ICT-PSP Project

# LIFE 2.0

## Geographical positioning services to support independent living and social interaction of elderly people

# ICT-PSP-270965

## WP1 –Analysis

## Deliverable 1.3: Ethical Protocol

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## Approvals

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# Table of Contents

# Section 1 Executive summary

This deliverable describes and discusses the Ethical Protocol of the LIFE 2.0 project. It provides background information on guidelines which we consider are relevant to the research to be conducted in the project[1], and on relevant legislation about privacy and security, which are important aspects of LIFE 2.0. The deliverable then addresses the general terms of the Ethical Protocol for the project that are relevant to the four countries in which research with older people is being and will be conducted in the project. Namely, the rules for informing the users, the purpose of the project, the methods related to users, their recruitment, period of the project, privacy in publication and dissemination of results, and contact details, are described. This is followed by templates of information sheets and informed consent forms, which will be adapted according to the requirements of the research conducted in each site (Barcelona, Aalborg, Joensuu, Milano). Examples of this adaptation are also provided. The annexes of this deliverable are samples of information sheets and informed consent forms used in the original language of each site.

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[1] With older people, but not dealing specifically with health related issues, but with social services provision.

# Section 2 Introduction

## 2.1 The goal of the deliverable and its context

As researchers working with human beings and ICT, we are bound to comply with an ethical code of research to preserve the rights of our human participants. This is especially important in LIFE 2.0, as we aim to promote a better and active ageing through improving existing ICTs, so in order to achieve this objective, we should give special consideration to how we deal with older people and the information they provide us during the project.

In LIFE 2.0, ethics are important to maintain the identity of our participants protected as well as their private information, to manage their information during and after the project and to guarantee their voluntary involvement in the research activities throughout the project. Exceptionally, some of our participants might become so enthusiastically engaged in the research that preserving their personal identity might become difficult, or doing so might limits their participation in the project, which is a positive sign for the research, and we should always support this within the LIFE 2.0 ethical code.

This deliverable presents the ethical protocol of the project. It discusses the background issues that motivate the protocol, together with its specific implementation in each country.

The deliverable has been written when the ethnographical work conducted during the first 9 months of the project has concluded. This ethnographical work was carried out without having discussed and agreed on an Ethical Protocol in advance. Guidelines inspired of those of a UK University department which seemed appropriate for the LIFE 2.0 were circulated by the WP1 coordinator, requesting the partners to follow an ethical protocol, and especially, to inform users about the terms and conditions of their participation in research, and ask them to sign informed consent forms. The partners who conducted the ethnographical research did so, in addition to following their usual ethical procedures, as part of their expertise in user-centred design.

This deliverable provides more detail about the ethnographical work already conducted than the work to be done during the pilot phase of the project, showing the importance of following ethical procedures in the project, even when an ethical protocol did not exist, at least in formal terms.

## 2.2 Some relevant guidelines for ethical research work and some relevant legislation

A number of guidelines have been designed to help researchers to follow ethical procedures in their research involving humans. Let us mention some relevant examples across the EU:

- the FP7 background information provides guidance for proposers[2], contains guidelines related to ethics review, and its check list addresses six issues, *Research on Human embryos/foetus*, *Research on Animals*, *Research Involving Developing Countries*, *Dual Use*, *Informed Consent*, and *Privacy*, the latter two being those relevant to LIFE 2.0. In fact, this deliverable deals mainly with the issue of Informed Consent, while the future D1.4 deliverable will deal with privacy (and also security) issues. There is more extended information[3] available from the FP7 site.

Other relevant sources include:

- The British Psychological Society provides a *Code of Ethics & Conduct*[4].
- The Spanish Association for Human – Computer Interaction (AIPO, *Asociación Interacción Persona Ordenador*) provides an ethical code in usability and Human-Computer Interaction (*Código ético de la investigación en usabilidad e Interacción Persona-Ordenador*[5]); we outline later on the codes of conduct of Àgora, a partner in

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[2] http://cordis.europa.eu/fp7/ethics_en.html

[3] http://cordis.europa.eu/fp7/ethics-ict_en.html

[4] http://www.bps.org.uk/sites/default/files/documents/code_of_ethics_and_conduct.pdf, last visited October 18, 2011

[5] http://usuarios.lycos.es/savonasacj/codigo_etico_AIPO.pdf, last visited October 18, 2011

LIFE 2.0. The Spanish relevant legislation about privacy issues is the law of protecting personal data (*Ley Orgánica de Protección de Datos de Carácter Personal*, BOE 298, 14/12/1999, Sec 1 pp. 43088 - 43099).

- In Denmark, the reference guidelines that can be used in the project are the personal data protection guidelines (*Sammenskrevet udgave af persondataloven*[6]) and the guidelines of the Danish Ethical Committee (*Høringssvar og udtalelser fra Det Etiske Råd*[7]). We discuss later on more detail about the specific details of legal regulations of Denmark.
- In Finland, a national advisory board on Research Ethics was founded in 1991 to deal with ethical questions and advances related to scientific research. The *Act about National advisory board on Research Ethics* (1347/1991) is available in the national legislative database[8]. The national advisory board for Research Ethics has published guidelines to conduct ethical research: *Good scientific practice and procedures for handling misconduct and fraud in science*[9]. One reference from other Finnish guidelines providers is The Office of the Data Protection *Ombudsma*, which is an independent authority operating in connection with the Ministry of Justice[10]. The Objective of the Office is to maintain and promote the right to privacy.
- In Italy, the *art.13 D. Lgs. 196/2003* about personal data treatment is key in the legislation protecting privacy issues in the participation of human beings in research activities.

## 2.3 The context of the different sites

The fine details of already existing ethical procedures in Barcelona (Spain), Aalborg (Denmark), Joensuu (Finland), Milano (Italy) are described next.

Àgora (in Barcelona) is an adult education centre involved in the project as a partner. A group of 20 older people are already involved in the research in LIFE 2.0, as well as in the centre, which is constantly seeking to get older people involved in the activities organised in the centre. Àgora draws on three key documents to run the centre and guarantee ethical issues in all the activities conducted in it: Declaration of Rights of the Participant Persons (*Declaració dels Drets de les Persones Participants*[11]), Ethical Code for a Democratic Education of Adult Persons (*Codi Ètic per una Educació Democràtica de Persones Adultes*[12]), and Ethical Code of the Associations of Barcelona (*Codi Ètic de les Associacions de Barcelona*[13]). These documents are available at the Àgora's web site. UPF is also heavily involved in user centred research in LIFE 2.0. UPF researchers (details provided later on) will attend Àgora twice per week (at least) in order to carry out field activities and to maintain participants' information of the evolution of the project. Researchers will initially be introduced in the "environment" by Àgora representatives, who are well-known people for our older people participants. We expect this will help UPF researchers to become known and integrated members of Àgora. There are two other project participants for the Barcelona location, ALU and i2CAT, which will be involved in some parts of the research, but will not usually be involved in regular contact with users.

In Aalborg, the municipality (AAK) and the university (AAU) are partners in the project and involved in dealing with users; participants will be mostly recruited through Aalborg

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[6] http://www.datatilsynet.dk/lovgivning/persondataloven/ and http://www.datatilsynet.dk/lovgivning/vejledninger/
[7] http://etiskraad.dk/Aktuelt/Hoeringssvar-og-udtalelser.aspx
[8] http://www.finlex.fi/fi/laki/alkup/1991/19911347 (in Finnish)
[9] http://www.tenk.fi/en/good_scientific_practice/Hyva_Tieteellinen_ENG.pdf
[10] http://www.tietosuoja.fi/1560.htm
[11] http://www.edaverneda.org/fitxers/declaracio_drets.pdf
[12] http://www.edaverneda.org/fitxers/codietic.pdf
[13] http://www.edaverneda.org/fitxers/ce_decaleg.pdf

Kommune, at *Kastanjegaarden*, which is an activity and training centre in Frejlev, which will be a central point, both for the ethnographic work already undertaken and for the pilot to be carried out during the second stage of the project. Participation of other older people who are not taking part regularly in activities of the training centre will be sought. Both AAK and AAU are involved in user centred activities and must follow the ethical protocols in dealing with users as part of these activities.

In Joensuu, Joensuun Kaupunki has been working with older people for years, and will be taking care, in collaboration with the other Joensuu partners, of the older people participants in the research. It will follow ethical protocols, which were established and followed in past research activities.

The Politecnico di Milano members, with the support of FHS, will be dealing with the older people participants in the research in Italy. They will comply with the ethical protocols based on respecting needs, uses and capabilities of the users as all their work is based on users' participation.

## 2.4 The role of the Ethical Protocol and modification or extension procedures

The Ethical Protocol of LIFE 2.0 has been created using general guidelines and local practices; it reflects different approaches, which depend on the constraints imposed by legislation in each country, and ethical codes of the research and end-user group partners.

The role of the Ethical Protocol is to ensure that the project is developed conforming to the ethical procedures. By formulating the Ethical Protocol in this deliverable, it is formally approved by the whole consortium, and it constitutes the foundation of the protocol.

Extensions or modifications related to the Protocol might be necessary as the project progresses. The editor of the deliverable (Josep Blat – UPF) will (i) receive proposals for extensions or modifications, (ii) review them, and, with the Project Coordinator (Neeli Prasad - AAU), (iii) submit them for formal approval of the LIFE 2.0 General Assembly. The eventual modifications or extensions approved will be included in a new version of the document, as annexes, to ensure that changes are properly recorded.

## 2.5 Summary of the deliverable content

The Ethical Protocol contains the protocol for dealing with users in detail; the different criteria for informing them about the goals of the project, the research methodologies, and the key researchers they will deal with. This protocol, which, in some cases, will probably need to be submitted to specific ethical committees, either within the institution or outside it, will depend on the site where the research will be conducted. This is presented first in the general terms of the whole project; and the specifics of the different sites are provided next.

The general aspects of the project as related to the users are presented next.

## Section 3 Ethical Protocol: general aspects

Inspired by the guidelines outined above, and by taking into account the local legislation, the Ethical Protocol should describe in detail the project itself, its methods and techniques in terms of how they relate to the users, and the procedures for informing them about their participation in research activities. In some cases, this protocol should be submitted to appropriate committees, as we have discussed in Section 2.

In this section, we describe the main aspects of the Ethical Protocol of LIFE 2.0 that we consider applicable to the whole project. We then show the information content forms which were provided to the participants during the ethnographical research. More details on the protocol on each site and the information provided in them are discussed in later sections.

We firstly discuss the general procedures for informing the participants, as the informed consent is crucial in an ethical protocol. The general procedures are followed by a subsection on information about the project, related to the users' participation in the research. Next, the methods and techniques of LIFE 2.0 related to the users are introduced, in general and with some specific aspects in each site. This is followed by the users' recruitment strategies. Finally, there are two formal subsections: start and duration of the project, and key responsible personnel, for the project and for each site.

### 3.1 Procedure for informing participants

The **protocol** describes the LIFE 2.0 objectives, design, methodology, and ethical considerations. This is to be followed when dealing with the participants and must include:

- A description of the written information provided to the project participants.
- A description of the procedures used by researchers to communicate oral information to participants.
- The declaration of consent for participants,
- Any advertising material used in recruiting participants.
- A description of the questionnaires and assessments that will be used.
- Other relevant materials including some aspects of the procedures to protect the privacy.
- The persons in the project who are contact points to end user participants and their contact information given to the participants.

Regarding the second item of the previous list, there are additional guidelines to follow when communicating oral information to participants, which are to be included in the protocol documents. These guidelines are for the project partner who communicates the information to the participants, describing which information is necessary to be communicated as well as how. These guidelines include:

- Who is providing the oral information (responsible partners or consultants, credentials or training required, etc.).
- How contact with participants is made (how they will be approached to participate).
- How follow-up contact will be conducted.
- How to ensure that the information sessions/interviews are undisturbed and how to proceed if disruptions occur.

The written information that participants are given (in paper or electronic form) will need to include some important information. This includes:

- Statement regarding participation in the research processes.
- The purpose, methods and scope of the research project clearly defined.
- Any foreseen risks, side effects, inconveniences occurred due to participation in the research, as well as predicted benefits for participation in the research, with a clear distinction of benefits for different stakeholders as well as for science, and circumstances which could result in a participants' exclusion from the research trial,

circumstances in which the trials would be discontinued and how to proceed in these situations.
- How data will be kept secure and private during the collection and use of information during the project.
    - What will be done with the collected data once the project ends.
    - How long data will be stored.
    - Who will be viewing and assessing data during the project.
- Where participants can obtain additional information on the project, including contact persons.

Written information given to participants should include: Heading, introduction, purpose, benefits, side effects, stress, risks, complications and inconveniences - preferably listed, exclusion and discontinuation, plan, contact person, information about financial matters, access to results, conclusion that requests the person to decide on the participation.

Furthermore, there are guidelines set in place to assist during the information to participants, when participants have expressed interest but have not yet signed consent forms. These guidelines are:

- The information will be planned so that the potential participants have sufficient time to absorb the information, reflect and ask questions.
- The information consists of an understandable presentation of the research project without using technical terms and communication is adjusted to the individual in terms of age, maturity, experience, etc.
- The information will include details on any foreseeable risks, side effects, complications and inconveniences.
- The information will include details on circumstances about which the potential participant is believed to be unaware, but which are important to the participant's decision.

When the information has been completed, there are guidelines to follow in keeping end users/participants informed on any changes that may affect them during the project research. These changes include:

- If new information is available regarding the risks, side effects, complications or inconveniences to be occurred.
- If the research design is altered, particularly if this is in relation to the person’s safety.

## 3.2 Purpose of the project

The LIFE 2.0 project aims at generating new opportunities for local interaction by creating new services for elderly people, based on the use of tracking systems. The objective of the project is to build product-service solutions that increase the opportunities for a) social contacts between elderly people in their local area, b) acquiring knowledge about people living in the areas and events occurring close by, c) getting knowledge about commercial services and assistance available in their area and d) offering their residual capabilities and skills to friends, family and other people of any age, living in their area.

The project team will work in collaboration with elderly people and with local senior services (such as activity centres) in well-defined areas. The project activities will consist in a series of rapid prototypes of solutions (services and products) that will be proposed to people living in those areas, tested and implemented with their collaboration. The prototypes will be generated in workshops involving all the members of the consortium and will be periodically evaluated by an evaluation panel, including elderly people associations, experts, companies and academic personnel, who will follow the development of such rapid prototypes towards economically feasible and socially desirable solutions.

## 3.3 Brief description of methods and measurements

One of the methods carried out in LIFE 2.0 is the *Ethnographic analysis on elderly people's independent life*. This analysis, undertaken in T1.1, will be based on on-site ethnographic observations of elderly people, their relatives and any other actors involved in their daily life – these three types of users are LIFE 2.0 users. Ethnographic techniques will be used, observing actors in their routine and their life context and involving them in the interpretation of data, the identification of critical needs and the definition of workable scenarios for the prototype phase. While this activity formally lasts for the first 9 months of the project, it is expected to be continued in a more informal way. Another technique involving users in the initial 9 months of the project will be *workshops involving users* for scenario building, use cases and requirements elicitation, and for the validation of scenarios and business framework; there will be local workshops, followed by a general one. These activities are part of T2.1 and T2.2.

When the LIFE 2.0 pilot is ready, it will be running for a period of 12 months after the installation and till the end of the project. In this period, the consortium will support technically elderly people, their families and caregivers. During this period *data will be collected*, for instance, related to users' routines and variations, attitudes about the use of technologies, innovative uses, users' opinion about the services, related problems and opportunities deriving from the use of the services. The collection of data will be done through video observations, situated interviews and cultural probes. A midterm workshop will involve users as well.

The expected number of users is around 50 (including 20 elderly people, 20 for the social circles – relatives and friends, and 10 caregivers) at each site, making a total of some 200 users.

Let us provide more details for each of the sites.

**Barcelona**

At the moment of writing this deliverable, the ethnographical study had already been conducted. In Barcelona, it consisted mainly of *in situ* observations and conversations with around 75 older people while using several ICTs. These fieldwork activities were conducted in Àgora's computer room; they started in December 2010 and they will be continued for the entire duration of the project. Focus groups to elicit everyday life stories were also conducted, as well as participatory design workshops to elicit ideas for LIFE 2.0 services and participants were asked to fill-in semi structured diary to describe their daily activities. Very detailed information is provided in D1.1.

For the pilot phase, during the testing of the services, in-situ observations in Àgora, while users interact and use the LIFE 2.0 service, will be carried out. Training lectures, workshops and focus groups will also be conducted to understand the attitude of older people towards the service. During these activities fieldnotes of observations and conversations, as well as pictures will be taken.

**Aalborg**

The ethnographic activity was articulated in workshops and focus groups, geographically based at the *Kastanjegaarden* training centre in Frejlev (which will also be a reference point for the pilot) and at Aalborg University. More detailed information on the activity is provided in D1.1.

The pilot phase will involve around 20 people between 65 and 75 years old (mostly among those who participate to activities at the Aalborg Kommune, at the *Kastanjegaarden* activity and training centre in Frejlev), 20 family members or friends, and caregivers or employees from Aalborg Kommune, *Ældre og Handikapforvaltning*. Control groups of older people, and of family and friends will be created. The activities of the pilot phase will be those described in general terms above.

**Joensuu**

The details of the ethnographic activities in Joensuu were provided in D1.1. For the pilot phase JK will conduct up to 10 semi-constructed diaries (self-documentation method), which will be independently written by older people about their everyday situations and interactions in a week period (inside and outside their homes, without researchers presence). The diaries creation will be discussed in meetings with researchers. The self-documentation period is started with guidance and after the week period the writings will be deepened by means of interviews. Both guidance and interviews will be conducted at participants' homes. The interviewers will record audio and write notes. The results will be refined in a workshop with (partly the same and partly new) participants and professionals with social, health and technological expertise.

**Milano**

Politecnico of Milano, in collaboration with FHS, developed a set of tools to develop the ethnographic study involving users (both men and women, all married and with an independent living style), namely a questionnaire, a diary, maps and a contextual interview. More details are provided in D1.1.

Politecnico of Milano, in collaboration with FHS, will prepare 10 diaries to be completed individually by users in their everyday activities, at their own home and/or outside, depending on where the activity will take place. Then the Politecnico researchers will conduct semi-structured interviews on the basis of the written materials by users (including pictures), after a training session period about the right use of devices made by researchers at users' home or in the university laboratories. Finally, researchers will analyse all the documentation in a workshop with users and with expertise from different areas (technology, social, design...). FHS will support Politecnico during the pilot phase.

### 3.4 Participants: recruitment methods, number, age, gender, exclusion and inclusion criteria

As we indicated previously, the users participating in LIFE 2.0 are mainly *elderly people living independently*. We regard elderly people in this project as individuals aged 65 and above. We do not target at other older people who experience serious declines in functional abilities that prevent them from enjoying an independent life (this will be an exclusion criterion): our participants will have the normal impairments (in vision, dexterity, etc.) related to ageing. As social life is important, we address as well *relatives of elderly people*, who are key members of the social circles, and who often struggle to take care of their older relatives in their everyday life. Other stakeholders we address in LIFE 2.0 services are *assistants and service providers*.

As indicated earlier, a target reference is 20 elderly participants per each of the four sites excluding relatives, friends and caregivers, with a gender balance. Their recruitment is locally done and explained in a later section.

### 3.5 Ethical considerations raised by the research and how to deal with them

I) **The participants do not want the researchers to take photos**. The researchers will not take photos of these participants.

II) **The participants allow the researchers to take photos but do not allow them to use the photos in publications or meetings**. Photos will only be used for analysing the material.

III) **A participant started in the project but decided to stop from being involved in it**. The material gathered from that participant will be used in the project provided that the participant does not withdraw permission for us to do that (see Informed Consent). Any participant can leave the project at any time, since their participation is voluntary.

IV) **Private information about the participants**. We will ensure that no reference to the participants' identity is made in any publication of the project.

V) **Debriefing of participants.** At the end of the in-depth interviews, focus groups, and design workshops, the researcher will read out the main results and ask the participants to agree on them. If the participants do not agree on the summary of results, the researcher will amend the summary until all participants agree on it.

VI) Any issues not covered here will be dealt with following the same principles inspiring the previous points.

## 3.6 Start date and duration of the project

The project will last for 3 years starting in November 2010. There will be research involving users (older people and stakeholders) throughout the project, with special activity related to ethnographical observation, participatory design of the services and platform, and testing of the services and platform. More detail about the timing of those activities has been already provided, and is recalled here. Ethnographic observation will be carried out mainly during the first 9 months of the project – although will continue throughout it - and participatory design will also be part of the initial period. After installation of service prototypes (around month 15 in the project) it is expected that testing will be lasting for one year, perhaps extending till the end of the project life.

## 3.7 Key researchers involved, responsible, and contacts

The *Coordinator* of the LIFE 2.0 project is Neeli Rashmi Prasad (CTIF-AAU); *Technical Coordinators* are Nicola Morelli and Rasmus H. Nielsen, both AAU; and *Quality Manager* is Albena Mihovska (CTIF-AAU).

The key researchers of the different sites are:

1) At the UPF, Professor Josep Blat, DTIC, Universitat Pompeu Fabra, C/ Tànger, 122-140 (room 426), josep.blat@upf.edu

2) At Aalborg, Neeli Prasad, Nicola Morelli, and Rasmus Nielsen

3) At Joensuu, Mirja Kälviäinen (NCP), Mirja.kalviainen@pkamk.fi, gsm: +358 407 0196

4) At the Milano site, for Politecnico, Francesca Rizzo, francesca.rizzo@polimi.it, Office phone: +39 02 23995871; Mobile phone: +39 338 9023959

## Section 4 Information for participants common to all sites

This section provides the template to be followed for the information for participants at all the four sites of the project.

### 4.1 Aims and general description of the project

LIFE 2.0 is a partially funded European project that aims to enhance the network of social interaction of older people within a local community, by providing them a set of personalized ICT based services. For its success, the project should involve users (older people, their relatives, social services). LIFE 2.0 proceeds in several steps.

The first phase consists of gathering information on everyday routines of older people in their social environment and their attitudes and interaction barriers.

The project will then proceed to define, through participatory activities, and then implement a set of services, including geolocalisation, aimed at addressing the needs emerged in the previous phase.

The implemented services will be tested by older people, their caregivers and their family members, in real setting such as their homes or several social centres in their neighbourhoods. The overall duration of LIFE 2.0 project is 36 months: November 2010 – October 2013, but the LIFE 2.0 services are aimed at being used also after the end of the project.

### 4.2 Your role in the project and how we will use your information

During the first 9 months of the project the research team will be gathering information, through interviews, discussion, diaries of the daily life by users, observations of activities, or discussion groups with different activities.

The research team will be collecting notes, results of these activities, in some cases recording audio and/or video or pictures, during this phase and for the duration of the project.

The information will be used to understand how to create services supporting a more intensive social interaction for an active ageing.

During the design of the services, participation in workshops to support or validate its design will take place.

During the pilot phase, the services will be installed in PCs and other devices that will be used by older people participants in the activity, and by relatives, and people from social services. The devices will be provided for free by the project. Participants will follow some training activities, and afterwards they will carry out some specific tasks, such as keeping diaries for some periods, interviews with researchers about the use of the services, and some discussion groups. The information will be used to evaluate the usefulness and usability of the services, as well as the potential evolution into products.

### 4.3 Your privacy and participation

Your name will not be used in conjunction with photographs or any material in publications and/or presentations.

All the information that you give the researcher will be stored securely and kept separate from any information you provide about your identity. Access to your data will be restricted to the people involved in this research, who will be REPLACE BY APPROPRIATE NAMES OF PEOPLE. If information about you is used for publications or presentation, we will ensure that no reference to your identity is made.

Your participation in this study is voluntary. You can withdraw from the study at any time without penalty or giving reasons. No undue risk arises from the participation in this study.

## 4.4 Debriefing

At the end of the RESEARCH ACTIVITY, NAME OF THE RESEARCHER will read out the main results and ask you to agree on them. If you do not agree on the summary of results, HE OR SHE will amend the summary until you agree on it.

You will also be invited to a debriefing session where RESEARCHERS will summarise the results of the research.

## 4.5 Consent form

You will be asked to sign a form saying that you are willing to participate in the study. The consent form will explain what will be asked and what will happen to any information that is collected. You will be given a copy of this form to keep.

If you would like to know more about this research and/or you have questions that cannot be answered by the researcher, please feel free to contact the principal investigator, ADD APPROPRIATE NAME HERE.

# Section 5 Informed Consent Form

The model of the Informed Consent Form is the following one.

**Informed consent statement for participation in research project**
Research project title: LIFE 2.0

**Declaration from the trial participant**
I have read this consent form. I have had the opportunity to discuss this research project with project staff. I have had my questions answered in a language I understand and the risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statement or implied statements. Any relationship (such as employee, student or family member) I may have with the study team has not affected my decision to participate. I have received written and oral information and I know the objectives, methods, advantages and disadvantages of my voluntary participation.
I understand that my participation in this project is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.
I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of my data by the partners in the LIFE 2.0 project (AAU, JK, POLIMI, UPF, AAK, TIS, I2CAT, ALU, NET TECHNOLOGIES BULL, FHS, CG, AGORA – see more information on the web of the project, http://www.life2project.eu/).
By signing this consent form, I have not waived any of the legal rights that I have as a participant in a trial study.
I give my agreement to participate in the project LIFE 2.0 and have received a copy of the written information about the project for my personal records.

Participant's name:
Date: Signature:

Do you wish to be informed about the results of the research project?
Yes No

# Section 6 Specifics of the Ethical Protocol in each of the sites

This section contains specific aspects of the Ethical Protocol at the different sites.

## 6.1 Barcelona

### *6.1.1 Participants: recruitment methods, number, age, gender, exclusion and inclusion criteria*

Seventy-five older people, among Àgora's participants, took part in the ethnographical study. Among these 75 participants, around 20 persons were asked to participate in activities such as focus groups and workshops. These 20 persons were selected based on their demonstrated interests in the LIFE 2.0 project. *Our preference went for seniors physically and mentally healthy and that can live independently at their homes*. Since we will carry on activities in Àgora throughout the duration of the project, we wish to involve an increasing number of participants and to have contact with family members of some of them.

In the pilot phase we will recruit people who participated in previous LIFE 2.0 activities as well as other persons who were less involved. Participants will be asked to invite their friends and family members. We will make informative sessions and training classes to support the use of the service. All people who own a PC will be invited to use the service. Additionally, we will select a group of people that will be provided with the devices bought by the consortium members (e.g. set-top-boxes, tablets).

Some representatives of the social service promoters of the local area will be also invited to use the service.

### *6.1.2 Key researchers involved, responsible, and contacts*

Professor Josep Blat, DTIC, Universitat Pompeu Fabra, C/ Tànger, 122-140 (room 426), josep.blat@upf.edu, 93 542 2172, is the principal investigator. The PhD students Valeria Righi (righi.vale@gmail.com), Susan Ferreira (susanferreira@gmail.com) and Andrea Rosales (andrucha@gmail.com) are involved as well. Dr Sergio Sayago, a postdoc at the School of Computing, University of Dundee, who was previously at the UPF and Àgora (sergiosayago@computing.dundee.ac.uk) is helping too.

### *6.1.3 Information Sheet for participants (translated and adapted)*

#### *6.1.3.1 Aims and general description of the project*

LIFE 2.0 is a partially funded European project that aims at enhancing the network of social interaction of older people within a local community, by providing them a set of personalized ICT based services. The project will proceed in several steps.

The first phase will consist of gathering information on everyday routines of older people and their attitudes and interaction barriers with technologies addressing issues such as: Who are the most relevant actors in elderly people independent life? How is their daily life organised? What are their most relevant interactions, how and when they take place? What kind of knowledge and familiarity do they have on the technologies and services used in the project?

The project will then proceed to define, through participatory activities, and implement a set of services aimed to address the needs emerged in the previous phase. The implemented services will be tested by older people, their caregivers and their family members, in real setting such as their homes or several social centres in their neighbourhoods. The overall duration of the LIFE 2.0 project is 36 months: November 2010 – October 2013, but the LIFE 2.0 services are aimed at being used also after the end of the project.

#### *6.1.3.2 Your role in the project and how we will use your information*

The research team will take notes of their first-hand observations and informal conversations with you while you are attending classes in Àgora[14]. A member of the research team might take photos and/or make photocopies of the artefacts ('things' created by you or that you use when you are learning and using ICT, such as paper notes) and also photos of how you use these artefacts while you are learning and / or using ICT throughout the study. You will be asked to participate in one or more discussion groups consisting in informal conversations about your daily life routine, together with other 4 or 5 participants, with Maria Angeles Serrano (Àgora) and with another member of the research team. They will last up to 1 hour each, take place in Àgora, and the first one will be carried out between December 2010 and January 2011. The researcher will take notes during the interview and use a video camera to record the session to help him/her to analyse the information you provide him/her. We will arrange the best date and time for you to come along and participate.

Between March and May 2011 you will be asked to participate in workshops to discuss ideas for the LIFE 2.0 services to be used in your neighbourhood. This activity will be conducted in groups of up to 10 participants and will last up to 90 minutes. We will ask you to comment ideas and suggest new ones accordingly to your personal opinion. A representative from Àgora and members of the research team of UPF will participate at the activity.

Between February and March 2011 you will be asked to fill a diary with the activities that you conduct daily for one week, inside or outside your home.

From December 2011, and for over a year; you will be asked to test several versions of LIFE 2.0 services giving us your opinion. You will have the possibility to participate in training sessions in which the research team will show you how to use these services and devices. You will be asked to access these services using your own PC or through the PCs in Àgora. Perhaps you will be provided with specific devices (e.g. TV, tablets) that you are allowed to carry with you or to install at your home. During the activities the researcher will take photos on your participation in the session and take notes of your comments and opinions.

#### *6.1.3.3 Your privacy and participation*

All the information that you give to the researchers will be stored securely and kept separate from any information you provide about your identity. Access to your data will be restricted to the people involved in this research, who will be Dr. Josep Blat, Dr. Sergio Sayago, Valeria Righi, Susan Ferreira and Andrea Rosales (from the Universitat Pompeu Fabra and University of Dundee), and Maria Angeles Serrano (from Àgora).

All the information you provide us in the project will be analysed and used for defining the services to implement in the LIFE 2.0 project, as well as for writing scientific reports and research papers that will emerge from the project.

Your name will not be used in conjunction with photographs or any material in publications and/or presentations.

Your participation in this project is voluntary. You can withdraw from the study at any time without penalty or giving reasons. No undue risk arises from the participation in this study.

Although we will not be able to give you any financial reward, we will invite you to drink coffee, tea and eat delicious biscuits during the length of the study.

#### *6.1.3.4 Debriefing*

At the end of the interviews or workshops, a researcher will read out the main results and ask if you agree with them. If you do not agree on the summary of results, the researcher will amend the summary until you agree on it.

You will also be invited to debriefings session where we will summarise the results of the project.

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[14] such as drop-in and hands-on sessions.

### *6.1.3.5 Consent form*

You will be asked to sign a form saying that you are willing to participate in the study. The consent form will explain what will be asked and what will happen to any information that is collected. You will be given a copy of this form to keep.

If you would like to know more about this research and/or you have questions that cannot be answered by the researcher, please feel free to contact the following person: Professor Josep Blat, DTIC, Universitat Pompeu Fabra, C/ Tànger, 122-140 (room 426), josep.blat@upf.edu, 93 542 2172. You might also contact: Valeria Righi, (righi.vale@gmail.com); or Susan Ferreira (susanferreira@gmail.com).

### *6.1.4 Informed Consent Form (translated and adapted)*

This **Informed Consent Form** is for a study that forms part of the LIFE 2.0 project, commissioned by European Union, in which Universitat Pompeu Fabra and *Escola d'Adultos Àgora Edaverneda* are taking part.

A team of researchers from UPF will conduct this study with the support of Maria Angeles Serrano from Àgora school. You can read more information about LIFE 2.0 project on this web page: http://www.life2project.eu/

This form contains information on the general procedure and conditions of the study.

Dear Participant:

Thank you for your interest in this study. This document describes what you will be asked to do for the study. This document also details the permissions we would like you to give us. Please read through it and then sign at the bottom to say that you understand and accept the conditions of this study. If you have questions, please feel free to ask Maria Angeles Serrano or any members of the research team.

1) You give permission to the **researcher to take notes** of his first-hand observations and conversations with you while you are using ICT in classes of Àgora throughout the study.

2) You give permission to the **researcher to take photos and / or make photocopies of the artifacts (**things created by you or that you use to help you learn and use ICT, such as paper notes) in Àgora throughout the study.

3) You give permission to the **researcher to take photos of you using the material in 2)** throughout the study.

4) You agree to take part in 1 **discussion group** about you daily routines. This activity consists in informal conversations about your daily life routines, and it will be conducted in group with other 4 or 5 participants that you know or feel confortable with. This conversation will be carried out with Maria Angeles Serrano and with other members of the research team. The discussion group will last up to 1 hour, take place in Àgora, and be carried out between **December 2010** and **January 2011**. The researcher will take notes during the interview and use a video camera to record the session to help him/her to analyse the information you provide him/her.

5) You agree to take part in **workshops** in which you will be asked to discuss and comment several scenarios of use of the service. This activity consists in informal conversations in a group of up to 15 participants that you know or feel comfortable with. The conversation will be carried out with Maria Angeles Serrano and with other members of the research team. The discussion group will last up to 2 hours, take place in Àgora, and be carried out between **March 2011** and **June 2011**. The researcher will take notes and photos during the session.

6) You agree to participate in **evaluation sessions** during which you will be asked to use and to evaluate prototypes created during this study. This activity might require you to take devices with you at home and use them during an extended period. This activity will be carried out from **February 2012** until the **end of the project**.

7) In case of damages of the devices, that might be caused during 6), you are required to report the problems to Maria Angeles Serrano or member of the research team. Under no circumstances you will be asked to pay for the damages.

8) During 6) members of the researcher team and technological partners of the consortium will monitor your activities with the devices, in order to gain information on possible software problems.

9) You agree to take part in **discussion groups** about the services that you will use in 6). This activity consists in informal conversations in a group of up to 10 participants that you know or feel comfortable with. The conversation will be carried out with Maria Angeles Serrano and with another member of the research team. The discussion group will last up to 2 hours, take place in Àgora, and be carried out between **March 2011** until the **end of the project**. The researcher will take notes and photos during the session.

10) You agree to participate in **training sessions** in which the researcher team and Maria Angeles Serrano will show you how to use the prototypes described in 6). This activity will take place in the Àgora's computer room and it will consist of 2-hour sessions that will be carried out once per week from **October 2011** until the **end of the project**.

11) You give permission to the researcher to use their notes, photos and other material you might provide them throughout this study in **scientific papers, technical reports and presentations** that will emerge from their work.

Maria Angeles Serrano will contact you to know the best date and time for you to participate in these activities. Your participation in this study is voluntary. You can leave the study at any time without penalty or giving reasons. No undue risk arises from the participation in this study.

All the information that you give to us will be stored securely and kept separate from any information you provide us about your identity. Access to your data will be restricted to Dr. Josep Blat, Dr. Sergio Sayago, Valeria Righi, and Sussan Ferreira (from Universitat Pompeu Fabra) and Maria Angeles Serrano Angeles Serrano (from Àgora). Your name will not be used in conjunction with photographs or any material in publications and/or presentations emerging from this project.

We are very grateful for your help. It is important that you understand that this research would not be possible without your participation. We hope that your contribution and our work can help to make ICT easier and more enjoyable to use by (older) people. Although we will not be able to give you any financial reward, we will invite you to drink coffee, tea and eat delicious biscuits during the length of the study.

Please date and sign this page below to indicate that you understand and accept the conditions of this study. Thank you very much.

Signature of the participant Signature of the researcher

## 6.2 Aalborg

### *6.2.1 Specifics of the Danish legislation*

According to Danish law[15], all research projects in Denmark involving human beings or any kind of human tissue, cells, etc. need permission from the proper regional ethics committee. The Danish Research Ethics Committee (REC) became a legal committee in 1992. Following the Helsinki II declaration of the World Medical Association (1975), an agreement was made between the Danish Medical Association, the Association of Danish Counties, the Danish Medical Research Council, and others to establish a REC system. In Denmark, all biomedical research projects must be submitted for approval; it is illegal and punishable by up to four

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[15] http://www.cvk.sum.dk/English/actonabiomedicalresearch.aspx

months in prison to begin a biomedical research project without REC approval, as clearly defined in Paragraph 6 of the law. This board should also be contacted about research based in other countries, if the study includes Danish participants. Other research based outside Denmark should seek approval from a relevant committee in the county where the study is based.

If the study is a biomedical project and based at Aalborg University, the applicant must seek ethical approval from the Regional Ethics Board of North Jutland. *Biomedical* should be interpreted broadly to include interventional studies, diagnostic studies involving some kind of bodily intrusion, studies that involve the use of drugs, health-related epidemiology, health-related sociology, and all projects were the participants are studied because they are or have been patients. If the research project falls outside the legal definition of a biomedical research project, it does not need REC approval; similarly, a REC can determine that a project falls outside the scope of biomedical research. In addition, certain projects, depending on the nature and content, need REC approval as well as approval from other bodies before they can begin. Some data-related provisions for the user are:

- information about you, including information about tissue and blood samples from you, will be stored according to the provisions specified in the Danish Act on Processing of Personal Data and the Health Act;
- you will be able to get access to research protocols according to the provisions of the Danish Open Administration Act. This means that you can gain access to all documents concerning your participation in the project apart from the parts containing business secrets or confidential information about others.
- you have the right to complain and compensation can be paid pursuant to the Act on the Right to Complain and Receive Compensation within the Health Service.

(*The above is published by the Danish National Committee on Biomedical Research Ethics*[16] *and is an example of content that must be attached to the written information about the biomedical research project*). One of the investigators of the research project must apply for permission from the North Jutland research ethics committee, and the application should conform with the *Guidelines about notification of a biomedical research project to the committee system on biomedical research ethics*. The investigator shall use an electronic application form[17] and send the application on paper as well as in electronic form. In the case of multi-national projects, permission from a Danish committee is always required. The REC will review the application only once it is complete and valid. This means it must include:

- Application form.
- The clinical trial protocol.
- Subject information and the informed consent procedure.
- A short resumé in lay terms.

Furthermore, it must be submitted all in Danish language, including the clinical trial protocol. If an application is rejected, the investigator can appeal to The Danish National Committee on Biomedical Research Ethics. Further information can be found at: *Den Centrale Videnskabsetiske Komité*[18] (The Central Scientific Ethical Committee).

On request of the consortium, the REC confirmed that the LIFE 2.0 project falls outside the scope of biomedical research and does not need REC approval. A notification will be sent to the committee, that will explain all the ethical issues related to the project and the way privacy, time and information issues will be handled. On the other hand, projects that involve establishing a database or register containing person-identifiable information need approval from the Registry Authority (*Registertilsynet*) and should establish data-protection provisions.

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[16] http://www.cvk.sum.dk/English/rightstrialsubject.aspx

[17] http://www.drvk.dk/anmeldelse

[18] http://www.cvk.sum.dk/CVK/Home/English.aspx

### 6.2.2 Participants: recruitment methods, number, age, gender, exclusion and inclusion criteria

*Ethnographic phase*

All participants have been recruited from the pilot site in Frejlev, Aalborg, where an activity and training centre for elderly has functioned as context and meeting point. The criteria for participation in the project have been focusing on that the seniors are physical and mentally healthy and that they, across the group of users, represent a broad example of what a senior is in the society of Denmark in 2011.

| **Average age** | 67 |
|---|---|
| **Gender** | |
| F | 8 |
| M | 5 |
| **Living** | |
| Suburban living | 7 |
| Urban living | 2 |
| Country living | 1 |

*Pilot phase*

The participants will mainly live in the Aalborg South-west area. Participants will be mainly recruited among people that attend activities in the activity and training centre of *Kastanjegaarden*. Other participants will be recruited, that may not be frequent visitors of the centre, but are somehow connected with the centre or with the other users.

Participants will also be requested to provide indications about family members and friends that can participate to the pilot.

It is assumed that at least 40% of the participants have a computer or any access device at home that allows them to access to LIFE 2.0 services

### 6.2.3 Key researchers involved, responsible, and contacts

At Aalborg the key researchers are Neeli Prasad, Nicola Morelli, and Rasmus Nielsen (the three from AAU; other researchers involved are Pernille Have (AAU), Carrie Peterson (AAU), Bayu Anggorojati (AAU), Anelia Mitzeva (AAK), Hanne Hjorth Andreasen (AAK), and Christoffer Mørch (IDEAAL).

### 6.2.4 Information Sheet for participants (translated and adapted)

#### 6.2.4.1 Aims and general description of the project

The objective of the LIFE 2.0 project is to make the network of social interactions more visible to elderly people, by providing them a set of collaborative ICT based services that track and locate people that are relevant to them (e.g., relatives, friends, assistants), giving them the chance to contact them with a phone call, a text message, as well as access to advanced multimedia content distribution systems (such as IPTV, interactive digital signage and webTV) or video telephony/conference solutions. This will give a better sense of safety to elderly people living independently and activate all the existing resources (e.g., local knowledge, social contacts, etc.) in the neighbourhood. The services proposed and tested in this project will come from the combined use of the advanced tracking technologies and social networking applications.

The LIFE 2.0 project will propose different level of services, from basic geographical positioning services, to services based on social interaction and to new value added services that increase the elderly people's access to commercial and public facilities in their own neighbourhood. The LIFE 2.0 project will be developed in three European locations (Pilots), besides Aalborg, Barcelona, Milano and Joensuu.

#### 6.2.4.2 Your role in the project and how we will use your information

*Ethnographic phase*

In the ethnographic analysis, the Aalborg group contacted users in the *Kastanjegaarden* activity and training centre, in order to organise a series of workshops, interviews and activities that could provide useful user-related information about the project. Details of the activities and results of the ethnographic analysis are included in D1.1.

*Pilot phase*

The pilot in Aalborg will be one of the four pilots in the project. In the pilot the services proposed in the LIFE 2.0 platform will be “prototyped” and proposed directly to the users (elderly people, their families and caregivers). The project will be strongly based on users’ participation, in order to make sure that the proposed services are user-friendly, accessible, transparent and easily communicated to users.

Key researchers will work in tight contact with users, supporting them in using the services in the platform, promoting the platform, recording the usage patterns of the platform (using the above mentioned techniques) and encouraging any forms of social and technical innovation derived from the use of the platform.

#### 6.2.4.3 Your privacy and participation

It follows the general statement.

#### 6.2.4.4 Debriefing

It follows the general statement.

#### 6.2.4.5 Consent form

**Statement of consent by the contributing participant**

I have received written and oral information and have sufficient knowledge of the ground, methods, advantages and disadvantages to be able to consent to participate in the project LIFE 2.0 workshop on the 25.01.2011 at the Kastanjegaarden.

I understand that I participate as a volunteer and anytime I can interrupt my participation in LIFE 2.0 at no cost to myself.

I hereby give permission to the working group behind LIFE 2.0: Aalborg Kommune, Aalborg University, Northern Europe EU Office and IDEAAL to use the physical and digital data collected from me for teaching and research, provided that my identity is anonymous.

I hereby give my consent to participate as user on the research project LIFE 2.0 and have received a copy of this "Declaration of consent" and physical information about the research for private use.

Participant name ________________________________

Date and signature________________________________

Do you want to be informed about the research results?

Yes                    No

## 6.3 Joensuu

### 6.3.1 Participants: recruitment methods, number, age, gender, exclusion and inclusion criteria

The participants for the ethnographic phase were invited through a seminar with *Eläkeliitto* (retired people’ union) regional meeting and with further postings to Eläkeliitto members. The seminar was organized together by the research group and the Eläkeliitto managers. The objective of seminar was to awaken interest for the research, get user participants and get feedback about diary directly from users. The final selected participants consisted of 8 people (5 females and 3 males, aged between 65-76 years old) living independently at home, houses ranging from blocks of flats to terraced houses and one family house further away from the city centre. The participants were mainly seniors living alone but also two seniors with spouses participated.

In the pilot phase participants will mainly live in the Joensuu district area. Recruitment will be done partly with Eläkeliitto (local associations) and in the context of their annual meetings. People who join some meetings will also be asked to invite their friends to participate to the pilot. All pilot participants will have already used computers or/and (simple) mobile phones that make it possible to access services that are tested. The level of computer skills varies and guidance is needed for most of participants.

### *6.3.2 Key researchers involved, responsible, and contacts*

At Joensuu, the responsible person is Mirja Kälviäinen (NCP), Mirja.kalviainen@pkamk.fi, gsm: +358 407 0196. Other persons are Vesa Kemppainen (NCP), vesa.kemppainen@pkamk.fi, gsm: +35840 7188060; Saara Newton (NCP) who is the contact about participation to LIFE 2.0 research, saara.newton@pkamk.fi, gsm +358 50 411 9217; and Satu Turkka (NCP), who is the contact with respect to technical issues, satu.turkka@pkamk.fi, gsm: +358 50 311 2695. Contact persons are also found in the Internet page: http://life2.fi.

### *6.3.3 Information Sheet for participants (translated and adapted)*

#### *6.3.3.1 Aims and general description of the project*

LIFE 2.0 aims for developing new services for independently living elderly people and their relatives and friends in order to support comfortable living at home, engaging in hobbies and making information transferring and getting help easier and more accurate to the time when it is needed. The services based on internet and mobile technology are planned to be in open markets by 2013.

#### *6.3.3.2 Your role in the project and how we will use your information*

*Ethnographic research phase*

For the participant the role is to take part in the research with an open mind. Information is collected through the interviews and the diary of which you are expected to fill in with your daily activities during a one-week period. You may take notes of activities, situation or experiences of each day of the week or by remembering past activities. After the period of self-documentation, the research member will go through the diary with you during the second interview. Your family members or close friends may also participate to fill in the diary with you or it can also be filled in as a couple.

The needed information is about your needs and experiences of everyday life. Also the gathered information is needed to find out the use of technological equipment and communication moments. The gathered information is handled confidentially for developing new services and technologies based on the understanding of the needs of individual. The information is stored in the research facility for the duration of the LIFE 2.0 project (2011-2013). Personal or contact details of the participants will not be transferred to a third party under any circumstances. Any information published will be handled and fixed carefully in order to protect the privacy of the participants.

*Pilot prototype phase*

In this phase, the services are tested and developed further. So that the service and user needs are met, the services are developed strongly with users in different phases. Developing main phases are: research (defining user requirements), pilot (testing prototypes) and commercializing to markets. Joensuu will be one of the four pilots.

#### *6.3.3.3 Your privacy and participation*

It follows the general statement.

The people involved in this research will be Mirja Kälviäinen, Vesa Kemppainen, Saara Newton and Satu Turkka.

#### *6.3.3.4 Debriefing*

At the end of the self-made diary, Saara Newton and Vesa Kemppainen will read out the main results and ask you to agree on them. If you do not agree on their summary of results, he or she will amend the summary until you agree on it.

You will also be invited to a debriefing session where Saara Newton, Vesa Kemppainen, Satu Turkka and Mirja Kälviäinen will summarise the results of the research project.

#### *6.3.3.5 Consent form*

You will be asked to sign a form saying that you are willing to participate in the study. The consent form will explain what will be asked and what will happen to any information that is collected. You will be given a copy of this form to keep. If you would like to know more about this research and/or you have questions that cannot be answered by the researcher, please feel free to contact the principal investigator, Mirja Kälviäinen.

Your task in the research is to fill a diary and participate in two interviews connected to the filling of the diary (first interview to meet each other and give guidance for the task and second interview to extend the information given in the diary). We wish you would fill in the diary during one week, describing separately different happenings during those days. The diary has been created just for this purpose. Altogether, we are looking for ten to fifteen participants into the research.

More information can be found in the attachment (Details of LIFE 2.0 Research). Details of the research will be also presented in the seminar on 19th of January.

### *6.3.4 Informed Consent Form (translated and adapted)*

(Consent Form is available also in separate document in English)

#### *6.3.4.1 You will be asked to do…*

You will be asked to sign this consent form, if you are willing to take part to this voluntary research in February 2011. The aim of the research is to develop future technologies and services that will support and ease healthy and comfortable independent living of elderly people.

#### *6.3.4.2 Your time*

Your participation time is appointed personally. The participation is possible during the two next months. To fill the diary takes about 1-2 hours per day in a period of one week. Two interviews before and after diary-period take about 2 hours each.

#### *6.3.4.3 Your privacy*

Your privacy is protected. Personal and contact details of the participants will not be transferred to a third party under any circumstances. Any information published will be handled and fixed carefully in order to protect the privacy of the participants (details in information sheet).

#### *6.3.4.4 Signature of the participant/Signature of the researcher*

I hereby give my consent/permission for participating in this research:

Signature Date Print name
My contact details (phone/email):

Consent received:

Signature of researcher Date Print name

## 6.4 Milano

### *6.4.1 Participants: recruitment methods, number, age, gender, exclusion and inclusion criteria*

Politecnico of Milano, together with FHS, recruited users for the first phase by organizing meetings in a social centre for elderly people and through Meglio Milano, the organisation which gets together single women living alone who want to play host to university students. This association recruits women living near the university campus, where Politecnico conducts the research and, to run the research, elderly who live near our university campus are recruited. This stimulates people and simplifies their movements from home to the university, to come into our laboratory to take part in workshops, meetings and laboratory tests.

For the first ethnographic phase Politecnico and FHS selected 30 people, from 65 to 75 years old, 13 men and 17 women, mainly married couples. We selected all people living independently, frequenting the social life of their neighbourhood, using public transport, all with a mobile phone, mainly with grandsons to take care, with a high skill of computer use and also some with little technical knowledge (to cover a big range of population).

In the pilot phase we will involve the majority of the users previously selected for ethnography (those who decide to be still part of our research) and also some new people recruited by the local association of single women living with university students.

### *6.4.2 Key researchers involved, responsible, and contacts*

At the Politecnico di Milano, Francesca Rizzo, francesca.rizzo@polimi.it, Office phone: +39 02 23995871; Mobile phone: +39 338 9023959 is the principal investigator. Other researchers involved are Margherita Pillan (margherita.pillan@polimi.it), Cabirio Cautela (cabirio.cautela@polimi.it), Fiammetta Costa (fcosta@polimi.it), and Serena Oliva (serena.oliva@polimi.it). At the Fondazione Housing Sociale, Monica Moschini: monica.moschini@fhs.it, office phone: +39 02 36683034; supported by consultant Ellida Massone (MeglioMilano): e.massone@meglio.milano.it.

### *6.4.3 Information Sheet for participants (translated and adapted)*

#### *6.4.3.1 Aims and general description of the project*

The LIFE 2.0 research intends to develop new services for elderly people and their relatives supporting their independent living at home and engaging their social life.

#### *6.4.3.2 Your role in the project and how we will use your information*

The research in the LIFE 2.0 project is divided in two different parts: ethnographic research and pilot phase.

For the ethnographic research you give to Politecnico of Milano and FHS information about youself through the questionnaire (information about you, your family and your use of technological devices), the personal diary (your activities of everyday life), and interviews (depending on what emerged from your diary).

All the information gathered is used only to develop services and technologies to support everyday life of elderly people supporting their independent life. Personal and contact details of the participants will not be transferred to a third party under any circumstances. Any information published will be anonymous in order to protect users' privacy.

For the pilot phase users give to Politecnico of Milano and FHS information about the interaction with the device given to them, and the services (based on internet and mobile technology) we will ask the participants to use, through testing the prototype devices and services.

#### *6.4.3.3 Your privacy and participation*

It follows the general statement. The people involved in this research will be Francesca Rizzo, Margherita Pillan, Fiammetta Costa, Cabirio Cautela and Serena Oliva, for Politecnico; and for Fondazione Housing Sociale, Monica Moschini and Ellida Massone.

#### *6.4.3.4 Debriefing*

At the end of the self-made diary, Francesca Rizzo or Fiammetta Costa or Serena Oliva and/or Monica Moschini, Ellida Massone will read out the main results and ask you to agree on them. If you do not agree on their summary of results, she will amend the summary until you agree on it.
You will also be invited to a debriefing session where Francesca Rizzo, Margherita Pillan, Serena Oliva and Fiammetta Costa and/or Monica Moschini, Ellida Massone, will summarise the results of the research project.

#### *6.4.3.5 Consent form*

You will be asked to sign a form saying that you are willing to participate in the study. The consent form will explain what will be asked and what will happen to any information that is collected. You will be given a copy of this form to keep. If you would like to know more about this research and/or you have questions that cannot be answered by the researcher, please feel free to contact the principal investigator, Francesca Rizzo.
We ask you:

- to fill in a personal diary every day when you use the device the University gave you for this research. We wish you to fill in the diary during one week, describing separately different things happening during those days. The diary has been created just for this purpose.
- to participate in two interviews about what you wrote in your diary.

### *6.4.4 Informed Consent Form (translated and adapted)*

#### *6.4.4.1 Consent form*

You will be asked to sign this consent form, if you are willing to take part in this voluntary research in February 2011.

> The LIFE 2.0 research intends to develop new services for elderly people and their relatives supporting their independently living at home, engaging their social life.
> I have received all the necessary information (written and oral) and I have sufficient knowledge to be able to consent to participate in the project LIFE 2.0. I participate as a volunteer and at anytime I can interrupt my participation in this research at no cost to myself.
> I hereby give permission to the working group behind LIFE 2.0: Politecnico of Milano, Fondazione Housing Sociale and Meglio Milano, to use the physical and digital data collected from me for research, provided that my identity is anonymous.
> I hereby give my consent to participate as user on the research project LIFE 2.0 and have received a copy of this "Declaration of consent" and physical information about the research for private use (according to *ex art.13 D. Lgs. 196/2003* about personal data treatment).
>
> Participant name
> Date, Place and signature

#### *6.4.4.2 Your time*

Your participation time is appointed personally. The participation is possible during two months. To fill in the diary takes about 1-2 hours per day (it depends on your everyday activities) and it will be carried out for the period of one week. Two interviews before and after the diary-period take about 1/2 hour each.

#### *6.4.4.3 Your privacy*

Your privacy is protected. Personal and contact details of the participants will not be transferred to a third party under any circumstances. According to the "Privacy Code" in operation from the 1st of January 2004 and according to the Italian D.Lgs. 196/2003, on "people privacy and other subjects referring on their personal data", the use of information regarding participants, will be based on accuracy, transparency and protection of privacy and rights of participants.

#### *6.4.4.4 Consent given and received*

I hereby give my consent/permission for participating in this research:
Signature , Place, Date, Print name

My contact details (phone/email):

Consent received:
Signature of researcher, Place, Date, Print name

My contact details (phone/email):

# Section 7 Conclusions

This deliverable has presented the Ethical Protocol of the LIFE 2.0 project, based on relevant guidelines of ethical research work, and taking into account relevant local legislation and common traditions.

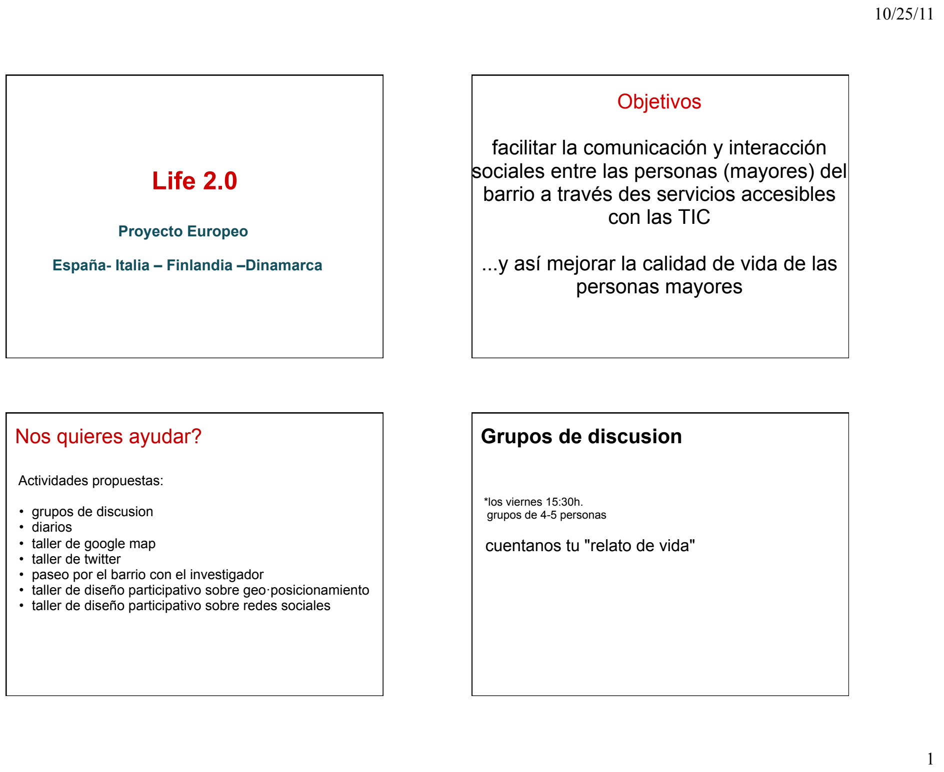
The deliverable presents first the general aspects of the protocol common to the four sites of the project, and second, the specific adaptation to the local aspects, including legislation. This specific part contains more detailed information of activities already carried out (ethnographical work) and less detail about the coming work, related to the pilot phase, which is in planning stage.

Some samples of specific material are annexed.

# Section 8 Appendices: some site material

## 8.1 Barcelona

### *8.1.1 Sample presentation to users (in Spanish)*



10/25/11

**Life 2.0**

**Proyecto Europeo**

**España- Italia – Finlandia –Dinamarca**

Objetivos

facilitar la comunicación y interacción sociales entre las personas (mayores) del barrio a través des servicios accesibles con las TIC

...y así mejorar la calidad de vida de las personas mayores

Nos quieres ayudar?

Actividades propuestas:

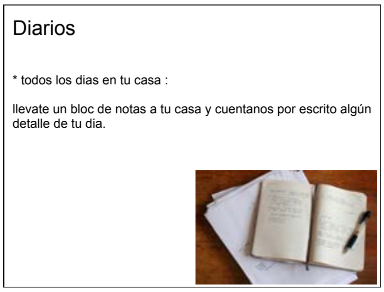
- grupos de discusion
- diarios
- taller de google map
- taller de twitter
- paseo por el barrio con el investigador
- taller de diseño participativo sobre geo·posicionamiento
- taller de diseño participativo sobre redes sociales

**Grupos de discusion**

*los viernes 15:30h.
grupos de 4-5 personas

cuentanos tu "relato de vida"

1



## Diarios

* todos los dias en tu casa :

llevate un bloc de notas a tu casa y cuentanos por escrito algún detalle de tu dia.

## Taller de google map

*vierne 21 Enero de 15:30 a 16:30 h
en un grupo de hasta 15 personas

aprenderemos a usar google map y crearemos un mapa colaborativo del barrio

## Taller de Twitter

los martes a las 13:30
grupo de hasta 15 personas

sabes que twitter es la red social mas popular de internet? aprende a usar twitter y entraras en el mundo de la red social de tus amigos.

## Taller de diseño participativo sobre geo-posicionamiento y redes sociales

*Jueves 11:30 - 13:00
grupo de hasta 15 personas

Dejamos de lado los ordenadores y discutimos sobre como podemos aprovechar los servicios de geo-posicionamento (como google map) y de las redes sociales (como twitter)

## Paseo por el barrio con el investigador

… nos gustaria acompañaros en algunas de vuestra actividad cuotidiana por el barrio…

### *8.1.2 Information sheet and information consent form for ethnographical work (Spanish)*

# Código de Ética

Hoja informativa: este documento está dirigido a los participantes.

Formulario de Consentimiento: este documento es para los participantes y los investigadores.

**Hoja de Información para los participantes Ágora**
Este documento presenta una descripción general del estudio: "Estudio etnográfico sobre la vida independiente de personas mayores". Un equipo de investigadores de la Universitat Pompeu Fabra (UPF) llevara a cabo este estudio con el apoyo de la Asociación Ágora a través de Vanessa Macarro. Este estudio se lleva a cabo en el marco del Proyecto LIFE 2.0, encargado por la Unión Europea, en el que la Universitat Pompeu Fabra y la Asociación Ágora están participando. Este documento también describe su papel en el estudio y cómo la información recopilada de usted se utilizará en ella. Una lista de los miembros del equipo investigador y su dirección de contacto se da al final de este documento.

**A. Objetivos y descripción general del estudio**
El objetivo del proyecto LIFE 2.0 (Vida 2.0) es hacer que la red de interacciones sociales más visibles para las personas mayores, proporcionándoles un conjunto de tecnologías de colaboración basadas en las TIC que siguen y localizan a las personas que son relevantes para ellos (por ejemplo, familiares, amigos, asistentes, etc.), dándoles la oportunidad de contactar con ellos con una llamada telefónica, un mensaje de texto, el acceso de sistemas multimedia avanzados (tales como IPTV, WebTV) o de telefonía de vídeo y soluciones de conferencias. El objetivo general del estudio que la Asociación Ágora llevara a cabo es contestar las siguientes preguntas:

- ¿Cuáles son los actores más relevantes en la vida independiente de las personas mayores?

- ¿Cómo está organizada la vida cotidiana de estos actores?

- ¿Cuáles son las interacciones más relevantes entre los actores, cómo y cuándo están colocadas las interacciones en su rutina?

- ¿Cuáles son las nuevas necesidades de los actores?

- ¿Qué tipo de conocimiento y familiaridad tienen las personas mayores sobre las tecnologías y los servicios y productos que se utilizan en el proyecto (GPS en los teléfonos móviles, Internet, computadoras, juegos de ordenador, televisión digital, IPTV)?

Los resultados de estos análisis proporcionarán una visión etnográfica de los usuarios día a día, incluida la observación de los usuarios sobre la actitud hacia la tecnología, los patrones de los movimientos rutinarios en la zona, los problemas y las posibles mejoras y se resumirán una serie de requisitos generales en la fase de diseño de la plataforma

La duración total del proyecto LIFE 2.0 es de 36 meses: noviembre 2010-noviembre 2013

**B. Su papel en el estudio y cómo se utilizará la información que nos proporcionan**

El equipo de investigación tomara notas de sus observaciones de primera mano y conversaciones informales con usted mientras usted está asistiendo a clases en Ágora y durante sesiones prácticas durante todo el estudio.

Un miembro del equipo de investigación sacara a fotos y / o hará fotocopias de los objetos que se utiliza cuando se está aprendiendo el uso de las TIC (tales como billetes de papel) y también las fotos de cómo usted utiliza estos objetos mientras están aprendiendo y / o usando las TIC durante todo el estudio.

Usted participará en un grupo de discusión. Esta actividad consiste en conversaciones informales sobre la rutina diaria de su vida, y que se llevara a cabo en grupos de cuatro o cinco participantes. Esta conversación se llevara a cabo con Vanessa y con otro miembro del equipo de investigación. El grupo de discusión va a durar hasta 1 hora, tendrá lugar en Ágora y se llevara a cabo en diciembre o enero de 2010. El investigador tomara notas durante la entrevista y hará uso de una cámara de video para grabar la sesión, para luego ayudarlo a analizar la información que le entregaran. Vamos a organizar la mejor fecha y hora para que usted pueda venir y participar en un grupo de discusión que mejor se adapte a su horario.

### B. Su privacidad y la participación

Toda la información que usted da a los investigadores se almacenara de forma segura y separada de cualquier información que usted proporcione sobre su identidad. El acceso a sus datos estará restringida a las personas involucradas en esta investigación, que será Valeria Righi, Susan Ferreira, Malon Guiller, y el Dr. Josep Blat (de la Universitat Pompeu Fabra) y Vanessa Macarro (Asociación Ágora).

Toda la información que usted nos proporcione en el proyecto será analizada y utilizada para la elaboración de informes científicos y trabajos de investigación que surgen del proyecto. Su nombre no será utilizado en conjunto con fotografías o cualquier material en las publicaciones y / o presentaciones.

Su participación en este proyecto es voluntaria. Usted puede retirarse del estudio en cualquier momento sin sanción o dar razones. La participación en este estudio no supone ningún riesgo para usted.

Al final de las entrevistas y talleres, Sergio comentara los principales resultados de la sesión y estos podrán modificarse hasta llegar a un acuerdo al respecto.

### D. Consentimiento

Se le pedirá que firme un formulario diciendo que está dispuesto a participar en el estudio. El formulario de consentimiento explica lo que va a pesar con toda la información que recoge. Se le dará una copia de este formulario.
Si desea saber más sobre esta investigación y / o si tiene preguntas por favor no dude en contacta con las siguientes personas:

Dr. Josep Blat
Dirección: Universitat Pompeu Fabra. DTIC Departamento. Calle Tanger, 122-140. Habitación 408
Correo Electrónico: josep.blat@upf.edu

Valeria Righi
Dirección: Universitat Pompeu Fabra. DTIC Departamento. Calle Tanger, 122-140. Habitación 301

Correo Electrónico: righi.vale@gmail.com

Susan Ferreira
Dirección: Universitat Pompeu Fabra. DTIC Departamento. Calle Tanger, 122-140. Habitación 301
Correo Electrónico: susanferreira@gmail.com

Guiller Malon
Dirección: Universitat Pompeu Fabra. DTIC Departamento. Calle Tanger, 122-140. Habitación 301
Correo Electrónico: gmalon@gmail.com

Vanessa Macarro
Dirección: Asociación Ágora, Carrer Selva de Mar, 215, 5ª pl.
Correo Electrónico: agora@edaverneda.org

**Formulario de Consentimiento Informado para los participantes de Ágora**
Este formulario de consentimiento informado es para el estudio: "Estudio etnográfico sobre la vida independiente de personas mayores". Un equipo de investigadores de la Universitat Pompeu Fabra (UPF) llevara a cabo este estudio con el apoyo de la Asociación Ágora a través de Vanessa Macarro. Este estudio se lleva a cabo en el marco del Proyecto LIFE 2.0, en el que la Universitat Pompeu Fabra".
Este formulario contiene información sobre el procedimiento y las condiciones generales del estudio.

Estimado participante:

Gracias por su interés en este estudio. Este documento describe lo que se le pidió que hiciera para el estudio. Este documento también detalla los permisos que le gustaría que nos dé. Por favor, lea y luego firme en la parte inferior conforme usted entiende y acepta las condiciones de este estudio. Si tiene preguntas, por favor no dude en preguntar a cualquier miembro del equipo de investigación.

1) Usted da permiso para que les investigadores tomen notas de sus observaciones de primera mano y conversaciones con usted mientras usted está utilizando las TIC en la Asociación Ágora a lo largo del estudio.

2) Usted da permiso para que les investigadores tomen fotos y / o hacen fotocopias de los objetos y las cosas creadas por usted o que se utilizan para ayudarle a aprender el uso de las TIC a lo largo del estudio.

3) Usted se compromete a participar en un grupo de discusión. Esta actividad consiste en conversaciones informales sobre las rutinas de la vida de su día a día, y se llevara a cabo en grupos de otros 4 o 5 participantes con quien usted se siente cómodo. Esta conversación se llevara a cabo con miembros del equipo de investigación. El grupo de discusión va a durar 1 hora aproximadamente, tendrá lugar en Ágora, y se llevara a cabo entre diciembre y enero de 2010. El investigador tomara notas durante la entrevista y usara una cámara de video para grabar la sesión para ayudarlo a analizar la información que le entregaran.

4) Usted acepta participar también en otras actividades que pueden llevarse a cabo dentro o fuera de la escuela Ágora. Entre las posibles actividades podrían ser:

- Que el investigador le acompañe durante una de sus actividades diarias de su elección (por ejemplo, ir al supermercado, llevar a su nieto a la escuela, ir al médico, ir a su bar favorito, dar un paseo por el barrio, ir a encontrarse con sus amigos)
- Participar en talleres que involucren tanto a sus amigos y miembros de la familia
- Entrevistas

5) Usted acepta de participar también en talleres en los que usted tendrá la posibilidad de probar los prototipos y productos finales resultantes de este estudio.

6) Usted da permiso a los investigadores a utilizar sus notas, fotos, y otros materiales que puedan surgir de este estudio en los artículos científicos, informes técnicos y presentaciones para sus trabajos.

La Sra. Vanessa, profesora de la asociación Ágora, se comunicara con usted para conocer la mejor fecha y hora para que usted participe en estas actividades.
Su participación en este estudio es voluntaria. Usted puede retirarse del estudio en cualquier momento sin sanción o dar razones.
La participación en este estudio no supone ningún riesgo para usted.

Su privacidad: toda la información que usted nos dé se almacenara de forma segura y se mantiene independiente de cualquier información que usted nos proporciones sobre su identidad. El acceso a sus datos estará restringida al Dr. Josep Blat, el Dr. Sergio Sayago, Righi Valeria, Malon Guiller y Ferreira Susan (de la Universitat Pompeu fabra) y la Sra. Vanessa macarro (Asociación Ágora). Su nombre no será utilizado en conjunto con fotografías o cualquier material en las publicaciones y/o presentaciones que salen de este proyecto.

Estamos muy agradecidos por su ayuda. Es importante que usted entienda que esta investigación no sería posible sin su participación. Esperamos que su contribución y nuestro trabajo puedan ayudar a hacer que las TIC sean más fácil y agradable de utilizar para las personas mayores.

Por favor, poned la fecha y firmad a continuación esta página para indicar que usted entiende y acepta las condiciones de este estudio.
Muchas gracias.

Nombre del participante:
Firma del participante:
Nombre del investigador:
Fecha: Mes / Día / Año
Firma del investigador:

## 8.2 Aalborg

### *8.2.1 Consent form used initially (in Danish)*

## Erklæring om samtykke - LIFE 2.0 workshop 25.01.11

Forskningsprojektets titel: LIFE 2.0

**Erklæring fra medvirkende deltager:**

Jeg har modtaget skriftlig og mundtlig information og har tilstrækkeligt kendskab til formålet, metoderne, fordelene og ulemperne til at kunne vedgive et "ja" til at deltage i projektet LIFE 2.0's workshop d. 25.01.11 på Kastaniegården.

Jeg er bekendt med at jeg deltager som frivillig og at jeg når som helst kan afbryde min deltagelse i LIFE 2.0 uden omkostninger for mig selv.

Jeg giver hermed tilladelse til at arbejdsgruppen bag LIFE 2.0: Aalborg Kommune, Aalborg Universitet, NordEuropas EU-Kontor og ideaal må anvende indsamlet fysisk og digital data på mig i forbindelse med undervisning og forskning under forudsætning af at min identitet bliver anonymiseret.

Jeg giver hermed mit samtykke til at deltage som bruger på forskningsprojektet LIFE 2.0 og har modtaget en kopi af nærværende "Erklæring om samtykke" samt fysisk informationsmateriale om forskningsprojektet til privat brug.

Deltagers navn:__________________________

Dato og underskrift:_______________________

Ønsker du også at blive informeret omkring resultaterne af forskningsprojektet?

☐ Ja ☐ Nej

**Erklæring fra ansvarshavende på LIFE 2.0:**

Jeg bekræfter at deltageren har modtaget skriftlig og mundtlig information om LIFE 2.0's workshop på Kastaniegården d. 25.01.11 og i den forbindelse også har haft mulighed for at stille opklarende spørgsmål til en kontaktperson inden afholdelsen af workshoppen.

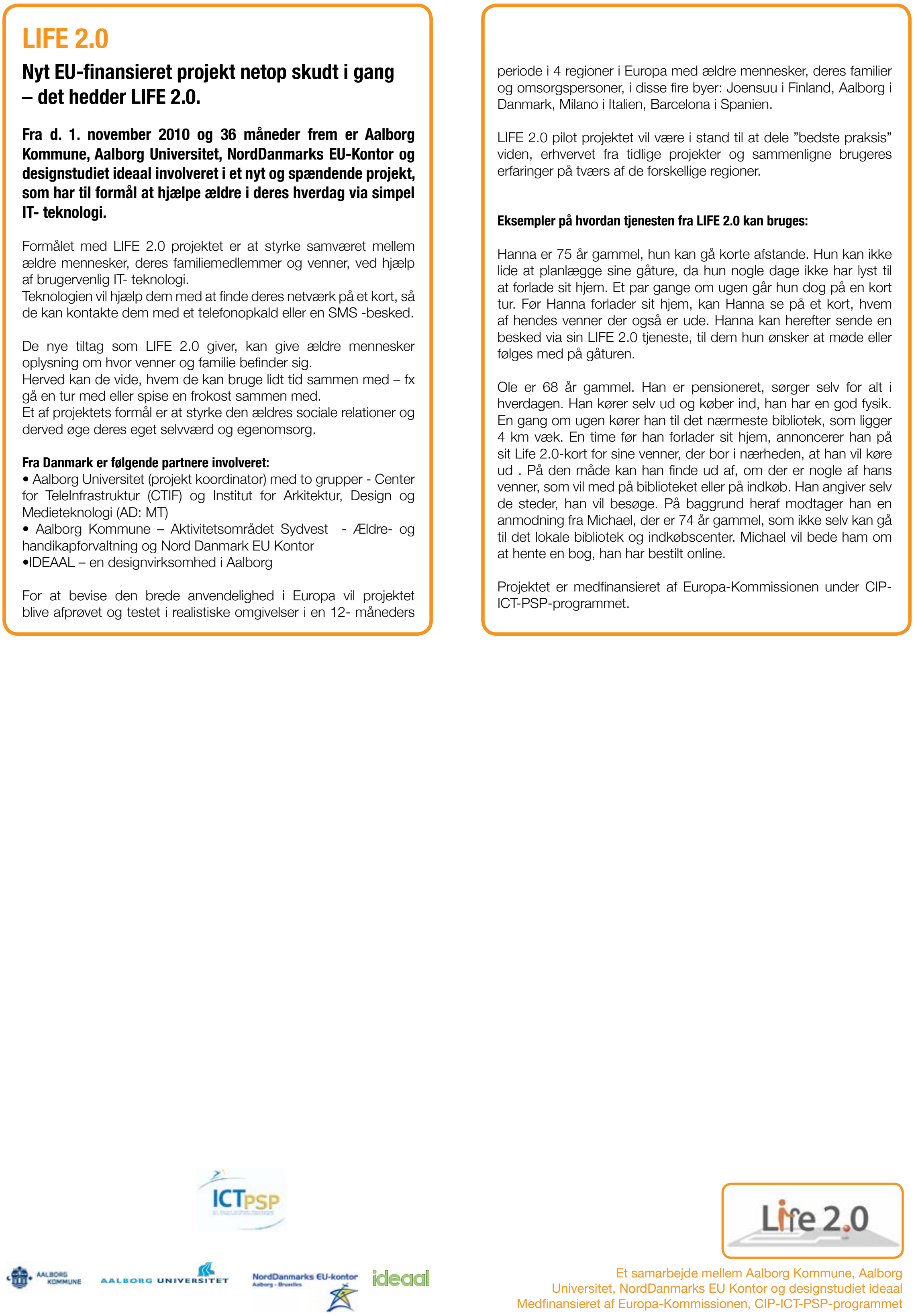
Jeg vurderer at der er udleveret og formidlet dækkende information om både projektet og nærværende workshop til deltageren så denne er i stand til at træffe en beslutning om at deltage i LIFE 2.0.

Ansvarshavendes navn:__________________________

Dato og underskrift:______________________________

LIFE 2.0 er medfinancieret af Europa-Kommissionen under CIP-ICT-PSP programmet

## *8.2.2 LIFE 2.0 information provided (in Danish)*



# LIFE 2.0

## Nyt EU-finansieret projekt netop skudt i gang – det hedder LIFE 2.0.

**Fra d. 1. november 2010 og 36 måneder frem er Aalborg Kommune, Aalborg Universitet, NordDanmarks EU-Kontor og designstudiet ideaal involveret i et nyt og spændende projekt, som har til formål at hjælpe ældre i deres hverdag via simpel IT- teknologi.**

Formålet med LIFE 2.0 projektet er at styrke samværet mellem ældre mennesker, deres familiemedlemmer og venner, ved hjælp af brugervenlig IT- teknologi.
Teknologien vil hjælp dem med at finde deres netværk på et kort, så de kan kontakte dem med et telefonopkald eller en SMS -besked.

De nye tiltag som LIFE 2.0 giver, kan give ældre mennesker oplysning om hvor venner og familie befinder sig.
Herved kan de vide, hvem de kan bruge lidt tid sammen med – fx gå en tur med eller spise en frokost sammen med.
Et af projektets formål er at styrke den ældres sociale relationer og derved øge deres eget selvværd og egenomsorg.

**Fra Danmark er følgende partnere involveret:**
- Aalborg Universitet (projekt koordinator) med to grupper - Center for TeleInfrastruktur (CTIF) og Institut for Arkitektur, Design og Medieteknologi (AD: MT)
- Aalborg Kommune – Aktivitetsområdet Sydvest - Ældre- og handikapforvaltning og Nord Danmark EU Kontor
- IDEAAL – en designvirksomhed i Aalborg

For at bevise den brede anvendelighed i Europa vil projektet blive afprøvet og testet i realistiske omgivelser i en 12- måneders periode i 4 regioner i Europa med ældre mennesker, deres familier og omsorgspersoner, i disse fire byer: Joensuu i Finland, Aalborg i Danmark, Milano i Italien, Barcelona i Spanien.

LIFE 2.0 pilot projektet vil være i stand til at dele ”bedste praksis” viden, erhvervet fra tidlige projekter og sammenligne brugeres erfaringer på tværs af de forskellige regioner.

**Eksempler på hvordan tjenesten fra LIFE 2.0 kan bruges:**

Hanna er 75 år gammel, hun kan gå korte afstande. Hun kan ikke lide at planlægge sine gåture, da hun nogle dage ikke har lyst til at forlade sit hjem. Et par gange om ugen går hun dog på en kort tur. Før Hanna forlader sit hjem, kan Hanna se på et kort, hvem af hendes venner der også er ude. Hanna kan herefter sende en besked via sin LIFE 2.0 tjeneste, til dem hun ønsker at møde eller følges med på gåturen.

Ole er 68 år gammel. Han er pensioneret, sørger selv for alt i hverdagen. Han kører selv ud og køber ind, han har en god fysik. En gang om ugen kører han til det nærmeste bibliotek, som ligger 4 km væk. En time før han forlader sit hjem, annoncerer han på sit Life 2.0-kort for sine venner, der bor i nærheden, at han vil køre ud . På den måde kan han finde ud af, om der er nogle af hans venner, som vil med på biblioteket eller på indkøb. Han angiver selv de steder, han vil besøge. På baggrund heraf modtager han en anmodning fra Michael, der er 74 år gammel, som ikke selv kan gå til det lokale bibliotek og indkøbscenter. Michael vil bede ham om at hente en bog, han har bestilt online.

Projektet er medfinansieret af Europa-Kommissionen under CIP-ICT-PSP-programmet.

Et samarbejde mellem Aalborg Kommune, Aalborg
Universitet, NordDanmarks EU Kontor og designstudiet ideaal
Medfinansieret af Europa-Kommissionen, CIP-ICT-PSP-programmet

### *8.2.3 LIFE 2.0 information provided in some activities (in Danish)*

## Introduktion

For at være i stand til at gennemføre projektet LIFE 2.0 har vi i arbejdsgruppen på AAU, Aalborg Kommune og NordDanmarks EU-Kontor brug for viden og indsigt i livet som ældre i Aalborg-området.

Vi vil gerne vide hvordan din dagligdag forløber, hvem du har kontakt til i løbet af ugen og hvilke ting du foretager dig, både alene og sammen med andre.

Noget af den viden vi er ude efter vil vi gerne indsamle allerede nu gennem dette spørgeskema samt de vedlagte postkort, og resten af vores spørgsmål vil vi præsentere for dig for d. 25.01.2011 til workshoppen på Kastanjegården. Til workshoppen skal du medbringe dette spørgeskema.

Vi håber at kunne finde ind til hvad det er der gør hver dag til en god dag, hvordan vi kan gøre dagene endnu bedre og forstå hvilke behov og ønsker man har til vores samfund, omgivelserne og ens eget lokale nabolag når man har nået pensionsalderen.

Spørgsmålene på de følgende sider omhandler emner som hobbyer, personlige evner, kendskab til elektroniske produkter og hvordan du transporterer dig selv.

Alt materiale vil blive håndteret fortroligt, men vil blive anvendt i undervisningsøjemed samt til interne arbejdsmøder.

Hvis du har spørgsmål til projektet, workshoppen eller der er noget som virker uforståeligt på de kommende sider, så ring til vores kontaktperson på projektet Pernille Have, Aalborg Universitet, på 31 50 02 51 eller kontakt Kaja eller Hanne.

## Om “LIFE 2.0”

### Nyt EU-finansieret projekt netop skudt i gang – det hedder LIFE 2.0.

**Fra d. 1 november 2010 og 36 måneder frem er Aalborg Kommune, Aalborg Universitet og NordDanmarks EU-Kontor involveret i et nyt og spændende projekt, som har til formål at hjælpe ældre i deres hverdag via simpel IT- teknologi.**

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De nye tiltag som LIFE 2.0 giver, kan give ældre mennesker oplysning om hvor venner og familie befinder sig.
Herved kan de vide, hvem de kan bruge lidt tid sammen med – fx gå en tur med eller spise en frokost sammen med.
Et af projektets formål er at styrke den ældres sociale relationer og derved øge deres eget selvværd og egenomsorg.

**Fra Danmark er følgende partnere involveret:**
- Aalborg Universitet (projekt koordinator) med to grupper - Center for TeleInfrastruktur (CTIF) og Institut for Arkitektur, Design og Medieteknologi (AD: MT)
- Aalborg Kommune – Aktivitetsområdet Sydvest - Ældre- og handikapforvaltning og Nord Danmark EU Kontor
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LIFE 2.0 pilot projektet vil være i stand til at dele ”bedste praksis” viden, erhvervet fra tidlige projekter og sammenligne brugeres erfaringer på tværs af de forskellige regioner.

**Eksempler på hvordan tjenesten fra LIFE 2.0 kan bruges:**

Hanna er 75 år gammel, hun kan gå korte afstande. Hun kan ikke lide at planlægge sine gåture, da hun nogle dage ikke har lyst til at forlade sit hjem. Et par gange om ugen går hun dog på en kort tur. Før Hanna forlader sit hjem, kan Hanna se på et kort, hvem af hendes venner der også er ude. Hanna kan herefter sende en besked via sin LIFE 2.0 tjeneste, til dem hun ønsker at møde eller følges med på gåturen.

Ole er 68 år gammel. Han er pensioneret, sørger selv for alt i hverdagen. Han kører selv ud og køber ind, han har en god fysik. En gang om ugen kører han til det nærmeste bibliotek, som ligger 4 km væk. En time før han forlader sit hjem, annoncerer han på sit Life 2.0-kort for sine venner, der bor i nærheden, at han vil køre ud . På den måde kan han finde ud af, om der er nogle af hans venner, som vil med på biblioteket eller på indkøb. Han angiver selv de steder, han vil besøge. På baggrund heraf modtager han en anmodning fra Michael, der er 74 år gammel, som ikke selv kan gå til det lokale bibliotek og indkøbscenter. Michael vil bede ham om at hente en bog, han har bestilt online.

Projektet er medfinansieret af Europa-Kommissionen under CIP-ICT-PSP-programmet.

## 8.3 Joensuu

### *8.3.1 Presentation provided to older users about LIFE 2.0 and another project (in Finnish)*

10/25/11

**Life 2.0**

**Paikannusteknologiaan liittyviä palveluja itsenäisen senioriasumisen tueksi**

**EU Smart Cities kokonaisuuden projekti**

Projekti parantaa ja kehittää palveluja kotona asuville senioreille. Tarkoituksena on tukea kotona asumista ja helpottaa yhteydenpitoa asukkaalle itselleen tärkeisiin ihmisiin tai palveluihin juuri silloin, kun se on tarpeen. Uutta seuranta- ja kulunohjausteknologiaa soveltavien palveluiden on tarkoitus olla markkinoilla 2013 mennessä.

Kehitettävien tuote-palveluratkaisujen tarkoitus on tukea: senioreiden sosiaalisia kontakteja, tiedon saamista lähellä asuvista ihmistä ja tapahtumista, tiedon saamista lähialueen palveluista ja avunsaannin mahdollisuuksista, senioreiden itsensä tuottamien palveluiden tarjontaa muille tahoille.

Kehitystyötä tehdään käyttäjälähtöisesti, ikäihmisten arjen tarpeita tutkimalla. Halukkaat osallistujat pääsevät kokeilemaan kehitettyä teknologiaa ja palvelujen käyttöä. Kokeilut (pilotit) toteutetaan neljässä eri maassa: Tanska (Aalborg), Suomi (Joensuu), Espanja (Barcelona) ja Italia (Milano).

1

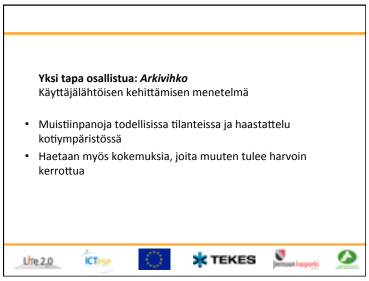
10/25/11

**Olisin kiinnostunut osallistumaan ja vaikuttamaan seuraavasti…**

LIFE 2.0 –projekti 1.11.2010 – 1.11.2013

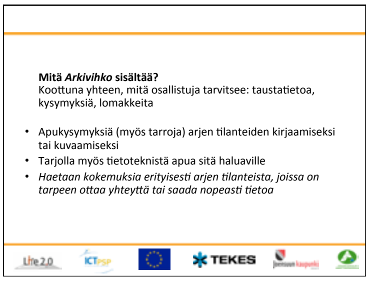
**Arkivihko, helmikuu 2011**
Tällä osallistavalla tutkimuksella pyritään kartoittamaan yhteydenpidon merkityksiä ja vaatimuksia yhteydenpidossa lähimpiin ihmisiin ja palveluihin. Tutkimukseen sisältyy kaksi haastattelua sekä noin viikon mittainen päiväkirjan täyttäminen.

**Pilotointi, loppuvuodesta 2011**
Pilotointi tarkoittaa uusien välineiden ja palveluiden kokeilemista ennen myyntiin tuloa. Halutessa voi toimia testaajana ja päästä kokeilemaan tulevia teknisiä palveluita, joilla pyritään helpottamaan arkielämän yhteydenpitoa.



**Yksi tapa osallistua: *Arkivihko***
Käyttäjälähtöisen kehittämisen menetelmä

- Muistiinpanoja todellisissa tilanteissa ja haastattelu kotiympäristössä
- Haetaan myös kokemuksia, joita muuten tulee harvoin kerrottua



**Mitä *Arkivihko* sisältää?**
Koottuna yhteen, mitä osallistuja tarvitsee: taustatietoa, kysymyksiä, lomakkeita

- Apukysymyksiä (myös tarroja) arjen tilanteiden kirjaamiseksi tai kuvaamiseksi
- Tarjolla myös tietoteknistä apua sitä haluaville
- *Haetaan kokemuksia erityisesti arjen tilanteista, joissa on tarpeen ottaa yhteyttä tai saada nopeasti tietoa*

**HILIMA**

**Hyvän ikäasumisen uudet liiketoimintamallit - kehitysympäristöjä ja käyttäjätietoa hyödyntämällä**

2

### TEKES/ Rakennettu ympäristö – ohjelmat

Ikääntyvien asumisympäristöistä kootaan kokemusperäistä käyttäjätietoa yritysten tuotteiden ja palvelujen kehittämiseen. Ikääntyvien asumisen kartoituksen kohteena ovat erilaiset asumismuodot ja –ympäristöt sekä kaupungeissa että maaseudulla.

Tuloksena syntyy ikääntyvien arjen itsenäistä asumista tukevia tuotteita, palveluja, joiden edelleen kehittämisessä ikäihmiset ovat itse mukana. Yrityksille syntyy lisäksi monituottajuuteen perustuvia liiketoimintamalleja. Hyvinvointiliiketoimintaa kehitetään yhteistyössä tutkimus- ja kehittämisorganisaa-tioiden, yritysten, käyttäjäjärjestöjen ja julkisen sektorin kanssa. Hanke vahvistaa Joe olemassa olevien kehittämisympäristöjen ja –tahojen yhteistyötä ja käyttäjälähtöistä kehittämistapaa.

Hankkeen toteutukseen osallistuu Abloy Oy, BLC Oy, Kiteen Huonekalutehdas Oy, Kontiopuu Oy, Laatukarjala Oy, Arkkitehtuuritoimisto Lappalainen&Korjonen Oy, Miratel Oy, FastRoi Oy, Väinö Korpinen Oy, Respecta Oy, Karostech Oy. Hankkeen toteutus, tulokset ja toimintamallit kytketään rakenteilla olevaan Joensuun kaupungin Senioripiha-ympäristöön. Senioripiha toimii valmistuttuaan ikäasumisen malli- ja kehitysympäristönä.

### HILIMA 1.12.2010 – 31.5.2012

**Asuinympäristön kartoitus,**
Tässä tutkimuksessa kootaan käyttäjätietoa hyvään ikä-asumiseen liittyen siten, että ikäihmiset saavat olla mukana vaikuttamassa uusien tuotteiden ja palveluiden kehittämiseen. Kartoitus toteutetaan haastattelemalla erilaisissa asumismuodoissa ja –ympäristöissä sekä kaupungeissa että maaseudulla.

**Kehittämispäivät,**
Kehittämispäivillä kehitetään yhdessä asiantuntijoiden ja ikäihmisten kanssa mahdollisia uusia tuotteita ja palveluita arkielämän ja kodin viihtyvyyden edistämiseksi.

**Kirjoituskilpailu, 19.1.2011 – 30.4.2011**
Kirjoituskilpailulla kerätään omakohtaisia muistoja ja kertomuksia tai vaikka tulevaisuuden unelmia asumiseen liittyen, ja parhaimpia kirjoituksia palkitaan.

**Tuotteiden tai palveluiden testaus,**
Halutessa voi toimia testaajana ja päästä kokeilemaan ja vaikuttamaan uusien hyvään ikäasumiseen liittyvien tuotteiden tai palveluihin kehittämiseen.

### *8.3.2 Information for the users about ethical aspects and consent form (in Finnish)*

# Lähtökohtia tutkimukselle

*Yli 65-vuotiaiden arjen asiointi ja yhteydenpito*

Kutsumme sinua helmikuussa 2011 toteutettavaan vapaaehtoiseen tutkimukseen, jonka avulla halutaan kehittää palveluja kotona asuville henkilöille ja heidän tuttavilleen. Tulevien palveluiden tarkoituksena on tukea kotona asumista, harrastamista ja helpottaa tiedon tai avun saamista juuri silloin, kun se koetaan tarpeelliseksi tai mielekkääksi. Internet- tai mobiiliteknologiaa käyttäviä palveluita on tarkoitus saada markkinoille 2013 mennessä.

**Kuka käyttää tietoja?**

Saatavia tietoja käyttää Pohjois-Karjalan ammattikorkeakoulu. Tutkimus kuuluu osana laajempaan EU-tutkimukseen (*Life 2.0 ICT* -hanke), jossa on mukana julkisia tutkimusorganisaatioita ja yrityksiä Suomesta, Tanskasta, Espanjasta ja Italiasta. Suomesta mukana ovat Joensuun kaupunki, Eläkeliitto ry:n Pohjois-Karjalan piiri sekä Respecta Oy. Osallistujien yhteyshenkilö on Saara Newton (040 371 7182) ja projektin johtaja FT Mirja Kälviäinen.

**Mihin tietoja käytetään?**

Tarvitsemamme tiedot liittyvät pääasiassa sinun arjen tarpeisiisi ja kokemuksiisi arjen sujumisesta. Haettava tieto liittyy myös esim. tietotekniikan käyttöön ja yhteydenpidon tilanteisiin. Käytämme tietoja luottamuksellisesti tarpeiden ymmärtämiseksi ja sitä kautta uusien palvelujen tai teknologian kehittämiseksi. Tietoja säilytetään tutkimustaholla hankkeen ajan (2011-2013). Henkilö- tai yhteystietoja ei luovuteta ulkopuolisille. Julkaistavaa tietoa käsitellään ja muokataan niin, ettei henkilöitä ole mahdollista tunnistaa.

**Miten tietoa kerätään?**

Tietoa kerätään alkuhaastattelulla sekä siten, että pidät ohjeistettuna päiväkirjaa viikon ajalta arkisista tilanteistasi. Osallistuja voi tehdä muistiinpanoja päiväkohtaisista tai aiemmin tapahtuneista tilanteista tai kokemuksista. Päiväkirja käydään seurantajakson jälkeen yhdessä läpi toisella haastattelukerralla, jolloin sinun on mahdollista saada apua myös arkisiin tietoteknologian ongelmiisi kotonasi. Osallistujien omat tuttavat voivat myös osallistua päiväkirjan laatimiseen ja se voidaan toteuttaa esim. pariskuntana.

**Onko osallistuminen mahdollista keskeyttää?**

Suostuminen tutkimukseen on vapaaehtoista ja osallistumisen saa peruuttaa milloin tahansa. Osallistumisen keskeyttämisestä ei tule seuraamuksia ja siihen mennessä saatuja tietoja käytetään vain osallistujan suostumuksella.

**Mitä osallistuminen edellyttää tai mitä siitä hyötyy?**

Osallistuminen edellyttää avointa, kehittämismyönteistä mieltä. Osallistuja pääsee vaikuttamaan tulevaisuuden palveluihin ja saa arviolta 1h ajan apua omiin pienimuotoisiin tietoteknisiin ongelmiinsa (esim. toisen haastattelukerran yhteydessä).

**Mistä saan lisätietoja tutkimuksesta?**

Lisätietoja saa yhteyshenkilöiltä (*Saara Newton 040 371 7182*) ja lisätietoa löytyy myös englanninkielisiltä www-sivuilta (http://www.life2project.eu).

Sivu 2(2)

## LIFE 2.0: Yli 65-vuotiaiden arjen asiointi ja yhteydenpito

*Suostuminen tutkimukseen*

**Tämän lomakkeen avulla** voit suostua osallistumaan helmikuussa 2011 toteutettavaan, täysin vapaaehtoiseen käyttäjätutkimukseen. **Tavoitteena on** kehittää tulevaisuudessa teknologiaa ja palveluja, jotka tukevat helppoa ja miellyttävää kotona asumista.

**Tehtävänäsi on** täyttää päiväkirjaa ja osallistua siihen liittyvään kahteen haastatteluun (aloitus ja lopetus). Toivomme, että vastaat päiväkirjan kysymyksiin ja ohjeisiin yhden viikon aikana. Päiväkirja (paperinen tai sähköinen) on laadittu tätä tarkoitusta varten.. Tutkimukseen haetaan kaikkiaan 10-15 erilaista osallistujaa.

**Lisätietoja on** liitteessä (kutsu tutkimukseen). Aihetta esitellään ja keskustellaan myös tilaisuudessa 19.1.

**Lomakkeen voi täyttää ja palauttaa** ao. tilaisuudessa 19.1 tai mielellään 27.1 mennessä Saara Newtonille. Lomake voidaan täyttää myös ensimmäisen haastattelun yhteydessä.

Saara Newton
Pohjois-Karjalan ammattikorkeakoulu
D'art muotoilun palvelukeskus
Sirkkalantie 12A,
80100 Joensuu

Gsm. 040 371 7182
saara.newton@pkamk.fi

Suostun osallistumaan vapaaehtoiseen tutkimukseen:

Allekirjoitus päiväys Nimen selvennys

Yhteystietoni (puh. nro/osoite):

**Suostumus vastaanotettu**

Tutkijan allekirjoitus päiväys Nimen selvennys

Sivu 1(2)

## 8.4 Milano

### 8.4.1 *Consent form provided to users (in Italian)*

L'Università del **Politecnico** di Milano

POLITECNICO DI MILANO
INDACO
DIPARTIMENTO DI
INDUSTRIAL DESIGN
DELLE ARTI
DELLA COMUNICAZIONE
E DELLA MODA

**ti chiede di collaborare al progetto di ricerca internazionale**

Life 2.0

**Geographical positioning services to support independent living and social interaction of elderly people**

**(Servizi di posizionamento geografico a supporto dell'autosufficienza e dell'interazione sociale degli anziani)**

**CONSENSO AL TRATTAMENTO DEI DATI**

Il trattamento dei dati personali è effettuato ai sensi del D.Lgs 196/03 "Codice in materia di protezione dei dati personali". Le informazioni personali non saranno mai divulgate al di fuori della ricerca in corso senza previo consenso dell'utente. L'utilizzo dei dati è finalizzato unicamente agli scopi della ricerca. Politecnico di Milano si impegna a proteggere la privacy degli utenti.

Io sottoscritto ......................................................................................................................

dichiaro di avere letto l'informativa sulla privacy e di aderire al progetto Life 2.0
insieme a Politecnico di Milano.

Firma ................................................................

### 8.4.2 *Ethical code provided to users (in Italian)*

GARANTE
PER LA PROTEZIONE
DEI DATI PERSONALI

Normativa - 16 giugno 2004 Bollettino del n. 51/giugno 2004, pag. 0

# Codice in materia di protezione dei dati personali
# A.4. Codice di deontologia e di buona condotta per i trattamenti di dati personali per scopi statistici e scientifici[19]

*(Provvedimento del Garante n. 2 del 16 giugno 2004, Gazzetta Ufficiale 14 agosto 2004, n. 190)*

**IL GARANTE PER LA PROTEZIONE DEI DATI PERSONALI**

Nella seduta odierna, con la partecipazione del prof. Stefano Rodotà, presidente, del prof. Giuseppe Santaniello, vice presidente, del prof. Gaetano Rasi e del dott. Mauro Paissan, componenti, e del dott. Giovanni Buttarelli, segretario generale;

Visto l'art. 27 della direttiva 95/46/CE del Parlamento europeo e del Consiglio del 24 ottobre 1995, secondo cui gli Stati membri e la Commissione incoraggiano l'elaborazione di codici di condotta destinati a contribuire, in funzione delle specificità settoriali, alla corretta applicazione delle disposizioni nazionali di attuazione della direttiva adottate dagli Stati membri;

Visto l'art. 12 del Codice in materia di protezione dei dati personali (d.lg. 30 giugno 2003, n. 196), il quale attribuisce al Garante il compito di promuovere nell'ambito delle categorie interessate, nell'osservanza del principio di rappresentatività e tenendo conto dei criteri direttivi delle raccomandazioni del Consiglio d'Europa sul trattamento dei dati personali, la sottoscrizione di codici di deontologia e di buona condotta per determinati settori, verificarne la conformità alle leggi e ai regolamenti anche attraverso l'esame di osservazioni di soggetti interessati e contribuire a garantirne la diffusione e il rispetto;

Visto l'art. 106, comma 1, del Codice il quale demanda al Garante il compito di promuovere la sottoscrizione di uno o più codici di deontologia e di buona condotta per i soggetti pubblici e privati, ivi comprese le società scientifiche e le associazioni professionali, interessati al trattamento dei dati per scopi statistici o scientifici;

Visto l'art. 106, comma 2, del medesimo Codice relativo a taluni profili che, sulla base di alcune garanzie, devono essere individuati dal codice di deontologia e di buona condotta per i trattamenti di dati per scopi statistici e scientifici;

Visto il provvedimento 10 febbraio 2000 del Garante per la protezione dei dati personali, pubblicato sulla *Gazzetta Ufficiale* della Repubblica italiana 25 febbraio 2000, n. 46, con il quale il Garante ha promosso la sottoscrizione di uno o più codici di deontologia e di buona condotta relativi del trattamento di dati personali per scopi statistici e di ricerca scientifica ed ha invitato tutti i soggetti aventi titolo a partecipare all'adozione dei medesimi codici in base al principio di rappresentatività a darne comunicazione al Garante;

Viste le comunicazioni pervenute al Garante in risposta al citato provvedimento del 10 febbraio 2000, con le quali diversi soggetti pubblici e privati, società scientifiche ed associazioni professionali hanno manifestato la volontà di partecipare all'adozione dei codici e fra i quali è stato conseguentemente costituito un apposito gruppo di lavoro, composto, in particolare, da rappresentanti dei seguenti soggetti: Conferenza dei rettori delle università italiane; Associazione italiana di epidemiologia; Associazione italiana di sociologia; Consiglio italiano per le scienze sociali; Società italiana degli economisti; Società italiana di biometria; Società italiana di demografia storica; Società italiana di igiene, medicina preventiva e sanità pubblica; Società italiana di statistica; Società italiana di statistica medica ed epidemiologia clinica; Associazione tra istituti di ricerche di mercato, sondaggi di opinione, ricerca sociale;

Considerato che il testo del codice è stato oggetto di ampia diffusione anche attraverso la sua pubblicazione sul sito

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[19] http://www.garanteprivacy.it/garante/navig/jsp/index.jsp?folderpath=Normativa/Italiana/II+Codice+in+materia+di+protezione+dei+dati+personali

Internet di questa Autorità, resa nota tramite avviso sulla *Gazzetta Ufficiale* della Repubblica italiana 20 maggio 2004, n. 117, al fine di favorire il più ampio dibattito e di permettere la raccolta di eventuali osservazioni e integrazioni al testo medesimo da parte di tutti i soggetti interessati;

Viste le osservazioni pervenute secondo quanto disposto dal citato avviso;

Rilevato che il rispetto delle disposizioni contenute nel codice di deontologia e di buona condotta costituisce condizione essenziale per la liceità e la correttezza del trattamento dei dati personali effettuato da soggetti privati e pubblici (art. 12, comma 3, del Codice);

Constatata la conformità del codice di deontologia e di buona condotta alle leggi e ai regolamenti in materia di protezione dei dati personali, anche in relazione a quanto previsto dagli artt. 12 e 104 e seguenti del Codice;

Considerato che, ai sensi dell'art. 12, comma 2, del Codice, il codice di deontologia e di buona condotta deve essere pubblicato nella *Gazzetta Ufficiale* della Repubblica italiana a cura del Garante e, con decreto del Ministro della giustizia, riportato nell'allegato A) al medesimo Codice;

Vista la documentazione in atti;

Viste le osservazioni formulate dal segretario generale ai sensi dell'art. 15 del regolamento del Garante n. 1/2000, adottato con deliberazione n. 15 del 28 giugno 2000 e pubblicato nella Gazzetta Ufficiale della Repubblica italiana n. 162 del 13 luglio 2000;

Relatore il prof. Gaetano Rasi;

**Dispone**

la trasmissione del codice di deontologia e di buona condotta per i trattamenti di dati personali per scopi statistici e scientifici, che figura in allegato, all'Ufficio pubblicazione leggi e decreti del Ministero della giustizia per la sua pubblicazione nella *Gazzetta Ufficiale* della Repubblica italiana, nonché al Ministro della giustizia per essere riportato nell'allegato A) al Codice.

*Roma, 16 giugno 2004*

IL PRESIDENTE
Rodotà

IL RELATORE
Rasi

IL SEGRETARIO GENERALE
Buttarelli

### A.4. Codice di deontologia e di buona condotta per i trattamenti di dati personali per scopi statistici e scientifici

sottoscritto da:

- Conferenza dei rettori delle università italiane
- Associazione italiana di epidemiologia
- Associazione italiana di sociologia
- Consiglio italiano per le scienze sociali
- Società italiana degli economisti
- Società italiana di biometria
- Società italiana di demografia storica
- Società italiana di igiene, medicina preventiva e sanità pubblica
- Società italiana di statistica
- Società italiana di statistica medica ed epidemiologia clinica
- Associazione tra istituti di ricerche di mercato, sondaggi di opinione, ricerca sociale

### Preambolo

I sottoindicati soggetti pubblici e privati sottoscrivono il presente codice, adottato sulla base di quanto previsto dall'art. 106 del decreto legislativo 30 giugno 2003, n. 196, recante il Codice in materia di protezione dei dati personali (di seguito denominato "decreto"), sulla base delle seguenti premesse:
1) le disposizioni del presente codice di deontologia e di buona condotta sono volte ad assicurare l'equilibrio tra i diritti e le libertà fondamentali della persona, in particolare il diritto alla protezione dei dati personali e il diritto alla riservatezza, con le esigenze della statistica e della ricerca scientifica, quali risultano dal principio della libertà di ricerca costituzionalmente garantito, presupposto per lo sviluppo della scienza, per il miglioramento delle condizioni di vita degli individui e per la crescita di una società democratica;
2) i ricercatori, singoli o associati, che operano nell'ambito di università, enti ed istituti di ricerca e società scientifiche, conformano al presente codice ogni fase dei trattamenti di dati personali effettuati a fini statistici o scientifici, indipendentemente dalla sottoscrizione del codice stesso da parte dei rispettivi enti e società scientifiche;
3) nell'applicazione del presente codice, i soggetti che ne sono destinatari osservano i princìpi contenuti nella Convenzione europea per la salvaguardia dei diritti dell'uomo e delle libertà fondamentali del 1950, ratificata con legge 4 agosto 1955, n. 848, nella direttiva 95/46/CE del Parlamento europeo e del Consiglio dell'Unione europea, nelle Raccomandazioni del Consiglio d'Europa R (83) 10 adottata il 23 settembre del 1983 e R (97) 18 adottata il 30 settembre 1997, nonché nelle altre disposizioni normative comunitarie e internazionali relative al trattamento dei dati personali a fini statistici e scientifici. Essi operano nel rispetto dei princìpi di pertinenza e di non eccedenza, intesa come non ridondanza del trattamento progettato rispetto agli scopi perseguiti, avuto riguardo ai dati disponibili ed ai trattamenti già effettuati dallo stesso titolare;
4) per quanto non disciplinato nel presente codice, si applicano le disposizioni previste dalla normativa in materia di dati personali, anche in relazione alla natura pubblica o privata del soggetto titolare del trattamento (artt. 18 e s. e 23 e s. del decreto). In particolare, i dati personali trattati per scopi statistici o scientifici non possono essere utilizzati per prendere decisioni o provvedimenti relativamente all'interessato, né per trattamenti di dati per scopi di altra natura;
5) per trattamento per scopi statistici si intende qualsiasi trattamento effettuato per le finalità di indagine statistica o di produzione di risultati statistici, anche a mezzo di sistemi informativi statistici (art. 4 del decreto);
6) per trattamento per scopi scientifici si intende qualsiasi trattamento effettuato per le finalità di studio e di indagine sistematica finalizzata allo sviluppo delle conoscenze scientifiche in uno specifico settore (art. 4 del decreto);
7) gli enti e i soggetti che applicano il presente codice osservano il principio di imparzialità e di non discriminazione nei confronti degli altri soggetti che trattano i dati per scopi statistici o scientifici. La sottoscrizione del presente codice è effettuata avendo riguardo, in particolare, alla rilevanza di tale principio in materia di comunicazione per scopi statistici o scientifici di dati depositati in archivi pubblici o che sono stati trattati sulla base di finanziamenti pubblici;
8) il decreto e il presente codice non si applicano ai dati anonimi;
9) ai trattamenti finalizzati alla realizzazione di attività di informazione commerciale e di comunicazione commerciale, nonché alle correlate ricerche di mercato si applicano le disposizioni dei codici di deontologia e di buona condotta previsti dagli articoli 118 e 140 del decreto.

### Capo I - Ambito di applicazione e principi generali

#### Art. 1. Definizioni

1. Ai fini del presente codice si applicano le definizioni elencate nell'art. 4 del decreto con le seguenti integrazioni:

a) "risultato statistico", l'informazione ottenuta con il trattamento di dati personali per quantificare aspetti di un fenomeno collettivo;
b) "unità statistica", l'entità alla quale sono riferiti o riferibili i dati trattati;
c) "dato identificativo indiretto", un insieme di modalità di caratteri associati o associabili ad una unità statistica che ne consente l'identificazione con l'uso di tempi e risorse ragionevoli, secondo i princìpi di cui all'art. 4;
d) "variabile pubblica", il carattere o la combinazione di caratteri, di tipo qualitativo o quantitativo, oggetto di una rilevazione statistica che faccia riferimento ad informazioni presenti in pubblici registri, elenchi, atti, documenti o fonti conoscibili da chiunque;
e) "istituto o ente di ricerca", un organismo pubblico o privato per il quale la finalità di statistica o di ricerca scientifica risulta dagli scopi dell'istituzione e la cui attività scientifica è documentabile;
f) "società scientifica", un'associazione che raccoglie gli studiosi di un ambito disciplinare, ivi comprese le relative associazioni professionali.

2. Salvo quando diversamente specificato, il riferimento a trattamenti per scopi statistici si intende comprensivo anche dei trattamenti per scopi scientifici.

#### Art. 2. Ambito di applicazione

1. Il presente codice si applica all'insieme dei trattamenti effettuati per scopi statistici e scientifici –conformemente agli *standard* metodologici del pertinente settore disciplinare–, di cui sono titolari università, altri enti o istituti di ricerca e società scientifiche, nonché ricercatori che operano nell'ambito di dette università, enti, istituti di ricerca e soci di dette società scientifiche.
2. Il presente codice non si applica ai trattamenti per scopi statistici e scientifici connessi con attività di tutela della salute svolte da esercenti professioni sanitarie od organismi sanitari, ovvero con attività comparabili in termini di significativa ricaduta personalizzata sull'interessato, che restano regolati dalle pertinenti disposizioni.

#### Art. 3. Presupposti dei trattamenti

1. La ricerca è effettuata sulla base di un progetto redatto conformemente agli *standard* metodologici del pertinente settore disciplinare, anche al fine di documentare che il trattamento sia effettuato per idonei ed effettivi scopi statistici o scientifici.

2. Il progetto di ricerca di cui al comma 1, inoltre:

a) specifica le misure da adottare nel trattamento di dati personali, al fine di garantire il rispetto del presente codice, nonché della normativa in materia di protezione dei dati personali;
b) individua gli eventuali responsabili del trattamento;
c) contiene una dichiarazione di impegno a conformarsi alle disposizioni del presente codice sottoscritta dai soggetti coinvolti. Un'analoga dichiarazione è sottoscritta anche dai soggetti –ricercatori, responsabili e incaricati del trattamento– che fossero coinvolti nel prosieguo della ricerca, e conservata conformemente a quanto previsto al comma 3.

3. Il titolare deposita il progetto presso l'università o ente di ricerca o società scientifica cui afferisce, la quale ne cura la conservazione, in forma riservata (essendo la consultazione del progetto possibile ai soli fini dell'applicazione della normativa in materia di dati personali), per cinque anni dalla conclusione programmata della ricerca.
4. Nel trattamento di dati idonei a rivelare lo stato di salute, i soggetti coinvolti osservano le regole di riservatezza e di sicurezza cui sono tenuti gli esercenti le professioni sanitarie o regole di riservatezza e sicurezza comparabili.

**Art. 4. Identificabilità dell'interessato**
1. Agli effetti dell'applicazione del presente codice:

a) un interessato si ritiene identificabile quando, con l'impiego di mezzi ragionevoli, è possibile stabilire un'associazione significativamente probabile tra la combinazione delle modalità delle variabili relative ad una unità statistica e i dati identificativi della medesima;
b) i mezzi ragionevolmente utilizzabili per identificare un interessato afferiscono, in particolare, alle seguenti categorie:

- risorse economiche;
- risorse di tempo;
- archivi nominativi o altre fonti di informazione contenenti dati identificativi congiuntamente ad un sottoinsieme delle variabili oggetto di comunicazione o diffusione;
- archivi, anche non nominativi, che forniscano ulteriori informazioni oltre quelle oggetto di comunicazione o diffusione;
- risorse *hardware* e *software* per effettuare le elaborazioni necessarie per collegare informazioni non nominative ad un soggetto identificato, tenendo anche conto delle effettive possibilità di pervenire in modo illecito alla sua identificazione in rapporto ai sistemi di sicurezza ed al *software* di controllo adottati;
- conoscenza delle procedure di estrazione campionaria, imputazione, correzione e protezione statistica adottate per la produzione dei dati;

c) in caso di comunicazione e di diffusione, l'interessato può ritenersi non identificabile se il rischio di identificazione, in termini di probabilità di identificare l'interessato stesso tenendo conto dei dati comunicati o diffusi, è tale da far ritenere sproporzionati i mezzi eventualmente necessari per procedere all'identificazione rispetto alla lesione o al pericolo di lesione dei diritti degli interessati che può derivarne, avuto altresì riguardo al vantaggio che se ne può trarre.

**Art. 5. Criteri per la valutazione del rischio di identificazione**
1. Ai fini della comunicazione e diffusione di dati, la valutazione del rischio di identificazione tiene conto dei seguenti criteri:

a) si considerano dati aggregati le combinazioni di modalità alle quali è associata una frequenza non inferiore a una soglia prestabilita, ovvero un'intensità data dalla sintesi dei valori assunti da un numero di unità statistiche pari alla suddetta soglia. Il valore minimo attribuibile alla soglia è pari a tre;
b) nel valutare il valore della soglia si deve tenere conto del livello di riservatezza delle informazioni;
c) i risultati statistici relativi a sole variabili pubbliche non sono soggette alla regola della soglia;
d) la regola della soglia può non essere osservata qualora il risultato statistico non consenta ragionevolmente l'identificazione di unità statistiche, avuto riguardo al tipo di rilevazione e alla natura delle variabili associate;
e) i risultati statistici relativi a una stessa popolazione possono essere diffusi in modo che non siano possibili collegamenti tra loro o con altre fonti note di informazione, che rendano possibili eventuali identificazioni;
f) si presume adeguatamente tutelata la riservatezza nel caso in cui tutte le unità statistiche di una popolazione presentano la medesima modalità di una variabile.

### Capo II - Informativa, comunicazione e diffusione

**Art. 6. Informativa**
1. Nella raccolta di dati per uno scopo statistico, nell'ambito delle informazioni di cui all'art. 13 del decreto è rappresentata all'interessato l'eventualità che i dati personali possono essere conservati e trattati per altri scopi statistici o scientifici, per quanto noto adeguatamente specificati anche con riguardo alle categorie di soggetti ai quali i dati potranno essere comunicati.
2. Nella raccolta di dati per uno scopo statistico, l'informativa alla persona presso la quale i dati sono raccolti può essere differita per la parte riguardante le specifiche finalità e le modalità del trattamento cui sono destinati i dati, qualora ciò risulti necessario per il raggiungimento dell'obiettivo dell'indagine -in relazione all'argomento o alla natura della stessa- e il trattamento non riguardi dati sensibili o giudiziari. In tali casi, l'informativa all'interessato è completata non appena cessano i motivi che ne avevano ritardato la comunicazione, a meno che ciò risulti irragionevole o comporti un impiego di mezzi manifestamente sproporzionato. Il soggetto responsabile della ricerca redige un documento -

successivamente conservato per tre anni dalla conclusione della raccolta e reso disponibile agli interessati che esercitano i diritti di cui all'art. 7 del decreto-, in cui sono indicate le specifiche motivazioni per le quali si è ritenuto di differire l'informativa, la parte di informativa differita, nonché le modalità seguite per informare gli interessati quando sono venuti meno i motivi che avevano giustificato il differimento, ovvero le ragioni portate per il mancato completamento dell'informativa.
3. Quando, con riferimento a parametri scientificamente attendibili, gli obiettivi dell'indagine, la natura dei dati e le circostanze della raccolta sono tali da consentire ad un soggetto di rispondere in nome e per conto di un altro in quanto familiare o convivente, l'informativa all'interessato può essere data per il tramite del soggetto rispondente, purché il trattamento non riguardi dati sensibili o giudiziari.
4. Quando i dati sono raccolti presso terzi, ovvero il trattamento effettuato per scopi statistici o scientifici riguarda dati raccolti per altri scopi, e l'informativa comporta uno sforzo sproporzionato rispetto al diritto tutelato, il titolare adotta forme di pubblicità con le seguenti modalità:

- per trattamenti riguardanti insiemi numerosi di soggetti distribuiti sull'intero territorio nazionale, inserzione su almeno un quotidiano di larga diffusione nazionale o annuncio presso un'emittente radiotelevisiva a diffusione nazionale;
- per trattamenti riguardanti insiemi numerosi di soggetti distribuiti su un'area regionale (o provinciale), inserzione su un quotidiano di larga diffusione regionale (o provinciale) o annuncio presso un'emittente radiotelevisiva a diffusione regionale (o provinciale);
- per trattamenti riguardanti insiemi di specifiche categorie di soggetti, identificate da particolari caratteristiche demografiche e/o da particolari condizioni formative o occupazionali o analoghe, inserzione in strumenti informativi di cui gli interessati sono normalmente destinatari.

Della modalità di pubblicità adottata, il titolare dà preventiva informazione al Garante.
5. Qualora il titolare ritenga di non utilizzare le forme di pubblicità di cui al comma 4, anche in considerazione della natura dei dati raccolti o delle modalità del trattamento, ovvero degli oneri che comportano rispetto al tipo di ricerca svolta, il titolare medesimo può individuare idonee forme di pubblicità da comunicare preventivamente al Garante, il quale può, in ogni caso, prescrivere eventuali misure ed accorgimenti.

**Art. 7. Consenso**
1. Il trattamento per scopi statistici o scientifici può essere effettuato da un soggetto privato senza il consenso dell'interessato qualora non riguardi dati sensibili o giudiziari e l'informativa ai sensi dell'art. 13 del decreto, nella parte riguardante la natura obbligatoria o meno del conferimento dei dati, evidenzi in dettaglio e specificamente le ragioni per le quali il conferimento è facoltativo.

**Art. 8. Comunicazione e diffusione dei dati**
1. È consentito diffondere anche mediante pubblicazione risultati statistici soltanto in forma aggregata ovvero secondo modalità che non rendano identificabili gli interessati neppure tramite dati identificativi indiretti, salvo che la diffusione riguardi variabili pubbliche.
2. I dati personali trattati per un determinato scopo statistico possono essere comunicati, privi di dati identificativi, a un'università o istituto o ente di ricerca o a un ricercatore per altri scopi statistici chiaramente determinati per iscritto nella richiesta dei dati. Il soggetto richiedente, nel predisporre il pertinente progetto di ricerca ai sensi dell'art. 3, si impegna a non effettuare trattamenti per fini diversi da quelli indicati nella richiesta e a non comunicare ulteriormente i dati a terzi; allega inoltre al progetto copia della richiesta di comunicazione. Il soggetto richiesto, titolare del trattamento originario, deposita la richiesta di comunicazione e il connesso progetto presso l'università o ente di ricerca o società scientifica cui afferisce, la quale ne cura la conservazione, in forma riservata, per cinque anni dalla conclusione programmata della ricerca.
3. Nel caso in cui il richiedente dichiari che non è possibile conseguire altrimenti il risultato statistico di interesse, dandone espressa motivazione nella richiesta di cui al procedente comma 2, è consentita anche la comunicazione dei dati identificativi. Il soggetto richiesto, valutata la motivazione, fornisce i dati nel rispetto del principio di pertinenza e di stretta necessità. Resta fermo quanto previsto dall'art. 9.
4. Le disposizioni di cui ai commi 2 e 3 si applicano anche alla comunicazione, e al conseguente trasferimento anche temporaneo, di dati personali a università o istituti o enti di ricerca o ricercatori residenti in un Paese appartenente all'Unione europea o il cui ordinamento assicuri comunque un livello di tutela delle persone adeguato.
5. Quando il trattamento per un determinato scopo statistico comporta il trasferimento anche temporaneo dei dati personali in un Paese, non appartenente all'Unione europea, il cui ordinamento non assicura un livello di tutela delle persone adeguato, il trasferimento è consentito sulla base di garanzie per i diritti dell'interessato comparabili a quelle del presente codice, prestate dall'ente o dal ricercatore destinatario del trasferimento medesimo tramite un contratto redatto secondo una tipologia autorizzata dal Garante ai sensi dell'art. 40 del decreto, anche su proposta di enti e società scientifiche.

**Art. 9. Trattamento dei dati sensibili o giudiziari**
1. I dati sensibili o giudiziari trattati per scopi statistici e scientifici devono essere di regola in forma anonima.
2. Quando gli scopi statistici e scientifici, legittimi e specifici, del trattamento di dati sensibili o giudiziari non possono essere raggiunti senza l'identificazione anche temporanea degli interessati, il titolare adotta specifiche misure per mantenere separati i dati identificativi già al momento della raccolta, salvo ciò risulti impossibile in ragione delle particolari caratteristiche del trattamento o richieda un impiego di mezzi manifestamente sproporzionato.
3. Quando i dati di cui al comma 1 sono contenuti in elenchi, registri o banche dati tenuti con l'ausilio di strumenti elettronici, sono trattati con tecniche di cifratura o mediante l'utilizzazione di codici identificativi o di altre soluzioni che, considerato il numero e la natura dei dati trattati, li rendono temporaneamente non intelligibili anche a chi è autorizzato ad accedervi e permettono di identificare gli interessati solo in caso di necessità.

4. I soggetti di cui all'art. 2, comma 1, aventi natura privata possono trattare dati sensibili per scopi statistici e scientifici quando:

a) l'interessato ha espresso liberamente il proprio consenso sulla base degli elementi previsti per l'informativa;
b) il consenso è manifestato per iscritto. Quando la raccolta dei dati sensibili è effettuata con modalità –quali interviste telefoniche o assistite da elaboratore o simili– che rendono particolarmente gravoso per l'indagine acquisirlo per iscritto, il consenso, purché esplicito, può essere documentato per iscritto. In tal caso, la documentazione dell'informativa resa all'interessato e dell'acquisizione del relativo consenso è conservata dal titolare del trattamento per tre anni;
c) il trattamento risulti preventivamente autorizzato dal Garante, a seguito di specifica richiesta ai sensi dell'art. 26, comma 1, del decreto ovvero sulla base di un'autorizzazione generale relativa a determinate categorie di titolari o di trattamenti, rilasciata ai sensi dell'art. 40 del decreto, anche su proposta di enti e società scientifiche.

5. Il trattamento di dati giudiziari da parte dei soggetti di cui all'art. 2, comma 1, aventi natura privata è consentito soltanto se autorizzato da espressa disposizione di legge o provvedimento del Garante emanato ai sensi dell'art. 27 del decreto.
6. I soggetti cui all'art. 2, comma 1, aventi natura pubblica possono trattare dati sensibili o giudiziari:

a) per scopi scientifici, nel rispetto dell'art. 22 del decreto, qualora provvedano con atto di natura regolamentare ad individuare e rendere pubblici i tipi di dati e di operazioni strettamente pertinenti e necessarie in relazione alle finalità perseguite nei singoli casi, aggiornando tale individuazione periodicamente, secondo quanto previsto dall'art. 20, commi 2 e 4, del decreto;
b) per scopi statistici, nel rispetto dell'art. 22 del decreto, qualora siano soddisfatte le condizioni di cui all'art. 20, commi 2, 3 e 4 del decreto medesimo.

**Art. 10. Dati genetici**
1. Il trattamento di dati genetici è consentito nei soli casi e modi previsti da apposita autorizzazione del Garante ai sensi dell'art. 90 del decreto.

**Art. 11. Disposizioni particolari per la ricerca medica, biomedica ed epidemiologica**
1. La ricerca medica, biomedica ed epidemiologica è sottoposta all'applicazione del presente codice nei limiti di cui all'art. 2, comma 2.
2. La ricerca di cui al comma 1 si svolge nel rispetto degli orientamenti e delle disposizioni internazionali e comunitarie in materia, quali la Convenzione sui diritti dell'uomo e sulla biomedicina del 4 aprile 1997, ratificata con legge 28 marzo 2001, n. 145, la Raccomandazione del Consiglio d'Europa R(97)5 adottata il 13 febbraio 1997 relativa alla protezione dei dati sanitari e la dichiarazione di Helsinki dell'Associazione medica mondiale sui princìpi per la ricerca che coinvolge soggetti umani.
3. Nella ricerca di cui al comma 1, l'informativa mette in grado gli interessati di distinguere le attività di ricerca da quelle di tutela della salute.
4. Nel manifestare il proprio consenso ad un'indagine medica o epidemiologica, l'interessato è richiesto di dichiarare se vuole conoscere o meno eventuali scoperte inattese che emergano a suo carico durante la ricerca. In caso positivo, l'interessato è informato secondo quanto previsto dall'art. 84 del decreto. Quando, per i motivi di cui al successivo comma 5, il consenso non può essere richiesto, tali eventi sono comunque comunicati all'interessato nel rispetto dell'art. 84 del decreto qualora rivestano un'importanza rilevante per la tutela della salute dello stesso.
5. Nella ricerca di cui al comma 1, il consenso dell'interessato non è necessario quando, ai sensi dell'art. 110 del decreto, sono soddisfatti i seguenti requisiti:

a) non è possibile informare l'interessato per motivi etici (ignoranza dell'interessato sulla propria condizione), ovvero per motivi metodologici (necessità di non comunicare al soggetto le ipotesi dello studio o la sua posizione di elezione), ovvero per motivi di impossibilità organizzativa;
b) il programma di ricerca è stato oggetto di motivato parere favorevole del competente comitato etico;
c) il trattamento è autorizzato dal Garante, anche ai sensi dell'art. 40 del decreto anche su proposta di enti e società scientifiche pertinenti.

**Art. 12. Attività di controllo**
1. Le università, gli altri istituti o enti di ricerca e le società scientifiche conservano la documentazione relativa ai progetti di ricerca presentati e agli impegni sottoscritti dai ricercatori ai sensi dell'art. 3, commi 1 e 2, e dell'art. 8, comma 2 del presente codice.
2. Gli enti di cui al comma 1:

a) assicurano la diffusione e il rispetto del presente codice fra tutti coloro che, all'interno o all'esterno dell'organizzazione, sono in qualunque forma coinvolti nel trattamento dei dati personali realizzato nell'ambito delle ricerche, anche adottando opportune misure sulla base dei propri statuti e regolamenti;
b) segnalano al Garante le violazioni del codice di cui vengono a conoscenza.

## Capo III - Sicurezza e regole di condotta

**Art. 13. Raccolta dei dati**
1. I soggetti di cui all'art. 2, comma 1, pongono specifica attenzione nella selezione del personale incaricato della

raccolta dei dati e nella definizione dell'organizzazione e delle modalità di rilevazione, in modo da garantire il rispetto del presente codice e la tutela dei diritti degli interessati.
2. Il personale incaricato della raccolta si attiene alle disposizioni contenute nel presente codice e alle istruzioni ricevute. In particolare:

a) rende nota la propria identità, la propria funzione e le finalità della raccolta, anche attraverso adeguata documentazione;
b) fornisce le informazioni di cui all'art. 13 del decreto ed all'art. 6 del presente codice, nonché ogni altro chiarimento che consenta all'interessato di rispondere in modo adeguato e consapevole, evitando comportamenti che possano configurarsi come artifici ed indebite pressioni;
c) non svolge contestualmente presso gli stessi interessati attività di rilevazione di dati personali per conto di più titolari, salvo espressa autorizzazione;
d) provvede tempestivamente alla correzione degli errori e delle inesattezze delle informazioni acquisite nel corso della raccolta;
e) assicura una particolare diligenza nella raccolta di dati sensibili o giudiziari.

**Art. 14. Conservazione dei dati**
1. I dati personali possono essere conservati per scopi statistici o scientifici anche oltre il periodo necessario per il raggiungimento degli scopi per i quali sono stati raccolti o successivamente trattati, in conformità all'art. 99 del decreto. In tali casi, i dati identificativi possono essere conservati fino a quando risultino necessari per:

a) indagini continue e longitudinali;
b) indagini di controllo, di qualità e di copertura;
c) definizione di disegni campionari e selezione di unità di rilevazione;
d) costituzione di archivi delle unità statistiche e di sistemi informativi;
e) altri casi in cui ciò risulti essenziale e adeguatamente documentato per le finalità perseguite.

2. Nei casi di cui al comma 1, i dati identificativi sono conservati separatamente da ogni altro dato, in modo da consentirne differenti livelli di accesso, salvo ciò risulti impossibile in ragione delle particolari caratteristiche del trattamento o comporti un impiego di mezzi manifestamente sproporzionato rispetto al diritto tutelato.

**Art. 15. Misure di sicurezza**
1. Nell'adottare le misure di sicurezza dei dati e dei sistemi di cui agli artt. 31 e seguenti del decreto e al disciplinare tecnico contenuto nel relativo allegato B), i titolari dei trattamenti di dati per scopi statistici curano anche i livelli di accesso ai dati personali con riferimento alla natura dei dati stessi ed alle funzioni dei soggetti coinvolti nei trattamenti.

**Art. 16. Esercizio dei diritti dell'interessato**
1. In caso di esercizio dei diritti di cui all'art. 7 del decreto in riferimento a dati trattati per scopi statistici e scientifici, l'interessato può accedere agli archivi che lo riguardano per chiederne l'aggiornamento, la rettifica o l'integrazione, sempre che tale operazione non risulti impossibile per la natura o lo stato del trattamento o comporti un impiego di mezzi manifestamente sproporzionato.
2. Qualora tali modifiche non producano effetti significativi sui risultati statistici connessi al trattamento, il responsabile del trattamento provvede ad annotare, in appositi spazi o registri, le modifiche richieste dall'interessato, senza variare i dati originariamente immessi nell'archivio.

**Art. 17. Regole di condotta**
1. I responsabili e gli incaricati del trattamento che, per motivi di lavoro e ricerca, abbiano legittimo accesso ai dati personali trattati per scopi statistici e scientifici, conformano il proprio comportamento anche alle seguenti disposizioni:

a) i dati personali possono essere utilizzati soltanto per gli scopi definiti nel progetto di ricerca di cui all'art. 3;
b) i dati personali devono essere conservati in modo da evitarne la dispersione, la sottrazione e ogni altro uso non conforme alla legge e alle istruzioni ricevute;
c) i dati personali e le notizie non disponibili al pubblico di cui si venga a conoscenza in occasione dello svolgimento dell'attività statistica o di attività ad essa strumentali non possono essere diffusi, né altrimenti utilizzati per interessi privati, propri o altrui;
d) il lavoro svolto è oggetto di adeguata documentazione;
e) le conoscenze professionali in materia di protezione dei dati personali sono adeguate costantemente all'evoluzione delle metodologie e delle tecniche;
f) la comunicazione e la diffusione dei risultati statistici sono favorite, in relazione alle esigenze conoscitive della comunità scientifica e dell'opinione pubblica, nel rispetto della disciplina sulla protezione dei dati personali;
g) i comportamenti non conformi alle regole di condotta dettate dal presente codice sono immediatamente segnalati al responsabile o al titolare del trattamento.

**Art. 18. Adeguamento**
1. La corrispondenza delle disposizioni del codice alla normativa, anche di carattere internazionale, introdotta in materia di protezione dei dati personali trattati a fini di statistica e di ricerca scientifica è verificata nel tempo anche su segnalazione dei soggetti che lo hanno sottoscritto. Ciò ai fini dell'introduzione nel codice medesimo delle modifiche necessarie al fine del coordinamento con dette fonti, ovvero, qualora tali modifiche incidano in maniera apprezzabile

sulla disciplina del presente codice, del pronunciamento di un nuovo codice ai sensi dell'art. 12 del decreto.

**Art. 19. Entrata in vigore**
1. Il presente codice si applica a decorrere dal 1 ottobre 2004.