and the type of processing they do.

In principle, all data controllers must notify supervisory authorities when they process data. Member states may provide for simplification or exemption from notification for specific types of processing that do not entail particular risks. Exception and simplification can also be granted, in conformity with national law, when the controller has appointed an independent officer in charge of data protection. Member states may require prior checking, to be carried out by the supervisory authority, before data processing operations that involve particular risks may be undertaken. Which types of processing operations involve particular risks is for the member states to determine.

When can personal data be processed?

Personal data can only be processed (e.g., collected and further used) if:

- The data subject has unambiguously given his or her consent, i.e., if he or she as agreed freely and specifically after being adequately informed;
- Data processing is necessary for the performance of a contract involving the data subject or in order to enter into a contract requested by the data subject, e.g., processing of data for billing purposes or processing of data relating to an applicant for a job or for a loan;
- Processing is required by a legal obligation;
- Processing of data is necessary to protect an interest that is essential for the data subject's life. An example is in the case of a car accident and the data subject is unconscious; emergency paramedics are allowed to give blood tests if it is deemed essential to save the data subject's life;
- Processing is necessary to perform tasks of public interests or tasks carried out by official authorities (such as the government, the tax authorities, the police, etc.).

Finally, data can be processed whenever the controller or a third party has a legitimate interest in doing so. However, this interest cannot override the interests or fundamental rights of the data subject, particularly the right to privacy. This provision establishes the need to strike a reasonable balance, in practice, between the business's interest of the data controllers and the privacy of data subjects. This balance is first evaluated by the data controllers under the supervision of the data protection authorities, although, if required, the courts have the final decision.

2.2   National regulations

In addition to the international standards, partners will act in accordance with community law as well as national conventions. User studies will be carried out in Austria, the Netherlands, and Romania; these national

laws will be applied. All partners will strictly adhere to the legal regulations and guidelines presented by the European Union and all participating countries. In the following section, national codes of conduct and laws for the protection of data, including all subsequent and future amendments that may apply, are identified while adhering to the European Data Protection Law (2013).

The Data Protection Acts, in each respective country, may differ slightly in their terminology; however, they all provide the same fundamental rights to those participating in the ProMe project. These fundamental rights provide individuals with secrecy of the data concerning the individual and the right to rectification of incorrect data, so long as there are no issues overriding the interests of others. This follows the European Data Protection Law (2013).

2.2.1 Austria

The "*Bundeskanzleramt: Österreichische Datenschutzkommission",* substituted by the Datenschutzbehörde, is the main ethical committee and regulatory organization in Austria. Its main aim is to safeguard the compliance with the data protection act and legislation. In Austria, the following legislation will have to be taken into account in the ProMe project:

Data Privacy and Security

Datenschutzgesetz (DSG 2000), BGBl. I Nr. 165/1999 [2]: This act regulates the protection of personal data in Austria (i.e., the Austrian implementation of the European directive on data protection).

Datenschutzverordnung des. BPräs: This legal ordinance controls basic principles on data investigation and processing, data usage, its transmission and deletion.

Informationssicherheitsgesetz (InfoSiG 2002), BGBI. I Nr. 23/2002 [9]: This act regulates basic rights of data privacy and the duty to give information.

Bundesgesetz über die Organisation der Universitäten und ihre Studien (Universitätsgesetz 2002): This Act supports the researchers and their research-based teachings, providing freedom to study and make available the knowledge and new approaches developed through the University.

Non-Discrimination

Wiener Antidiskriminierungsgesetz (LBI 35/2004) [10]: This act regulates the abatement of discrimination referring to the access to social, health, and education, as well as public services. It focuses on the non-discrimination and equal treatment regarding sex, age, disability, ethnic group, religion, ideology, and sexual orientation.

2.2.2   Romania

AGIR, by its activity, is considered a personal data processing operator. The two laws below were adopted by the Romanian Parliament as implementation of Directive 95/46 on the Protection of Individuals with regard to the Processing of Personal Data:

Law no. 677/2001 of 21st of November 2001 on the protection of individuals with regard to the processing of personal data and the free movement of such data (published in the Official Journal of Romania, Part I No. 790.5) [consolidated version on: 02/04/2012].

Any processing of personal data, can be performed only if the data subject has given express and unequivocal consent to the processing. Personal data intended to be processed must be:

- processed in good faith and in accordance with the legal provisions in force;
- collected for specified, explicit, and legitimate purposes; further processing of personal data for statistical, historical, or scientific research shall not be considered incompatible with the purpose of collection if carried out in compliance with this Act, including those concerning the notification to the supervisory authority and with the guarantees concerning the processing of personal data provided by the rules governing the statistical or historical or scientific research;
- adequate, relevant, and not excessive in relation to the purpose for which they are collected and subsequently processed.

The National Supervisory Authority for Personal Data Processing is regulated by Law no. 102/2005 regarding the set up, organisation, and functioning. The National Supervisory Authority for Personal Data Processing has its headquarters in Bucharest and is set up as a public authority, autonomous and independent in relation to any other public authority, natural or legal person, with legal personality, exercising its attributions according to the present law, as well as to the special laws regulating the activity of personal data processing and the free movement of the data. It aims at protecting the fundamental human rights and liberties of the natural persons, in particular the right to private and family life with regard to personal data processing and free movement of these data. The National Supervisory Authority's powers and duties are set up by Law no. 677/2001 on the protection of individuals with regard to the processing of personal data and the free movement of such data.

The legislation related to the protection and care of older people in Romania also includes the Law No. 17/06.03.2000 – Social care of old people (Legea nr 17/06.03.2000 - Asistenta sociala a persoanelor varstnice, and the Ordinance 246/27.03.2006 – Approval of minimal specific quality standards for old people (Aprobarea stadardelor de calitate minime specific persoanelor varstnice).

2.2.3   The Netherlands

The Dutch Data Protection Authority (CBP) supervises compliance with legislation regulating the use of personal data. The CBP primarily supervises compliance with and application of the Dutch Data Protection Act

[Wet bescherming persoonsgegevens (Wbp)], the Police Data Act [Wet politiegegevens (Wpg)], and the Municipal Database (Personal Files) Act [Wet gemeentelijke basisadministratie persoonsgegevens (Wet GBA)].

The CBP is convinced that self-regulation will contribute effectively to the achievement of the individual's fundamental right to the protection of their privacy. As such, the Authority is promoting the appointment of a data protection officer and is encouraging companies to formulate a code of conduct for their branch of industry or sector. Based on this statement, the NFE (National Foundation for the Elderly) has created a code of conduct for our sector as a charity foundation for the elderly. This code of conduct refers to all projects of the NFE that involve volunteers and is focused on issues of privacy and data protection. The code of conduct is still in progress and will be submitted to the CBP committee when finished. Some of the main regulations that have been defined at the moment are:

- Only necessary data of volunteers is collected, not more than absolutely required for the project;
- Personal data is only saved for the time required for the project;
- Personal data is only used for the objectives of the project;
- Reports on projects will never identify individual persons unless express permission has been given;
- The volunteer is informed on the objectives of the project, on the nature of the National Foundation for the Elderly and on other involved organisations.

In compliance with the Dutch Data Protection Act (Wbp) and the code of conduct for our sector, the NFE created an informed consent form that has to be signed by all participants of the interviews, focus groups, and pilots that will be executed within the ProMe project. This form clearly states the privacy rights of the participants and the compliance of the project with these rights.

3. IMPLEMENTATION OF THE ETHICAL PERSPECTIVE IN PROME

After the overview of ethical principles and regulations at an international, European, and national level that we will adhere to in ProMe in section 2, this section will describe how these principles and regulations will be implemented in ProMe in the actual project work.

3.1 Overview ProMe

In order to define a complete ethical plan, it is important to define first clearly what we are doing in ProMe and who the target groups are. The ethics in ProMe are about what the project partners should do:

- For the good of those who are targeted as users,
- For the good of those who are collaterally affected,
- For the common good more generally.

The key focus of ProMe is to create a platform that allows for **effective intergenerational collaboration and learning**. ProMe aims at connecting people who want to support their professional development by drawing on external experience, support, challenge, and expert knowledge with people who want to share their experience and contribute to the professional success of others.

We define our target groups as follows:

- Retirees, with a rich professional career, who want to put their expertise, knowledge, and experience to good use;

- Experienced professionals (still professionally active) willing to share their expertise, knowledge, and experience with other more junior members of their 'trade';

- Juniors in a field of expertise, professional role, project, career switch, looking for a job, etc…who are seeking for external support for their professional development.

We want to contribute to the wellbeing and quality of life of the members of our target group through:

- Intergenerational collaboration (solidifying social cohesion and inclusion);

- Providing an opportunity to facilitate the exchange of experience and **tacit**[1] knowledge in order for it not to be 'lost' when people retire from an active professional career, but passed on to others;

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[1] We assume that the added value of ProMe will be mainly focusing on the use, sharing, and capturing of tacit knowledge as opposed to explicit knowledge. *"… Tacit knowledge is highly personal. It is hard to formalize and therefore difficult to communicate to others ...tacit knowledge is deeply rooted in action and in an individual's commitment to a specific context ...tacit knowledge consists partly of technical skills and partly of mental models, beliefs and perspectives so ingrained that we take them for granted and cannot easily articulate them."* (Nonaka, 1991) Explicit knowledge is knowledge that is easily expressed, captured, stored, and reused and therefore already accessible in most cases on the Internet. The experienced supporter (Mentor or Coach) in ProMe could help to make the already explicit knowledge more accessible by directing and orienting the 'junior users' towards the information and explicit knowledge they need in a certain situation or facing a specific professional problem.

- Stimulating, specifically with the population of retired professionals, their volitional contribution to the community (in the form of sharing knowledge and experience and support others in their professional endeavours and aspirations);
- Supporting people's professional and career development.

The ambition is to create an online platform that will enable and facilitate:

- People to enter a 'collaborative relationship';
- People to make a personal commitment to each other based on their mutual expectations and needs;
- The sustainability of these collaborative relationships over time (make sure both parties continue to put energy in it to make it work).

The functionalities of ProMe serve as a basis for the development of an innovative mentoring and coaching concept between professionals of different ages. Nevertheless, they also raise a number of ethical concerns. In particular:

- The need to respect privacy and confidentiality associated with the user's stored profile, information and usage data as well as any other stored personal data;
- The need to ensure the security of shared personal data;
- The need to ensure that the ProMe platform and its underlying structures and interfaces are motivating, ergonomic, and overall understandable by end-users (especially for older people that have little experience with digital solutions);
- The need to ensure that the persons involved in the research are fully informed about the project and the objectives of the trials and agree to such participation and scope (informed consent);
- Risk assessment (insurance for participants);
- The need to ensure transparency of the collected data management by the final system and during its pilots;
- Incentives (e.g., financial inducements);
- Use of personal data for research;
- Data storage and handling processes;
- Processes of anonymization.

These concerns are even more important in the ProMe project, given that the platform is based on the trust of its users and a large amount of data will be available on both professional but probably also private data. Referring to the ProMe work plan, the following work packages raise ethical issues or concerns.

WP No.	WP title	WP leader	Ethical issues foreseen
1	Project management	PLUS	Ethical issues are management in T1.2 by NFE.
2	User requirements and iterative evaluations	PLUS	Yes, involvement of research participants and the collection of personal and profile information, including storage, retrieval, and processing of personal data.
3	System design and development	GLUK	Yes, ensuring the technical components meet levels of

			security for risks
4	System integration and Experimentation	SIVECO	Yes, integration of available security and authenticity technologies.
5	Exploitation strategies, Business Case, and Dissemination	INV	No

The ethical processes will be conducted in collaboration between the ethical task leader (NFE), the end user partners (AGIR, EURAG, and NFE), and the corresponding WP leads.

3.2 Data treatment and privacy in ProMe

Based on the European guidelines and regulations and the objectives of ProMe, we can conclude that data treatment and privacy is one of the major ethical concerns in the project. As mentioned, the consortium will follow the 95/46/EC Privacy directive of 4th April 1995 about individual protection for personal data management and distribution.

Data is considered personal when it enables anyone to link information to a specific person, even if the person or entity holding that data cannot make that link. Examples of such data include address, bank statements, credit card numbers, and so forth. Processing is also broadly defined and involves any manual or automatic operation on personal data, including its collection, recording, organization, storage, modification, retrieval, use, transmission, dissemination or publication, and even blocking, erasure or destruction (Directive 95/46/EC, Article 2b). Recommendations are separated on seven categories, following the EU Directive 94/46/EC categorization:

- **Notice -** Subjects whose data is being gathered should be notified of this action.

- **Purpose -** The collection of data should be stored only for specific purpose(s). E.g. for specific research purposes.

- **Consent -** Personal information should not be transmitted to third parties without permission from its subject.

- **Security -** Once acquired, personal data should be retained in safe and secure place, protected from potential abuse, theft, or loss.

- **Disclosure -** Research participants whose personal data is being obtained, should be informed of the project collecting such data.

- **Access -** Research participants are enabled to demand access to their personal data and allowed to reform any wrong information.

- **Accountability -** Research participants should be able to set the personal data collectors responsible for the application of all seven of these principles above.

3.2.1 Informed research participants

The protection of the privacy of the research participants is a responsibility of the researchers involved in the studies that include end users. Privacy means that the participants can control the access to personal information. The participants should be informed about the confidentiality policy that is used in WP2 on user involvement. The research participants have to be able to control the dissemination of the collected data. All involved research participants will be informed previously that their data will be protected and encrypted and that it will only be used for the ProMe research for scientific purposes within the consortium, banning any kind of dissemination for commercial activities, etc. An informed consent form will provide them the information about how data will be handled and they will give their consent to the consortium to use the data for scientific purposes. Both the researchers from the end user partners and users will sign the consent form. This issue will be further elaborated on in a specific section on the informed consent (see Annex A).

3.2.2 Anonymization

Anonymization is required to protect the user's identity. This means that only relevant attributes, i.e., gender, age, etc., are documented. The identity of participants will only be maintained in the informed consent form. The name of the persons and any kind of identification data will appear on the informed consent forms, of which one copy is kept by the project investigator and the other one by the person participating to the ProMe user requirements processes. All data will then be anonymized by assigning a numerical code to each user (local database), and stored accordingly (e.g., Subject 1, Subject 2, etc.). All data will also be anonymized in internal reports, internal communications, and external publications (e.g., paper publications or the deliverables).

3.2.3 Data storage and transfer

AAL research ethics focus on the importance of secure storage, management, and accessing of the related information; data must be stored in a secure environment with control access and other security measures obeyed (e.g., proper temperature control). Additionally, sensitive information needs to be stored in the appropriate hardware means, in the appropriate structure and format, corresponding to the related requirements (e.g., paper, disk, etc.). Accessibility to the information needs to be maintained controlled and the networking configurations should not allow data duplication of circulation.

Data transfer in both electronic and other ways will, therefore, be monitored. Data storage and management considerations also impose thoughts concerning (a) the duration of storage of the sensitive information and (b) if any back up policies shall be implemented. For example, the duration of the storage should define the extent of time needed until data will be removed in accordance with the level of importance of the data. This procedure ensures avoidance of the inappropriate use and dissemination of the information.

In the scope of WP2 on the user requirements, iterative evaluations, and pilot studies, the ProMe project will record and store information about end users. This document provides the end user partners of the project with concrete guidelines for data handling to the partners and will ensure that they follow best practices and give appropriate assurances regarding data acquisition, processing, storage, and transmission. Each end user partner will be accountable in case of information compromising.

Any questionnaires or input acquired in the scope of the ProMe user involvement processes (especially WP2) will be handled in the strictest confidence – the results will be entered immediately into a database or XLS files from where each set of results will be given an automatic number and the personal details omitted. The questionnaires themselves will be kept in a folder, which is kept in a lockable drawer. The questionnaires will be destroyed at the end of the project. Additionally, all personal data can be modified and even erased on request from the person, e.g., on an XLS file or via an easy to use interface on the related ProMe databases. Also, the user should be able to inquire about his/her stored data.

3.2.4   Secure data destruction

In order to prevent the crack of sensitive data and the leak of insecure information, the project intends to apply safe methods on destructing its data, after the extent of their need. The aim is to guarantee that data is completely destroyed with absolutely no chance of retrieval and to deny unauthorized access to any information. The way of destruction depends on the type of the files. Various techniques will be applied in paper, CDs, DVDs, floppy disks, USB drives, etc. The responsible deconstruction staff that will deal with encrypted data will be examined and have signed confidential agreements.

3.2.5   Risk related to data and privacy

In the scope of WP3 and WP4 in order to protect users' privacy on the ProMe platform during the pilot and beyond, several security measures and protocols will be implemented during the project.
The consortium will pursue the fulfilment of the European Directive during the project and all sensitive data will be encrypted and protected during storage and transmission, which takes place across third-party networks (such as the Internet) so that user's identity and privacy will not be compromised. Integration with standards available security and authenticity technologies, such as single sign-on management or LDAP will be analysed. Various implementations will provide a level of user-security in accordance with open-source security standards. State of the art firewalls, network security, encryption, and authentication will be used to protect collected data. Firewalls prevent the connection to open network ports and exchange of data will be through consortium known ports, protected via IP filtering and password. Where possible (depending on the facilities of each partner and pilot site), the data will be stored in a locked server and all identification data will be stored separately. A metadata framework will be used to identify the data types, owners, and allowable use. This will be combined with a controlled access mechanism and in the case of wireless data transmission with efficient encoding and encryption mechanisms. Pretty Good Privacy (PGP) technology could be used to provide

cryptographic privacy and authentication for data communication. PGP could be used for signing, encrypting, and decrypting texts, e-mails, files, directories, and whole disk partitions.

3.2.6   New technologies for security reasons

The security of precious data demands the ability to avoid data theft regardless of the level of cracking techniques. Therefore, the encryption, file and record locking, integrity, the passwords mechanisms as well as the traceability of the data acquisition systems need to be constantly updated to prevent the possibility of decoding the data management system in any level and disseminating private information.

3.3   ProMe ethical procedures

The ProMe partners will apply well-established procedures, which are commonly used in research involving humans (including ethical clearance) and well-known to the end user partners. The main ethical management guidelines and principles to be followed in ProMe are summarized in this section.

3.3.1   Respect of and compliance with national rules and regulations

The participants, who will be involved in the project, will take part in a pilot study. The pilot study will be conducted in a 'natural' environment on the home computer of older and younger end users. All end user partners will be required to obtain ethical approval(s) from the relevant ethical committee(s) in the institution, region or country where the pilot study is carried out. This is the most appropriate means of protection, since it means that the legal, professional, religious, and other contexts of the country in question will be taken into account and the evaluation will be more independent than relying only on the ProMe ethical guidelines. Thus, the consortium shall implement the project in full respect of the legal and ethical national requirements and code of practice. Whenever authorizations have to be obtained from national bodies, those authorizations shall be considered as documents relevant to the project.

3.3.2   Protection of personal data and measures to guarantee security and confidentiality

In general, collection, storage, and distribution of all data will be subject to standard requirements as described in Section 3.2, involving briefing and consent of participants. Users will be informed of the purpose and nature when personal data is collected and will have to consent in writing. The researcher of the study and his/her co-workers will inform participants that they are in a position to refuse to participate, especially if they have a direct or indirect financial or contractual link with the research institution.

3.3.3   Enforcement of standard privacy rules

Standard database privacy rules will be enforced. Ownership of data will be made explicit to the participants. Each participant will have an opportunity to receive a copy of the stored data. Efforts will be made to ensure the traceability of material in such databases. Personally identifiable data transfer collected within the EU will not be made available to parties outside the EU unless the countries concerned comply with the EU directive

95/46/EC. Personally identifiable data will not be made publicly available unless it is accompanied by a certificate from the originator of the database specifying the conditions under which it may be released and the warrant for so releasing it.

3.3.4   Relation with research participants

With the involvement of research participants it will be important to take into account that we are working with older people who may be frail. Friendliness, service quality, and consulting authority are important. The following criteria should be particularly noted:

- Older people are sensitive to politeness, obligingness, and assistance.
- Older people are especially timely; they usually come in time, often even earlier than agreed, so punctuality is important. They are willing to wait a little, but it should not take too long.
- Older people are pleased with little surprises; small gestures for purchases and gifts are almost always accepted with joy. Personal good wishes on special occasions are very well received and long-time regular customers are pleased with Bonuses.
- Older people are less confident; many have fears to be overreached or not to be well versed with technology and electronics. Moreover, they fear to buy something wrong or to receive no service afterwards. Therefore, they like sellers who they know and who they trust.
- Older humans need acknowledgment and appreciation; they want to be taken seriously and importantly.
- Older humans are grateful; that leads to customer connection and to far recommendation. Many older humans continue to tell their purchase experiences to others.
- For the research activities, it will be important to treat the research participants according to well-accepted principles, which seem obvious but are often forgotten.
- Give Clear instructions in simple, short sentences.
- A caring, but also specific and clear, tone should be used.
- Repeat important information when needed several times.
- Let them always finish their sentences.
- Take them serious.
- Make sure that they understand everything what you tell them (no foreign words).
- Speak loud and clearly.
- Write complicated procedures down.
- Always maintain eye contact.

3.4   Local ethical procedures

Each end user partner will be responsible for establishing and implementing all ethical procedures that are relevant to the respective country (see Section 2) and request of permissions from relevant authorities, drafting of material necessary for obtaining permissions, drafting of informed consent forms, etc. The three

end user parties in the project will also approve all research activities involving human participants. Their responsibility is to guarantee the best quality of social, psychological, and public health attention to older people and to maintain the fundamental ethical principles that research involving potentially vulnerable human beings need to be considered.

The end user partner managers will also review those ProMe deliverables that entail ethical issues, notably of the project. An audio-conference or physical meeting will be held when appropriate in order to discuss the status and evolution of ProMe ethical procedures. These communication activities will be more frequent during the phases of evaluation and pilot studies. If necessary, one or more independent ethic experts will be invited to advise the ProMe partners on a merit and need basis with respect to the establishment of ethical procedures.

3.5   Informed consent

In order to provide research participants with the maximum transparency, the ProMe project will implement informed consent. By signing informed consent documents, research participants agree to a controlled breach of their privacy for a specific purpose and a specific period of time. In case an individual does not agree with such a temporary breach, /he retains the right to withdraw. Individuals need to be aware of the:

- Methods used for handling personal data,
- Justification for requesting/obtaining their data,
- Duration of data use and storage, and
- Guarantees concerning the rightful use of data.

Therefore, any research action that might impede privacy requires informed consent. This means that in the Ethical Issues Table, if the applicant ticks one of the two privacy topics, the "informed consent" section also needs to be ticked. The main aspects of 'informed consent' are the following:

- The potential participant must be given sufficient information in order to be able to make a choice of whether or not to participate. That is based on an understanding of the risks and alternatives in an environment, which is free from any coercion.
- The decision of the potential participant on the consent issue must be evidenced. The participant needs to agree that her/his data will be used for a specific research scope and is aware of the meaning of such use.

ProMe will employ informed consent processes associated with all its users, both young and old. This is also a requirement imposed at the national level (i.e., the countries of the various partners). Informed consent is the process by which a participant will be fully informed about the research in which s/he is going to participate. It originates from the legal and ethical rights a participant has to direct what happens to his/her body and personal data and from the ethical duty of the researcher to involve the participant in research. Seeking the consent of an individual to participate in research reflects the right of an individual to self-determination and also his/her fundamental right to be free from bodily interference, whether physical or psychological and to

protect his/her personal data. These are ethical principles recognised by law as legal rights. A distinction between three informed consent elements is possible: the information given, the capacity to understand it, and the voluntariness of any decision taken. Respect for persons requires that participants, to the degree they are capable, be given the opportunity to choose what shall or shall not happen to them. This opportunity is provided when adequate standards for informed consent are satisfied. The written information, as well as the sought informed consent corresponds to information gathered from the revised version of the Helsinki Declaration of 1964, as lastly amended in Tokyo, 2004, and the Convention of the Council of Europe on Human Rights and Biomedicine (1997).

3.5.1   Basic elements

In order to involve a human being as participants in research activities, the ProMe researcher will obtain the legally effective informed consent of the participant or the participant's legally authorized representative. All investigators within ProMe will seek such consent only under circumstances that provide the prospective participant or the representative sufficient opportunity to consider whether or not to participate and that minimize the possibility of coercion or undue influence. The information given to the participant or the representative will be in a language understandable for the participant or the representative. No informed consent, whether oral or written, may include any exculpatory language through which the participant or the representative is made to waive or appear to waive any of the participant's legal rights or releases or appears to release the investigator, the sponsor, the institution, or its agents from liability for negligence.

The respective informed consent forms for each country are enclosed in the annexes of this report.

4.　ETHICAL PROCEDURES IN THE PROME PILOT

This section complements the previous sections and will go further into the ethical issues during the pilot running. First it will highlight the issues in relation to the involvement of end users in the pilot study and secondly it will go further into ethical considerations regarding the relationship between end users (mentors and Mentees) and the ProMe platform. This part is related to the deployment ethics of ProMe.

4.1　Ethical Guidelines for the Pilot

The ProMe project will conduct three pilots in three different countries. The pilots will run for 3 months on an integrated version of the platform. At least 90 end users (Mentors and Mentees) will participate in the pilot study. The research participants will use the platform in a 'natural' environment, meaning that they will have the opportunity to assess the platform and get active as Mentor or Mentee according to their needs, wishes, and preferences. The aim is to receive further input on the ProMe platform and processes it supports by end users. Additionally to the ethical guidelines mentioned in section 3, the pilot will take specific considerations into account related to ethical issues.

4.1.1　Inclusion and exclusion criteria

End users will be recruited to participate in the pilot, according to the ethical guidelines set out in section 3, using the Informed Consent and taking into account all privacy and data protection measures. The ProMe project will involve end users that correspond to the target group defined in D2.1 on Personas and Scenarios. The end users can be both, younger people, who are looking for support or older end users, who want to use their knowledge and help others. The pilot study does explicitly not include or exclude end users based on their age. Instead it focuses on their need for support or for knowledge sharing.

4.1.2　Drop out strategy

End users, who participate in the pilot, will be extensively informed about their rights as study participants. They are fully aware that they can drop out of the study at any moment of their choosing and are not obliged to participate. The ProMe partners will involve end users into the pilot, taking a 10 percent margin as drop out ratio, making sure that the study results are still valid. Additionally, the pilots will allow for end user participants to start at a later phase in the pilot, as this would also be a normal scenario within the running of the platform.

4.1.3　Exit strategy

Users in the pilot study might become accustomed to the service they are using. Especially the relationships people are making on the platform, as well as the support they receive through these relationships are considered as valuable results from the pilot. To avoid an abrupt disruption to these relationships, the platform will be made available to the users even after the project has finished. Study participants can continue being active as Mentors or Mentees on the beta version, while the technical partners are further refining and

improving the final version. The end users will be informed that they are using a beta version, not a market ready product.

4.1.4   Pilot moderator

During the pilot the partners in each country will be responsible for assigning a moderator to the platform, who will supervise the platform activities and when necessary intervene. End users can report inappropriate actions on the platform, as will be described in the following sections, to the moderator. The moderator will have the right to eliminate inappropriate content or remove a user, who violates the platform agreement. After the project ending a pilot moderator must also be assigned to the beta version to make sure that participants can continue a pleasant use of the platform.

4.2   Privacy and confidential issues in relationships

Some of the ethical implications expected are about the privacy and about confidential issues members of the ProMe platform will have. Below, expected issues and possible solutions will be outlined.

4.2.1   Sharing personal data of one user with another user

The ProMe platform is not intended to share personal data with third parties (e.g. address, phone number). Users should exchange such data only directly with the person they are collaborating with, and not to a third user, unless they have their consent. The ProMe platform will include a warning in the terms of use in which users will be informed not to share personal data of one user with another. The platform is completely transparent in allowing the registered user to choose what types of data they want to make public and to whom. There will be a warning in the code of conduct and user agreement (see Annex A: Code of Conduct & User Agreement) on this. If a user notices his or her address being shared without his/her agreement more often, they can report it to the ProMe platform moderators who can delete the specific message or reprimand the user.

4.2.2   Selling or sharing personal data with third parties

ProMe will have a strict policy on sharing with or selling personal data to third parties (e.g. commercial agencies, telemarketers, etc.): It is not allowed in any way. As illegal sharing or selling personal data of another person without their approval is prohibited by European law as well, ProMe will remove users who do so. All legal effects (e.g. sanctions) will be for the user who breaches with this ProMe platform rule and thus, with the EU legislation. If it occurs that data is being sold or shared with third parties, users affected can not only report ProMe but also have the possibility to report their case to the local Data Protection Authority in each country.

4.2.3   Personal or confidential issues

ProMe warns users to take into account, which confidential information they share on the platform, especially when it is business related. ProMe will provide a disclaimer indicating that it will not be responsible for the outcomes of shared confidential information on the platform by users. The disclaimer will state that users are responsible for the information they share themselves on the platform.

4.2.4   ProMe use of data

It is prohibited by European law for ProMe to share user data with or sell to third parties without approval of the user. ProMe will provide a clear option where the user can indicate whether his/her data can be used for statistical and research purposes. ProMe will use personal user data for statistical analysis purposes to further improve the platform. Personal data will be handled according to EU legislation. When user data is used for publications, it will be processed anonymously. Users will be able to look into the results of this research on request.

4.3   Contents

The following section relates to the content made by users on the public profile sections of ProMe. These issues and the way ProMe deals with them are described below.

4.3.1   Inappropriate content

Something that happens on almost every platform is unwanted or inappropriate content. There is a diverse variety of things that can be thought of here, for example, inappropriate photos or language. Users are advised not to do so. If users spot inappropriate content, they can report it and the moderator will take care of it, either by warning the user with the inappropriate content on his/her profile or delete this user altogether. The moderator will have the right to immediately delete inappropriate content even though no user complains about it. Automatic reporting will be made based on a list of inappropriate words to alleviate the task of the moderator.

4.3.2   Identity dishonesty

ProMe platform is based on the accurateness of the information provided by people. Therefore users will be informed that they are obliged to provide accurate information on their person and identity. The moderator will be able to scan profiles in order to make sure that they are not faked. Other users, who notice a faked profile, can report this to the moderator, who can delete the faked profile, who disables the false account and wipes all information associated with the name from the account. The moderator doesn't delete the account from the servers for safety and security reasons. A person, who has an account that has been wiped, can still claim his/her profile back and create a new one with permission form the moderator.

4.4   Collaboration

The following section describes the issues that may occur when two persons start to collaborate on ProMe.

4.4.1   Prejudice and racism

ProMe wants all users to feel welcome. Therefore, prejudice and racism are very unwanted and will be banned according to EU law. Racism is defined as behaviour or language based on a belief in relation to a person 's particular race, colour, descent, national or ethnic origin, demonstrating an inherent prejudice intended to offend, insult, humiliate or intimidate.

Within the Code of Conduct and User Agreement (see Annex A) users are informed on these viewpoints of ProMe and warned about their immediate banning of the platform when such behaviour or content is demonstrated. Users can file a complaint towards the ProMe moderator on this behaviour, who will then investigate the complaint. However, within the User Agreement, it is indicated that ProMe cannot be held responsible for any legal consequences a user may experience because of racism and prejudice.

4.4.2   (Online) blackmailing, extortion

Both blackmailing and extortion are prohibited by a diversity of European laws reflected in section 4.7. ProMe advises users who fall victim to such behaviour to go to their local police station for help. ProMe itself cannot be held responsible for the consequences of blackmailing, extortion or any other form of this, but has a zero tolerance policy for this behaviour and will therefore remove users who do so with no chance of returning on the platform in any way.

4.4.3   (Online) bullying and harassment

Currently, the laws on online bullying and harassment are rather minimal. However, data protection legislation is also applicable in most of these cases, which makes it possible for affected users to file a complaint. There are some local laws against stalking and harassment. However, these are mostly based on offline activities and can be found in section 4.7. ProMe advises users, who fall victim to such behaviour to go to their local police station for help. ProMe warns users to always think about the data they share online and encourages users to report inappropriate behaviour so ProMe can handle this effectively. However, while certainly not approving (online) bullying and harassment, ProMe cannot be held responsible for the consequences of it.

4.4.4   Arguments

It is possible that two users won't be able to get along and that there will be an argument. ProMe stands against this behavior and encourages users to report inappropriate behavior. However, ProMe is not a mediator in conflicts and cannot be held responsible for any outcomes related to this.

4.4.5   Incorrect information supply or support

Users are strongly advised to think about what the other party needs to know for a solid collaboration that is based on trust. However, users also need to ponder what they do and don't tell. The Mentee needs to take always the precaution of 'checking' the information or advice s/he gets from the Mentor before s/he uses or implements that advice in his or her organization. We advise also the Mentees to share as much as possible what is discussed in the mentoring sessions with their managers and co-workers in the organization in order to make sure that when they apply an advice from their Mentor, it is in compliance with the processes, policies, industrial vision, etc. of their organization or company. If the Mentor and Mentee cannot reach a common understanding, it is best for Mentor and Mentee to look for another collaboration partner. ProMe is aware that this might happen, but cannot be held responsible for the consequences of said support.

4.4.5.1   Support leading to a situation endangering the Mentees career

The ProMe platform is created to connect a Mentor and Mentee to each other and to have an easy, online workspace for them in mutual trust. During collaboration itself, users will have to fairly assume responsibility of the role of the platform and take their own responsibility. ProMe cannot be responsible for any results of the support given, nor the results of the support followed.

4.4.6 Feedback spamming

Users will be able to leave feedback about other users they have worked with after the collaboration ended. Fake feedback is not wanted here. To make sure fake feedback spamming is in control, users will only be able to leave feedback for those users they have worked with, so not for every other user they want to give feedback. Leaving relative negative feedback is allowed, but users will have to mind their wordings, as foul language of any kind will be treated as inappropriate profile content (not for the profile owner but for the one who left it). ProMe is not responsible for the feedback left and the consequences of it.

4.5 Intellectual Property Rights (IPR)

As users may share their (professional) documents and ideas, intellectual property rights (IPR) is an issue to take into account. Also, new ideas may be developed during collaboration. These issues and their relation to ProMe are all described below.

4.5.1 Documents stolen, shared with or sold to third parties

First of all, there are different protection rights such as patents, copyright, trademark, trade secrets, and industrial design rights. Second, the Enforcement Directive (Directive 2004/48/EC) states all sanctions for cases of IPR infringement. All IPR rights have fair exceptions, with each country having differences in IPR legislations on its own, these should be taken into account. Although Mentor and Mentee will share knowledge they gained throughout the relationship, based on a trustful relationship, they are advised to not hand over any documents to third parties. ProMe complies with IPR legislation, but is not responsible for originality of the content posted or used by users from the platform.

4.5.2 New documents, ideas or inventions

It is very well possible that people who collaborate discover something new. Whenever this happens, it is up to these people themselves to find a way to deal with the intellectual property rights. ProMe is a platform for matching Mentors and Mentees, while also offering an online workplace. ProMe is not responsible for any new documents or ideas or inventions that flourish out of the platform, nor the IPR rights belonging to them.

4.6 Business and professional environments

A lot of the issues already described earlier should also be taken into account for business and professional environments. These will be described briefly below.

4.6.1 Abuse of company information

It is the responsibility of the Mentee to think carefully about what information s/he will and will not share with a Mentor about the company. ProMe is not responsible in any way for the abuse of company information shared by the Mentee, nor for the consequences of it.

4.6.2   Given advice that goes against the company culture or instructions

A Mentor and a Mentee should discuss these kinds of issues if they occur so that a possible resolution can be found. If a Mentor, even though s/he is aware of certain variables, keeps advising the Mentee to do things against his or her company culture or instructions, it might be best for Mentor and Mentee to look for another collaboration partner. ProMe is aware that this might happen, but cannot be held responsible for the consequences of said advice and/or behavior.

4.6.3   Shadow managing

Shadow managing means that the Mentor will manage the Mentee and thereby competes with the real manager of the Mentee. The Mentor should at all times take into account the workplace of the Mentee and know that s/he is not the real boss or manager of the Mentee. Here as well goes that Mentee should take his/her own responsibility and make sure his/her relationship with the Mentor does not interfere negatively with his/her manager.

4.6.4   Business damage

During collaboration itself, users will have to fairly assume responsibility of the role on the platform. They should take their own responsibility and establish a good Mentor-Mentee relationship that does not damage the business they are working for. ProMe cannot be held responsible for any results of the support given, nor the results of the implemented support.

4.7   Summary overview

The following table gives a summary overview of the ethical issues and related considerations and implications for ProMe and the legislation and protection within ProMe.

Ethical Issue/Consideration/Implication in ProMe	Protection in ProMe/in general
Sharing personal data with other users	Warning in the terms of use - users have to take their own responsibility
Fairly and lawfully processed personal data (sharing or selling data to third parties)	Article 6 of the Directive 95/46/EC Article 5 of the Regulation EC COM (2012) Permanent ban from the ProMe Platform
Processed, for limited purposes, personal data (sharing or selling data to third parties, but also using data for improving the ProMe platform)	Article 7, 8 of the Directive 95/46/EC Regulation (EC) No. 45/2001 Article 16, Treaty of Lisbon
Inappropriate profile content, identity or skill dishonesty.	Possibility to report. User warning and/or (permanent) ban from the ProMe platform
Racism	Article 10, 21, 22, 23 of the CFREU
Blackmailing, extortion and/or bribery	Article 317 Penal law (the Netherlands)

	Article 470 Penal code (Belgium)
	Section 253, Chapter 20, Criminal code (Austria)
	Article 207 and 289, Penal Code (Romania)
	Permanent ban from the ProMe Platform
(Online) bullying and harassment	Article s285b, Penal code (the Netherlands)
	Article 442, Criminal code (Belgium)
	Article 107a, Criminal Code (Austria), anti-stalking law including cyber bullying and harassment.
	Article 206 and 208, Penal Code (Romania)
	Permanent ban from the ProMe Platform
Arguments and cooperation failure	Users have to settle this by themselves.
	Reporting only possible when inappropriate behaviour occurs (e.g. bullying or harassment).
Feedback spamming	System solves this: Only possible to rate users who you have been mentoring/a Mentee of.
Incorrect advice, advice endangering Mentee's career or other people	Users have to take their own responsibility
Information conflicting with the users 'background (moral, belief, etc.) or company culture	Article 10, 22 from the CRFEU
IPR-related issues	Copyright, Patent, Trademark, Trade secrets, Industrial design rights
	Enforcement Directive (Directive 2004/48/EC) – for sanctions only, no legislation on itself
Abuse of company information	Unless in a form of blackmailing, bribery, or harassment of any kind, no legislation. Users have to take their own responsibility.
Shadow managing	Users have to take their own responsibility – maybe look for another collaboration partner.
Business damage	Users have to take their own responsibility in giving out advice and/or following it.

5. ETHICAL DECLARATIONS TABLE

The following ethical declaration table is from the DoW and provides an overview of the ethical issues in the ProMe project and where the correspondent information can be found in the present document.

Ethics declaration of proposals in the AAL Programme	Relevant section
How is the issue of informed consent handled?	Section 3.5
What procedures does the proposal have to preserve the dignity, autonomy, and values (human and professional) of the end users?	Section 3.2 ProMe ethical procedures and Section 3.3 Local ethical procedures
If the proposal includes informal carers (e.g., relatives, friends or volunteers) in the project or in the planned service-model - what procedures exist for dealing with ethical issues in this relationship?	N.A.
If the proposal includes technology-enabled concepts for confidential communication between the older person and informal and formal carers, service providers and authorities – what procedures are planned for safeguarding the right to privacy, self-determination, and other ethical issues in this communication?	Section 3.2 data treatment and privacy in ProMe
What "exit" strategy for the end users involved in the project does the proposal have (in terms of end users leaving the project during its implementation and after the project's end)?	Section 4.1
How are the ethical dimensions of the solution targeted in the proposal taken into account? (Brief description of distributive ethics, sustainability, et.al.)	Section 4.2

6. CONCLUSION

This report gives an overview on the research ethics within the ProMe research activities. Based on an overview of international, European, and national regulations and guidelines on ethical issues, the report has detailed the different procedures that will be implemented during the first phase of the ProMe research. The second version of this document (delivered in month 18) complements this by detailing the ethical issues during the pilot running of the ProMe project.

The document gives insight in how ProMe handles ethical issues, not only during the project and research but also after the project has ended and the platform is taken into use. Multiple European laws have been described to give a good insight in legislation regarding privacy and personal data, amongst others. Some laws (e.g. on harassment and extortion) are currently only described for the countries involved in the ProMe project. If it happens to be that other countries take part in using the ProMe platform as well, local laws should be looked up to inform the user about their rights.

Next to describing several legislations, this document also described how ProMe will use these legislations for several ethical implications. Other issues are tackled by means of the user agreement. Many issues are also the responsibility of the user him-/herself. ProMe cannot be held responsible for any consequences in these cases. Finally, the code of conduct and the user agreement will be presented to the user before they create an account and start using the ProMe platform, which they will have to sign-in in order to show that they not only know the rules, but also their rights. Hopefully, this will not only give the user some insight on how to use the platform but will also make the ProMe platform a place where people can collaborate in a nice, friendly, and safe manner.

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Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data. http://eur-lex.europa.eu/legal-content/EN/ALL/?uri=CELEX:31995L0046

Bundeskanzleramt: Österreichische Datenschutzkommission: https://www.dsb.gv.at/

Dutch Data Protection Authority (CBP) http://www.dutchdpa.nl/Pages/home.aspx

ANNEX A: CODE OF CONDUCT & USER AGREEMENT

ProMe is an online platform enabling intergenerational professional mentoring and coaching oriented relationships.

To use this service, you agree that (1) you are an individual professional seeking or offering voluntary mentoring support or (2) that you are an organisation authorised to use the ProMe platform to support coaching or mentoring relationships between individual members of your organisation, and (3) that you will only create one authorised ProMe account per individual user. This service is free of charge.

Your ProMe account belongs to you. You agree to (1) use a strong secure password, (2) use the platform only for its intended purpose of mentoring, and (3) respect any other terms and conditions that the ProMe platform may create. You are responsible for deciding to access or use third party applications or sites that may link from our platform. You must at all times respect the current agreement.

You agree that **you will not** act dishonestly or unprofessionally, including posting inappropriate or objectionable content. You agree that **you will** use your real name in your profile and an image that is your true likeness. You agree that **you will not** harass, abuse or harm any other ProMe user. By virtue of law or common rules applicable to communities such as our platform, you have obligations towards the platform and the other users.

You own the content and information that you submit or publish to the platform, including your profile information. You are responsible for the information you share with other users and for any advice you give or follow. You must not provide information to us and/or other users, which you believe might be harmful to your personal, professional or social status. You will respect intellectual property rights, which may belong to third parties.

You can end your relationship with the ProMe platform by deleting any information and closing your account except to the extent that you shared it with other users and they copied or stored it. You agree that we may access, store, and use any information that you provide in accordance with the terms of our Privacy Policy.

You may terminate your use of this service at any time. Any violation of the present agreement may lead to the restriction, suspension or termination of your account by us. We do not provide any express warranties or representations including, without limitation, any warranties of merchantability, fitness for a particular purpose, title, accuracy of data, and non-infringement.

The ProMe platform protects your personal information using up-to-date industry standard security software. **We do not** provide your personal information to any third party. Continuing to use our services after we publish or communicate a notice about changes to our Privacy Policy means that you consent to changes.

ANNEX B INFORMED CONSENT AUSTRIA

ProMe: Professional Intergenerational Cooperation & Mentoring

Datum: Salzburg, Januar 2016

Informative Einverständniserklärung

Name des Projektes:	ProMe – Professional Intergenerational Cooperation & Mentoring
	ProMe – Berufliche Generationenübergreifende Kooperation & Beratung
Projektnummer:	AAL-2013-6-026
Art des Projektes:	kooperatives Projekt
Dauer des Projektes:	36 Monate
Start des Projektes:	2014
Ende des Projektes:	2017
Fördergeber:	EU
Förderprogramm:	AAL Joint Programme
Ausschreibung:	Call 6 – ICT-based Solutions for supporting occupation in life of older adults
Koordinator:	Manfred Tscheligi, Universität Salzburg
Versuchsleiterin:	Katja Neureiter
Institution:	Universität Salzburg

Die im Folgenden beschriebene Studie ist Teil des Forschungsprojektes ProMe – Professional Intergenerational Cooperation & Mentoring (Berufliche generationenübergreifende Kooperation & Beratung). Dieses Projekt wird durch die Europäische Union (EU) und dem Ministerium für Verkehr, Innovation und Technologie (BMVIT) im Auftrag der FFG (Österreichische Forschungsförderungsgesellschaft) innerhalb des Förderprogramms AAL Joint Programme finanziert.

Diese Einverständniserklärung enthält eventuell Begriffe und/oder Informationen, die Ihnen nicht geläufig sind. Bei Bedarf fragen Sie sich bitte an den/die VersuchsleiterIn um weitere Informationen zu erhalten. Gerne können Sie eine Kopie dieser Einverständniserklärung anfordern, um über den Sachverhalt nachzudenken oder mit ihrer Familie darüber zu sprechen bevor sie eine Entscheidung treffen. Wir versichern ihnen jederzeit die Einhaltung der aktuellen Gesetzgebung.

I. EINLEITUNG:

Sie wurden zur Teilnahme an dieser Studie vom Projekt ProMe eingeladen. Bevor Sie sich einverstanden erklären, lesen Sie sich bitte diese informative Einverständniserklärung aufmerksam durch. Zögern Sie bitte nicht, Fragen zur Studie zu stellen um sicher zu gehen dass Sie Ziel und Ablauf sowie Nutzen und Risiken der Studie vollständig verstanden zu haben.

II. ZIEL DER STUDIE:

ProMe ist ein internationales Projekt, das älteren Erwachsenen im Übergang von der Berufstätigkeit in die Pensionierung eine sinnvolle Möglichkeit bietet ihr berufliches Wissen weiterzugeben. Ziel des Projektes ist es eine Internet-Plattform zu entwickeln, die generationenübergreifenden Wissensaustausch ermöglicht und dadurch die Kooperation zwischen älteren und jüngeren Menschen fördert.

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III. TEILNAHME AN DER STUDIE UND MÖGLICHE TEILNAHME AM STUDIENDESIGN:

Für die Teilnahme suchen wir ältere Menschen im Übergang von der Berufstätigkeit zur Pension und darüber hinaus, die Interesse haben ihr berufliches Wissen weiterzugeben. Wir adressieren auch jüngere Menschen, die sich vorstellen können beispielsweise Coaching in Anspruch zu nehmen. Schließlich richten sich unsere Studie auch an ExpertInnen (zum Beispiel professionelle BeraterInnen).

Die vorliegende informative Einverständniserklärung enthält Informationen über die aktuelle Untersuchung (z.B. Ziel und den Zweck). Bitte fragen Sie nach, wenn Sie etwas nicht verstanden haben. Bitte unterschreiben Sie nicht, wenn Sie sich nicht sicher sind, dass Sie alle Aspekte der Studie verstanden haben.

Die Teilnahme an der Studie ist vollkommen freiwillig. Sie können Ihre Teilnahme jederzeit ohne rechtliche oder anderweitige Konsequenzen beenden (siehe Punkt VII. Vertraulichkeitserklärung). Am Ende der Studie erhalten Sie eine finanzielle Aufwandsentschädigung in der Höhe von 20 Euro für ihre Teilnahme *(Da die Aufwandsentschädigung von Dauer und Art der Studien abhängig ist, kann sich diese für die Feldstudien, die eher umfangreich sind, um ca. 20 Euro erhöhen).*

IV. STUDIENBESCHREIBUNG:

Entsprechend der unterschiedlichen Projektphasen werden verschiedenste Studien stattfinden. Im folgenden Abschnitt werden die einzelnen Studien kurz beschrieben. Je nach Studie wird der entsprechende Teil im IC angeführt und je nach Zielsetzung noch genauer ausgeführt.

Studie 1 (Workshops):

Ziel des Workshops ist es, Erwartungen und Bedürfnisse unterschiedlicher Zielgruppen zu erheben, zum Beispiel inwiefern ältere Menschen bereit sind ihr erworbenes Wissen zu teilen und welche Unterstützung sie dabei benötigen. Darüber hinaus wird auch erhoben welche Erwartungen beispielsweise jüngere Menschen an Berater haben. Es werden Szenarien entwickelt, die die unterschiedlichen Perspektiven von beiden Zielgruppen widerspiegeln.

Studie 2 (Interviews):

Im Rahmen des Projekts richten wir uns auch an ExpertInnen, die Wissen und Erfahrung im Bereich Beratung/Coaching haben. Die Interviews zielen darauf ab, Einblick in bewährte Methoden und Vorgehensweisen zu gewinnen als auch mögliche Probleme und wie diese bewältigt werden können zu erfassen. Die aus den Interviews gewonnene Information wird in einem weiteren Schritt für die Entwicklung eines online Fragebogens verwendet, der dazu dient BeraterInnen aus unterschiedlichen Bereichen zu erreichen und vielfältige Einblicke zu gewinnen.

Studie 3 (Umfrage):

Im Rahmen der Online-Umfrage, die wir im Rahmen des ProMe Projektes durchführren, wollen wir untersuchen welche Bedürfnisse die Zielgruppe hat um erworbenes Wissen zu teilen. Dabei sind wir beispielsweise daran interessiert wie viel Zeit man bereit ist aufzuwenden oder mit welcher Motivation Aktivitäten auf der Plattform durchgeführt werden. Darüber werden auch Technologieaffinität und generelles Interesse an neuen Technologien der Zielgruppe untersucht.

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Studie 4 (Design-Workshops)

Mit Hilfe von Design-Workshops werden Themen aus vorangegangen Interviews mit Experten und aus Umfragen und Workshops mit Endnutzern weiter exploriert. Basierend auf den gewonnenen Erkenntnissen zu den Bedürfnissen der Zielgruppen und den Informationen aus Expertensicht sollen erste Design-Ideen für die Plattform entwickelt werden. EndnutzerInnen als auch ExpertInnen und DesignerInnen sind an diesem Prozess beteiligt.

Studie 4 (Evaluierung von ersten Entwürfen):

Zur Evaluierung der Benutzerfreundlichkeit des Systems werden Studien mit EndnutzerInnen durchgeführt. Die einzelnen Komponenten der Plattform werden zunächst auf Basis von Design Sketches (erste Design-Entwürfe), später auf Basis von Prototypen (erstes Modell der Plattform) sowohl in Workshops als auch Nutzerstudien im Labor untersucht.

Studie 5 (Feldstudie):

Schließlich wird die Plattform unter realen Bedingungen im Rahmen einer Feldstudie untersucht. Dabei haben die Zielgruppen die Möglichkeit die Plattform in ihrem Zuhause und mit ihrem sozialen Netzwerk zu testen und zu bewerten.

V. MÖGLICHE RISIKEN:

Es bestehen für Sie keinerlei Risiken, wenn Sie an dieser Studie teilnehmen.

VI. NUTZEN DER STUDIE:

Mit der Teilnahme an dieser Studie und den Beiträgen hinsichtlich der Bedürfnisse und persönlicher Anforderungen werden das Verständnis und das Wissen rund um die Anforderungen älterer Menschen hinsichtlich technischer Lösungen erhoben. Darauf aufbauend kann das im Rahmen dieses Projekts entwickelte System an die erhobenen Ansprüche angepasst und daher leichter verständlich und zugänglicher gestaltet werden.

VII. VERTRAULICHKEITSERKLÄRUNG:

Alle Ihre persönlichen Angaben und die erhobenen Daten werden vollkommen vertraulich und anonym behandelt und werden keinerlei persönliche Identifikationsdaten enthalten. Ihre Identität kann zu einem späteren Zeitpunkt keinesfalls über die erhobenen Daten rückverfolgt werden. Die in dieser Studie gesammelten Informationen werden in Berichten zu diesem Projekt und/oder in wissenschaftlichen Beiträgen in Form von statistischen Auswertungen und/oder Szenarien erscheinen, ohne persönliche Informationen zu nennen. Es wird zu keiner Zeit möglich sein die Quelle der Informationen zurückzuverfolgen:

Österreich: Das „Bundesgesetz über den Schutz personenbezogener Daten (Datenschutzgesetz 2000 - DSG 2000)"

> „Gemäß dem Datenschutzgesetz informieren wir Sie darüber, dass jegliche Art privater Daten, die wissenschaftlich genutzt werden, von der Universität Salzburg derart codiert werden, sodass Ihr Name oder andere persönliche Informationen nicht identifiziert werden können. Die von Ihnen zur Verfügung gestellten privaten Daten werden derart gespeichert, dass nur die Universität Salzburg auf diese Daten Zugriff hat. Private Daten werden nicht an dritte Parteien, die nicht an dem ProMe Projekt beteiligt sind, weitergegeben."

Die Ergebnisse dieser Studie können in wissenschaftlichen Magazinen publiziert werden oder für weitere Studien verwendet werden, immer unter der Gewährleistung der absoluten Anonymität. Das Foto-, Ton- und Videomaterial, das während der Studie erstellt wird, wird in weiterer Folge zu Analysezwecken, zur Erarbeitung der entsprechenden Studien- und Projektergebnisse bzw. zu Marketing-, Werbe- und PR-Zwecken des Forschungsprojektes

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herangezogen. Hierzu können Sie getrennt zustimmen. Auch dieses Material wird anonymisiert (Stimmen und Personen werden unkenntlich gemacht).

Die Teilnahme an der Studie und die Angabe privater Daten ist vollkommen freiwillig. Die von Ihnen erteilte Berechtigung der Nutzung der Daten ist solange gültig, bis dieses Projekt abgeschlossen ist. Bei einem eventuellen Rücktritt können allerdings Daten nur dann aus der Studie ausgeschieden werden, wenn diese noch nicht anonymisiert wurden. Eine Anonymisierung der Daten erfolgt in der Regel im Zuge der Auswertung und ist nur bis zu 3 Wochen nach Abschluss der Studie möglich. Auch bereits publizierte Dokumente oder abgeschlossene Projektberichte, in denen Ihre Daten enthalten sind, können dann nicht mehr verändert werden. Wenn Sie sich zu einem Rücktritt entscheiden, wenden Sie sich bitte an den/die StudienleiterIn.,

Die Entscheidung, die Vollmacht zur Nutzung und Veröffentlichung der entstandenen Daten zu erteilen erfolgt auf freiwilliger Basis. Falls Sie sich dazu entscheiden, Ihre Einwilligung nicht zu erteilen oder von Ihrer Einwilligung zurücktreten, können Sie nicht an dieser Studie teilnehmen.

VIII. EINVERSTÄNDNIS FÜR WEITERE STUDIEN KONTAKTIERT ZU WERDEN:
Gerne würden wir Sie für weitere Forschungsprojekte und Studien kontaktieren. Ihr Einverständnis dazu erfolgt auf freiwilliger Basis. Im Falle Ihrer Einwilligung gehen Sie keinerlei Risiken und Verpflichtungen ein.

Hiermit erteile ich dem/r VersuchsleiterIn und seinen/ihren ForschungsmitarbeiterInnen die Erlaubnis, mich für weitere Forschungsprojekte im Bereich der Informations- und Kommunikationstechnologien für ältere Personen zu kontaktieren.

Datum: ....

Unterschrift: ....

IX. KONTAKTPERSON:
Wenn Sie weitere Informationen bezüglich Ihrer Rechte als StudienteilnehmerIn oder der Durchführung der Studie selbst benötigen, Sie weitere Fragen haben oder Sie während der Teilnahme an der Studie Verletzungen erlitten haben, kontaktieren Sie bitte die Versuchsleiterin:

Human-Computer Interaction & Usability Unit
ICT&S Center, Universität Salzburg
Sigmund-Haffner-Gasse 18
5020 Salzburg

Ansprechperson: Katja Neureiter
Mail: katja.neureiter@sbg.ac.at
Telefon: +43.662.8044.4816
http://www.icts.sbg.ac.at

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X. BESTÄTIGUNG:

Ihre Teilnahme an dieser Studie ist nur dann möglich, wenn Sie diese informative Einverständniserklärung eigenständig unterzeichnen. Wenn Sie das nicht möchten, bitten wir Sie, nicht an dieser Studie teilzunehmen.

Ich habe diese Einverständniserklärung gelesen und ihren Inhalt verstanden, beziehungsweise wurde sie mir klar verständlich vorgelesen. Alle meine Fragen bezüglich der Studie und meiner Teilnahme daran wurden beantwortet.

Bitte zutreffendes ankreuzen:

☐ Ich habe diese Einverständniserklärung gelesen.

☐ Diese Einverständniserklärung wurde vorgelesen von: ....

Meine Fragen wurden beantwortet von: ....

Ich erkläre mich damit einverstanden, dass meine Antworten und Informationen unter den oben erläuterten Bedingungen für wissenschaftliche Zwecke verwendet werden. Ich stimme freiwillig zu, an dieser Studie, durchgeführt von *der Human-Computer-Interaction Unit des ICT&S Centers der Universität Salzburg* und den Mitgliedern des Forschungsprojektes *ProMe – Professional Intergenerational Cooperation & Mentoring* teilzunehmen. Ich habe verstanden, dass ich ein Recht auf eine Kopie dieser Einverständniserklärung habe und bestätige den Erhalt einer unterzeichneten Kopie. Daher wird mir eine Kopie ausgehändigt.

Vor- und Nachname von dem/r TeilnehmerIn (in Blockbuchstaben)

....

Datum / Ort...

Unterschrift..

Vor- und Nachname von dem/r VersuchsleiterIn:

....

Datum / Ort...

Unterschrift..

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XI. NUTZUNG VON FOTO- , VIDEO- UND TONMATERIAL

Als Teil dieses Forschungsprojekts, werden Fotografien, Video- und Tonaufnahmen während der Teilnahme an der Studie erstellt.

Ich erkläre mich damit einverstanden, dass Fotografien, Video- und Tonaufnahmen, die während der Studie erstellt werden, unter den oben erläuterten Bedingungen für wissenschaftliche Zwecke verwendet werden (z.B. für Analysezwecke, zur Erarbeitung der entsprechenden Studien- und Projektergebnisse bzw. zu Marketing-, Werbe- und PR-Zwecken des Forschungsprojektes ProMe zu nutzen). Ich habe verstanden, dass alle Informationen vertrauensvoll behandelt werden und anonymisiert berichtet werden.

Vor- und Nachname von dem/r TeilnehmerIn in Blockbuchstaben

....

Datum / Ort...…

Unterschrift...…..………

Vor- und Nachname von dem/r VersuchsleiterIn:

....…

Datum / Ort...…...………….

Unterschrift...…...……………………

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ANNEX C INFORMED CONSENT THE NETHERLANDS

Toestemmingsformulier

Beste deelnemer,

Deze focus groep sessie wordt uitgevoerd binnen het onderzoeksproject ProMe door het Nationaal Ouderenfonds in samenwerking met de Universiteit van Salzburg. Het onderzoek is gericht op de ontwikkeling van een digitaal platform waarmee ouderen en jongeren hun professionele kennis kunnen delen. Het project bestaat uit zeven partners uit Nederland, Oostenrijk, Roemenië, en het Verenigd Koninkrijk.

De workshop wordt uitgevoerd door het Nationaal Ouderenfonds onder begeleiding van Nina van der Vaart en duurt ongeveer 1,5 uur. Het doel is meer informatie te vergaren over de verwachtingen en behoeften van potentiele eindgebruikers (zowel mentoren als mentees).

Rechten van de deelnemers:

- De deelnemers mogen op elk moment van de workshop stoppen.
- Alle vragen van de deelnemers worden beantwoordt.
- Alle antwoorden zijn vertrouwelijk.

Het materiaal (video, vragenlijsten, etc.) wordt gebruikt voor het onderzoek binnen het ProMe project. Dit materiaal wordt niet buiten het project verspreid en wordt anoniem verwerkt voor mogelijke publicaties.

Met uw handtekening geeft u uw toestemming voor het vergaren van de data binnen de studie met de genoemde doeleinden.

U bevestigt dat u voldoende geïnformeerd bent over het project en dat uw vragen naar tevredenheid zijn beantwoordt. U weet dat u deze sessie op elk moment kunt verlaten.

Plaats en datum:_____

Naam:_____

Handtekening:_____

ANNEX D INFORMED CONSENT ROMANIA

ICT&S Center
Advanced Studies and Research in Information
and Communication Technologies & Society
University of Salzburg

Professional Intergenerational
Cooperation and Mentoring
ProMe

THE GENERAL ASSOCIATION
OF THE ENGINEERS IN ROMANIA

Formular de consimţământ (Workshop în cadrul proiectului ProMe)

Stimate participant,

Studiul este realizat de către Departamentul *Om-Computer, Interacţiune si Aplicabilitate* din cadrul *Centrului de Studii Avansate şi de Cercetare a Tehnologiilor si Societatii Informaţiei si Comunicatiilor, Universitatea din Salzburg*, în cooperare cu *Asociatia Generala a Inginerilor din România*. Acesta se concentrează pe dezvoltarea unei platforme care sa dea posibilitatea adultilor in varsta sa isi impartasesca experienta si cunostintele profesionale. Toate materialele (de exemplu: casete audio sau video), precum şi toate datele suplimentare colectate în timpul studiului vor fi utilizate pentru analiza scopurilor proiectului ProMe şi vor fi interpretate în scopul de a răspunde la întrebări legate de cercetarea care vizeaza obiectivele studiului. De asemenea, datele vor fi utilizate ca baza pentru publicaţii stiintifice.

Toate materialele vor fi folosite numai sub anonimat şi datele primare nu vor fi transmise către terte părţi din afara proiectului.

Prin semnătura dumneavoastră vă dati acordul irevocabil pentru ca toate datele colectate în cadrul acestui studiu sa poata fi utilizate în scopurile menţionate mai sus şi va angajati sa nu ridicati nicio pretenţie faţă de Universitatea din Salzburg şi membrii ei, sau fata de orice alta institutie implicata în proiect.

De asemenea, confirmati că ati fost informat suficient cu privire la proiect, ca s-a raspuns satisfacator la întrebările dumneavoastră şi că ati avut posibilitatea de a abandona participarea în orice moment.

Calea Victoriei 118, Bucuresti, Romania, 25.07.2014

Nume (cu majuscule):

Semnătură: