Social Innovation on active and healthy ageing

for sustainable economic growth

Deliverable D1.2

Ethical Framework Review

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Document Review

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V1		E. Urdaneta	Comments to each partner
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Acronyms & abbreviations

Item	Description
AA	Active Ageing
AAI	Active Ageing Index
ADAPEI	Association départementale de parents et amis de personnes handicapées mentales
BCC	Basque Culinary Center
CODERPA	Comité Départemental des Retraités et Personnes Agées
CT or CTorinno	Citta di Torino
DFKI	Deutsches Forschungszentrum Fuer Kuenstliche Intelligenz
EC	European Commision
EU	European Union
EURAG	Eurag Bund Fur Die Altere Generation Europas
ICT	Information and communications technology
INGEMA	Fundacion Instituto Gerontologico Matia
INVESTORNET	Mermaid Venture Aps-Investornet Gate2growth Dk Gate2financing Dk Brabo Ventures Denmark
ISCTE	Instituto Universitario De Lisboa
KMU	Knowledge Management Unit
LMIC	Low- and middle-income countries
NGO	Non-governmental organization
PSSRU	Personal Social Services Research Unit
RRI	Responsible Research and Innovation
SFEP	Servizio Formazione Educazione Permanente
TEC	Technology Experience Café
UN	United Nations
UN ECOSOC	United Nations Economic and Social Council
UNECE	United Nations Economic Commission for Europe
UPPA	Université de Pau et des pays de l'Adour
USFD	The University of Sheffield
WHO	World Health Organization
WP	Work Package

Table of Contents

1. Introduction

Work Package 1 seeks to promote a social innovation incubator as a means to provide a framework to the different types of stakeholders working in the field of active and healthy ageing. This will deepen the coordination of stakeholders for a more active participation of societal actors in research and the promotion of social innovation and responsibility in such research. To do so, SIforAGE is developing an '*Active and Healthy Ageing Help Desk for Science in Society Issues*' (Task 5.1).

Ethics is a pivotal element in such endeavour as SIforAGE must carefully ensure that the ethical aspects of the project are wisely and carefully considered. Whether it is the adequate protection of each individual's private data or the rights of users, SIforAGE partners will be properly trained to make sure that an ethics-based approach to end-users, participants and collaborating organisations be in place.

This Ethical Framework Review will serve various purposes: (a) it will provide a common ground for a common language amongst the project's partners; (b) it will offer ethical guidelines to these partners in the different aspects of the projects and their activities; and, (c) it will set the conceptual basis for the *Round table and training session on ethics and social responsibility in ageing research* (task 6.2).

Being Ethics a field where no prescriptions are instructed, but rather one where recommendations on how to better run and carry out actions are based on widely accepted values, the Ethical Framework Review will be in dialogue with the human rights framework where prescriptions are actually binding.

Following this introduction, section two covers an overview of what ethics is and why it is pertinent to the project; then, section three offers an examination of all the possible situations the project partners may encounter during the project and the ethics recommendations provided; section four presents an appraisal of the state-of-the-art in ethics legislation for each of the partners' countries of origin so as to identify innovations in this field that can boost mutual learning activities; and, finally, section five deals with a set of recommendations for policy development and project management on active and health ageing.

2. The contribution and importance of Ethics to research and innovation on active and healthy ageing

Active ageing (AA) is overall a policy framework (1), that has been enhanced by solid theoretical construction (2–5) undertaken in the past years. Less acknowledged, though, are the ethical implications of both the active ageing framework and its promotion by public and private actors in the fields of research and social innovation. Is it the promotion of AA good for society? How does the promotion of AA can be done without causing harm? What ethical tools can nourish the AA approach?

In this view, the promotion of active and health ageing approach is deemed as linked to the ethics-based responsibility of scientific knowledge to be used for the improvement of society.(6,7) Moreover, ethics experts have stressed the need to view the fight against chronic, non-communicable diseases and other health conditions as an ethics duty (8).

The promotion of active ageing is, therefore, rooted in a deep understanding of the ethical duty of science to seek benevolence and prevent harmfulness. Active ageing is thus an ethical duty of public and private actors towards the common good.

Simultaneously, the support and promotion of research and innovation on AA is expanding in high-income countries and also in low- and middle-income countries (LMIC)(9). Consequently, cooperation and collaboration between EU countries and LMIC is, too, expanding in every field, including AA.

Comprehensive and appropriate ethics-based approaches can inform EU-funded and promote actions on AA. This section puts forward a common framework for the SIforAGE partners so their actions are sensitive to and appropriately nurtured by an ethics-based approach to AA.

2.1   What is ethics and what is it for? The four-principle framework

Defining ethics is difficult to pin down. Almost everyone can come up with an opinion on what ethics is and how important it is for every field in life. Yet, opinions do not make a definition that is standard and operational. In the vast ocean of definitions, there if one(10) that is twofold yet simple: on the one hand, ethics refers to '*standards of right and wrong that prescribe what humans ought to do, usually in terms of rights, obligations, benefits to society, fairness, or specific virtues*'; and, on the other hand, '*ethics refers to the study and development of one's ethical standards.*' Therefore, being ethical in difficult situations is challenging (11) across professions, work fields and countries (12). Despite this difficulty, ethics is central to science and politics, to research and innovation, to policy-making and policy implementation. Every field of human action is subject to facing ethical challenges, hence the need for ethical guidance.

Ethics is not the same as rights. This distinction is of massive importance. Rights are ethically-informed and based, and they can be claimed via the different legal instruments set out to contain and develop the various rights frameworks. Ethical standards are not legal instruments, but a set of moral principles that serve as guidance on what is good and wrong, on how to act for the benefit of one self and others. Throughout history, rights (legal instruments) have sometimes bear unethical situations (e.g., discrimination against women, against people of non-white skin colour, against persons with specific diseases or disabilities, against persons of certain ages, against sexual behaviours or identities, etc.). But ethics is not above rights, either. It is at the same level in dialogue with rights because the latter can be claimed to call attention to unethical situations.

In order to be operative, ethics needs a framework that operationalises the core definition. A robust and widely-accepted framework was developed by Beauchamp and Childress(13). Such framework

encompasses four principles: (i) respect for autonomy; (ii) beneficence; (iii) non-maleficence; and, (iv) justice. Although originally built for the field of biomedical ethics, it is today extensively used by a large array of professional fields with dealing with ethics. Regardless of multiple criticism and review that consider the pour-principle framework as imperialist, inapplicable, inconsistent or inadequate (14–17), it is today the most-accepted common framework for biomedical ethics and social medicine (18–20).

A brief, useful definition of the four principles is needed for the SIforAGE partners to use when dealing with of facing ethical dilemmas and for guidance on the everyday life of the project. The following short definition have been taken from Gillon (18).

- *Respect for autonomy*: It is the moral obligation to respect the autonomy of others in so far as such respect is compatible with equal respect for the autonomy of all potentially affected.

- *Beneficence*: It is the moral obligation to produce benefit to the person, user, or patient with minimal harm. So, this principal is to be kept together with the non-maleficence one as the aim to produce net benefit over harm. It is important to define whose benefit and whose harm is likely to result from our actions. Beneficence and respect for autonomy interact to enhance empowerment.

- *Non-maleficence*: In those circumstances where there is no moral obligation (or possibility) to produce a benefit, there is a moral obligation no to produce any harm.

- *Justice*: It is the moral obligation to act on the basis of fair adjudication between competing claims. Gillon(18) proposes to subdivide justice in three categories: fair distribution of scarce resources (distributive justice), respect for people's rights (rights based justice) and respect for morally acceptable laws (legal justice). In relation to this principal, the concepts of equality and equity are also important and it should be noted that equally is not the same as justice. In this view, equals must be treated equally, but those who are unequal can be treated unequally. Equity goes far beyond equally and refers to the need to avoid unnecessary and preventable differences or inequalities(21–23); therefore equity refers to social justice (24,25).

2.2   Ethics, research and social innovation

Research is the pillar of science. Investing in science and research are overwhelmingly viewed as a positive action of public policy mainly because individuals and society trust science and they increasingly do so throughout time (26–30). This confidence in science is largely due to the believe that it will seek the benefit, not the harm, of societies and individuals, that it will lead to progress and development, and that it is based on fair standards.

This societal confidence in science and research entails ethical responsibilities. Such perspective fits seamlessly the European Union's framework on Responsible Research and Innovation (RRI) (31), which is being embroidered into the very fabric of Horizon 2020. RRI consist of six keys: (i) Engagement: all societal actors – researchers, industry, policymakers and civil society – and their joint participation in the research and innovation process, in accordance with the value of inclusiveness; (ii) Gender Equality: all actors, women and men, are on board; (iii) Science Education: enhancing the current education process to better equip future researchers and other societal actors with the necessary knowledge and tools to fully participate and take responsibility in the research and innovation process; (iv) Open Access: providing free online access to the results of publicly-funded research (publications and data); (v) Ethics: research and innovation must respect fundamental rights and the highest ethical standards; and, (vi) Governance: Policymakers have a responsibility to prevent harmful or unethical developments in research and innovation. This policy umbrella key seeks to develop harmonious models for Responsible Research and Innovation that integrate public engagement, gender equality, science education, open access and ethics.

RRI is central to achieving the SIforAGE objective[*] and to attain the highest ethical standards in deploying the project. RRI and SIforAGE call attention to the need for societal actors (including researchers, citizens, policymakers, businesses, and civil society) to cooperate throughout the entire research and innovation process pertaining active and healthy ageing to ensure a better alignment of processes and results with societal concerns and expectations.

3. An ethical framework for SIforAGE: situations and recommendations

The procedure of informed consent is broadly accepted and carried out. Nevertheless, ethics implies much more than informed consent. Although ethics go beyond informed consent, this procedure is extremely important for research and social innovation projects (32) as it mainly pertains to the principles of respect for autonomy and beneficence. The following are operationalised definitions of the four principles as regards SIforAGE. Persons and organisations participating in the project follow the following four principles of ethics:

- **Respect for autonomy**: With the general aim of promoting the participants' cognitive and functional abilities, participation in the project and in all of its activities should be based upon a process of informed consent and the participant's right to control his or her personal information will be respected at all times (this includes issues of confidentiality and data security). This principle is related to participation, which is known as essential to health and wellbeing (33). Respecting participants' views and even emotions is also important, as this is

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[*] Objective : To strengthen the cooperation mechanisms and tools among the stakeholders working along the value chain of active and healthy ageing, with the aim of improving the performance of the European Union competitiveness and growth, through research and innovative products for more and better lives

deemed to be a fundamental part of narrative ethics in research (34) and it thus contain powerful pedagogical value, a core element for the mutual learning activities that SiforAGE is undertaking. In SIforAGE, carers are given enormous importance due to the role they play in an ageing society. Seeking their participation and that of those they care for must be based on ethical standards and respect for their autonomy (35,36).

- **Beneficence**: The project and all its activities should benefit the participant according to his or her own conception of the good (this is a non-paternalistic interpretation of the principle, and includes making sure that participants hold authentically those conceptions). The project and the persons conducting activities within the project should seek and promote the empowerment of users.

- **Non-maleficence**: The project and all its activities should not harm the participant, or put him or her under unacceptable risk (this includes risks to privacy). Any potential risks should be disclosed and discussed.

- **Justice**: The project and all its activities should take into account the legitimate interests of third parties, and not incorporate or promote any bias based on gender, culture, nationality, or other sources of social prejudice (this includes fair selection of the subjects for the activities). Benefits of the study will be shared with the involved communities (this includes publication of the results of the study).

3.1   Applying ethics to common and everyday situations in the project

The following sections analyse in detail the most common and potential scenarios facing the project partners. The four ethical principles should serve as ethical guidance.

3.1.1   Recommendations for the inclusion of stakeholders (participants and collaborating organisations)

Participation and involvement of stakeholders can be done in various fashions and can also involve controversies, including the definition of what a stakeholder is. The following are recommendations to guide project development with respect to inclusion of stakeholders.

- **Definition of stakeholder**: A stakeholder is any individual or organisation that is likely to be affected by the decision and activities the project performs or intends to perform and by the decisions taken within the project. Stakeholders usually hold an interest and sometimes different stakeholders can hold competing interests. The project managers and implementers should be aware of this and, first, acknowledge the existence of diversity

within the stakeholder community, make efforts so all stakeholders acknowledge the existence of others and other interests, and promote dialogue amongst them. Stakeholders holding an interest or performing actions that harm others stakeholders or potentially harm others in a manner that is unethical to the four principles stated beforehand cannot take part in the project and it will not be included (v.gr., stakeholders holding discrimination agendas against older persons, stakeholders holding only a a pure and simple financial interest in projects dealing with active and healthy ageing but overlooking ethical principles).

- **Ethical claim of participation**: Stakeholders claiming that they want to participate or that they have the right to participate because they work for or on the field of ageing, as well as older persons can take part in the project as long as they abide by the four principles aforementioned and follow the mechanisms set up by the project managers and implementers to channel their participation and inclusion.

- **Diversity if to be sought after**: Recognising that the so-called older persons is not a homogenous population group, the inclusion of different individuals and organisations should be sought after in terms of **age** (not only persons aged 65 or older, but also younger ones), **sex** (even though women make up the majority of the +65 population, they are half of the population across age groups so a balanced sex ratio according to age should be encouraged), **gender and sexual diversity** (the sexuality of older persons is still highly overlooked in projects dealing with their participation, including political participation; therefore, appropriate actions to encourage participation of groups or organisations working on sexuality-related issues with respect to older persons should be set in place); **socioeconomic position** (evidence suggest that the better-off are more likely to benefit from innovation and services put in place for the most in need, which in turn reinforces inequities across population groups, including age groups; therefore project manager and implementers should be alert so as to actively look for the participation of older individuals from different socioeconomic positions and make special efforts to actively include individuals from deprived or poor-resource settings and from low-inconme groups, especially when it comes to older individuals); **race/ethnicity/culture** (Europe is a mosaic of cultures; yet, individuals and populations groups from different racial, ethnic or cultural backgrounds face the more or specific barriers to equally participate in society; project managers and implementers should be alert so as to avoid any intentional or unintentional actions leading to exclusion or discrimination based on these grounds; they should actively look for the inclusion and participation of usually less visible and community-engaged individuals and groups because of these grounds); **health status and disabilities** (healthy individuals are more likely to participate in society because they face less barriers to participation and

because participation channels usually target more healthy individuals; however, persons with disability are also healthy individuals with specific requirements that need to be addressed by organisations and institutions encouraging social participation; therefore, project managers and implementers should be aware of the different baseline levels people with and without disabilities have and provide or adopt the necessary actions so everyone can enjoy their right to participation in an equitable manner); **context and settings** (urban settings are usually more privileged in terms of possibilities of and channels for social participation and activities; thus, project managers and implementers should actively make efforts to encourage the inclusion of individuals and organisations from rural settings and also from less privileged urban settings); **occupation and employment status** (often times, actions and projects targeting older persons are designed as leisure activities; however, there are cases of older persons still active in the employment market; moreover, middle-aged individuals can also be strongly interested in active and healthy ageing-related activities, but they face the barrier of time constrains as many of these opportunities are designed as "leisure" time activities ; therefore, project managers and implementers should attempt to balance the inclusion of individuals active in and retired from the employment market irrespective of their age as long as they are intensely interested in active and healthy ageing, as well as social innovation and participation); and, **education level** (often times, more educated individuals can more easily get involved in social participation activities because they are more familiarised with the codes, languages and mechanics of participation; in fact; research has found that sometimes less educated individuals are less engaged in community or social innovation activities because they are not reached by these activities and not because they are not interested; therefore, project managers and implementers will actively work to reach the usually less reached populations groups by projects and activities dealing with active and healthy ageing, social participation and social innovation; they will set up the necessary mechanisms to disseminate information and facilitate participation in an equitable fashion).

- **Mechanisms for inclusion**: Participation requires rules and easy-to-understand mechanisms, especially if equitable access to participation opportunities is sought after. Therefore, project managers and implementers in the SIforAGE project will clearly inform individuals and organisations of the mechanisms and rules, including compliance mechanisms, to be observed if they are willing to participate in the project activities. Efforts should deliberately be made towards making information, including written and oral communications, clear, accessible and easy to understand.

3.1.2 Recommendations for the collection of personal data

Personal data is a very sensible piece of information. Project managers and implementers should at all times follow the corresponding European and national legislation governing these matters. This included the need that to inform participating stakeholders of their rights (v.gr., use, access, retrieve, delete) and obligations (v.gr., accurate, true and actual) with respect to the information they provide project managers and implementers with.

A special emphasis should be put into the use of informed consent in all the activities of the project that require this procedure (see Annex 1 to view an example of one of the informed consent forms used in the project).

3.1.3 Recommendations for handling personal data

As mentioned previously, personal data is a very sensible piece of information. Project managers and implementers should at all times follow the corresponding European and national legislation governing these matters. Besides the need that to inform participating stakeholders of their rights (v.gr., use, access, retrieve, delete) and obligations (v.gr., accurate, true and actual) with respect to the information they provide project managers and implementers with, SIforAGE programme managers and implementers should have clear and traceable procedures and mechanisms for handling personal data, including storage, access and use of such data.

Again, a special emphasis should be put into the use of informed consent in all the activities of the project that require this procedure (see Annex 1 to view an example of one of the informed consent forms used in the project).

3.1.4 Recommendations for organising activities with participants and collaborating organizations

There are multiple forms in which participation can be encouraged and channelled. This includes public hearings, workshops, conferences, online and in situ training, coordination with end-users' association and other grassroots and umbrella organisations, public-private partnerships, participation in NGO for a, collaboration with Intergovernmental fora, etc. At all times SIforAGE programme managers and implementers should act according to the four principles aforementioned and when in doubt they should consult with their supervisor or with the project coordinators.

Situation	Recommendations	Other remarks

	Stakeholders usually hold an interest and sometimes different stakeholders can hold competing interests. The project managers and implementers should be aware of this and, first, acknowledge the existence of diversity within the stakeholder community, make efforts so all stakeholders acknowledge the existence of others and other interests, and promote dialogue amongst them.	A definition of stakeholder is needed.
Inclusion of stakeholders (participants and collaborating organisations)	Stakeholders claiming that they want to participate can do so as long as they abide by the four principles.	Project managers and implementers should set up procedures and mechanisms to channel their participation and inclusion.
	The inclusion of different individuals and organisations should be sought after in terms of age; sex; gender and sexual diversity; socioeconomic position; race/ethnicity/culture; health status and disabilities; context and settings; occupation and employment status; and education level.	Project managers and implementers should set up actions and mechanisms to encourage diversity in the participants.
Collection of personal data	Personal data is a very sensible piece of information. Project managers and implementers should at all times follow the corresponding European and national legislation governing these matters.. A special emphasis should be put into the use of informed consent in all the activities of the project that require this procedure (see Annex 1 to view an example of one of the informed consent forms used in the project).	This included the need that to inform participating stakeholders of their rights and obligations with respect to the information they provide.
Handling personal data	SIforAGE programme managers and implementers should have clear and traceable procedures and mechanisms for handling personal data, including storage, access and use of such data.	SIforAGE programme managers and implementers should act according to the four principles aforementioned and when in doubt they should consult with their supervisor or with the project coordinators.
Recommendations for organising activities with participants and collaborating organizations	There are multiple forms in which participation can be encouraged and channelled. This includes public hearings, workshops, conferences, online and in situ training, coordination with end-users' association and other grassroots and umbrella organisations, public-private partnerships, participation in NGO for a, collaboration with Intergovernmental fora, etc.	

Figure 1: Summary of ethical recommendations

4. Final recommendations

This final section presents a set of brief recommendations for policy development and project management on active and health ageing.

4.1. Ethics-related recommendations concerning policy development on ageing, social innovation, mutual learning and social mobilisation

SIforAGE programme managers and implementers, when interacting with policy makers, decision makers and the experts that assist and advise them, should use and disseminate appropriate ethics-based approaches to language, communication and action.

When involved in policy making process and policy dialogue, SIforAGE programme managers and project should be informed not only by the best evidence available, but also by the appropriate ethics-based approaches in order to effectively promote active and healthy ageing.

4.2. Ethics-related recommendations for projects on ageing, social innovation, mutual learning and social movilisation

SIforAGE programme managers and project should be trained in ethics-based approaches and legal standards before engaging in project implementation and also during implementation as ethical questions and challenges constantly arise.

SIforAGE

Annex 1: Example of informed consent form

Titolo del progetto di ricerca: "SIforAGE – Social Innovation on active and healthy ageing for sustainable economic growth"

Ricercatore Responsabile per l'Italia: Ileana Leardini

Città di Torino – Direzione Politiche Sociali – Scuola Formazione Educazione Permanente

Nome del Partecipante:

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Ileana Leardini, Città di Torino – Direzione Centrale Politiche Sociali – SFEP

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- BASQUE CULINARY CENTER, Spagna

Le informazioni raccolte potranno inoltre essere comunicate a:

- La Commissione Europea
- Coordinatore Scientifico del Progetto SIforAge:
  Elena Urdaneta, Basque Culinary Center

  Ps. Juan Avelino Barriola 101 20009 San Sebastian – Spain, Tel: +34943574500

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_____

Firma dell'interessato

Annex 2: example of an informed consent form

FOGLIO INFORMATIVO PER LA RICHIESTA DI CONSENSO INFORMATO

TITOLO DELLA RICERCA:

Progetto "SIforAGE", finanziato dalla Commissione Europea con contratto n. 321482 nell'ambito del 7° Programma Quadro per la Ricerca – Scienza nella Società.

Programma di Lavoro – WP2 – Task 2.3: "Organizzazione dei Caffè Tecnologici".
Ciascuno dei 4 Caffè Tecnologici organizzati a livello europeo coinvolgerà anziani con caratteristiche diverse; a Torino verranno coinvolti nell'uso del portale "Torino Facile" al fine di testare quali tipi di strumenti siano meno inclini ad agire in modo "minaccioso" per le capacità e la considerazione di se' degli anziani. In particolare, l'interesse è concentrato sull'analisi degli eventuali effetti minacciosi che gli stereotipi degli anziani possono avere rispetto all'utilizzo di strumenti tecnologici (come un portale di servizi erogati attraverso internet).

A) SCOPO DELLO STUDIO:

Questo studio è parte del progetto di ricerca co–finanziato dalla Commissione Europea. Lo scopo generale è il rafforzamento degli strumenti a disposizione e dei meccanismi di cooperazione tra gli stakeholder che operano nel settore dell'invecchiamento sano ed attivo: dagli scienziati agli utenti finali, dalla società civile alle pubbliche amministrazioni e ai divulgatori scientifici. Il fine è quello di migliorare la performance competitiva e di crescita dell'Unione Europea, attraverso la ricerca e lo sviluppo di prodotti innovativi per vite migliori e più lunghe.

Le è stato chiesto di partecipare perché il progetto necessita del contributo di persone differenti e di specifici gruppi di partecipanti.

La partecipazione a questa ricerca Le permetterà di avere una visione dall'interno di un progetto di ricerca internazionale e Le darà l'opportunità di interagire con applicazioni e dispositivi innovativi. Nel lungo periodo, il suo aiuto contribuirà allo sviluppo di tecnologie più fruibili.

B) SOGGETTI PARTECIPANTI:

Stimiamo che aderirà a questo studio un numero di partecipanti pari a 40.

I criteri di selezione dei partecipanti saranno identificati in maniera appropriata rispetto agli scopi che la ricerca si propone e saranno definiti senza alcuna distinzione di razza, sesso, o relative alla situazione, con lo scopo di testare strumenti innovativi nell'ambito dell'e–government, per identificare le soluzioni più adeguate in relazione alle capacità e alle condizioni degli anziani partecipanti alla ricerca (fasce di età 55-65 e +65).

C) DESCRIZIONE DELLA RICERCA:

Nello specifico, nel Caffè Tecnologico attraverso incontri informali si cercherà di migliorare la conoscenza delle dinamiche di approccio alle tecnologie da parte del campione, delle difficoltà legate all'ambiente socio culturale, all'ambiente fisico e alla disponibilità di risorse sul territorio.

Il Caffè Tecnologico coinvolgerà anziani con caratteristiche diverse. Le varie esperienze produrranno risultati registrati su schede di valutazione; tale lavoro costituirà un input per consolidare, rivedere o ri–orientare le nuove tecnologie collegate alla ricerca sull'invecchiamento e il loro sviluppo.

I risultati saranno di supporto alla costruzione di un'analisi delle barriere che gli anziani devono superare per utilizzare la tecnologia; essi potranno influenzare lo sviluppo di tecnologie interessanti e disponibili per l'uso da parte di persone anziane.

D) COSTI:
La Sua partecipazione al Caffè Tecnologico è gratuita.

I costi per l'organizzazione dello studio sono finanziati dalla Commissione Europea.

E) RISERVATEZZA:
Le informazioni private che La riguardano e che La identificano potrebbero essere usate o condivise per gli scopi del progetto di ricerca.

Un'autorizzazione separata denominata "Modulo di autorizzazione per il consenso informato alla ricerca" Le descriverà i modi in cui l'ente e i membri del progetto SIforAGE garantiranno la Sua privacy e la riservatezza dei Suoi dati.

Lei non acconsentirà all'uso dei Suoi dati prima di aver firmato il modulo di autorizzazione. Non potrà partecipare allo studio senza aver firmato tale modulo di autorizzazione.

F) PARTECIPAZIONE VOLONTARIA E AUTORIZZAZIONE:
La Sua decisione di partecipare o non partecipare a questo studio è completamente volontaria. Se Lei decidesse di non prendere parte allo studio, ciò non inciderà sul tipo e sul livello di assistenza che riceve e non vi sarà alcuna perdita dei benefici a cui ha altrimenti diritto.

La Sua decisione di dare o non dare l'autorizzazione all'uso e alla diffusione delle sue informazioni mediche private per gli scopi dello studio è anch'essa totalmente volontaria; ad ogni modo, se Lei si rifiutasse di firmare il modulo di autorizzazione o se ritirasse la Sua autorizzazione, non potrà ulteriormente partecipare allo studio.

G) RITIRO DALLO STUDIO E/O RITIRO DELL'AUTORIZZAZIONE
Qualora Lei decidesse di prendere parte allo studio, potrà ritirarsi dalla partecipazione in qualunque momento senza alcuna penalità o perdita dei benefici a cui ha diritto.

Lei potrà anche ritirare la Sua autorizzazione all'uso o alla divulgazione delle sue informazioni personali. Se decide di ritirare il Suo consenso, Le chiediamo di contattare il Ricercatore Responsabile e di metterlo a conoscenza della Sua decisione.

Il Ricercatore Responsabile per l'Italia del Progetto può essere contattato al seguente indirizzo:

Ileana Leardini, Città di Torino – Direzione Centrale Politiche Sociali – SFEP

Via Cellini, 14 Torino tel. 011/4428910 - 11. Mail: sfep@comune.torino.it

Si ricordi che il ritiro dell'autorizzazione influisce esclusivamente sull'uso e sulla condivisione dell'informazione seguenti alla ricezione della Sua richiesta scritta e che Lei non può ritirare l'Autorizzazione per gli usi e le divulgazioni che sono già state effettuate o che devono continuare ad essere effettuate al fine di completare analisi o report dei dati per la ricerca.

Il Ricercatore Responsabile o un altro membro del team di ricerca discuterà con Lei ogni Sua considerazione che riguardi l'interruzione della Sua partecipazione allo studio. Verrà informato su come ritirare la propria partecipazione dallo studio e potrebbe esserLe chiesto di tornare per un controllo finale.

Il Ricercatore Responsabile può anche decidere di escluderLa dallo studio per una serie di ragioni. Alcune possibili motivazioni per il ritiro di un soggetto dalla ricerca potrebbero essere riferite al manifestarsi di stress mentale o fisico o relative ad un peggioramento delle condizioni di salute o ad altre situazioni che potrebbero rivelarsi pericolose per Lei. Inoltre, qualora Lei non volesse o non potesse seguire le istruzioni fornite dal ricercatore, la sua partecipazione allo studio verrebbe interrotta.

CONFERMA DELLE INFORMAZIONI

Parte della procedura di consenso include la Sua autorizzazione alla partecipazione alla ricerca sopra descritta. Lei dovrà esprimere, su un modulo a parte, il Suo consenso all'utilizzo, per gli scopi dello studio, dei dati personali in materia di informazioni sensibili e informazioni di salute.

Se Lei non vuole autorizzare l'uso di queste informazioni, non dovrebbe acconsentire alla partecipazione allo studio.

Con la sottoscrizione del presente modulo dichiaro di aver letto e compreso tutte le informazioni sopra riportate e di aver ottenuto risposta a tutte le domande proposte.

Nome in stampatello del partecipante

_____/_____

Firma del partecipante /Data

_____

Nome in stampatello della persona che ottiene il consenso

_____/_____

Firma della persona che ottiene il consenso/Data

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