Virtual coaching to support a healthy and meaningful life of older adults and employees in their retirement process

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0.5	09.07.2020	Elske Stolte	Added information on Dutch Ethical National Legislation
1.0	20.07.2020	Sara Santini	Integration from Austria and the Netherlands accepted and minor formal changes

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1 EXECUTIVE SUMMARY

This document is aimed at describing all ethical procedures of the project, including detailed roles and responsibilities of the Ethics Committee in Austria, Italy and the Netherlands according to the different data collections strategies, which will be carried out in the three countries i.e. pre-trial through focus-groups in Austria and trial with the use of the digital coach in Italy and the Netherlands.

The overall objective of this document lies in providing guidelines for an implementation of the AgeWell study in Austria, Italy and the Netherlands that can address all ethics issues in accordance to ethical standards, national regulations and relevant EU directives, e.g. 95/46/EC. To this purpose, this document first identifies every ethics issue that can arise during the pre-trial and trial implementation and explains how every issue will be addressed by the consortium.

The specific objectives of this document are to proof how to: a) respect privacy and intimacy of the involved end users; b) ensure the confidentiality of personal data transmitted to external services: c) achieve a high level of security regarding potential risks and critical situations during the use of the digital coach.

1.1 METHODOLOGICAL APPROACH

The AgeWell project aims at developing a technology which can help older workers and retirees experiencing a successful, happy and healthy retirement by means of contents and activities that can improve their physical activity, socialization and mindfulness. This deliverable is devoted to the treatment of the ethics issue which can occur during the life-cycle of the project. The document provides a review of the standing national and international legislations on Ethics concerning research projects involving human beings. It therefore shows how the AgeWell consortium will address the ethics issues arising during the trial, in order to meet the required ethic standard both at national and international level.

The document is closely related to:

D1.2 “Data protection and privacy”

D2.1 “Focus group plan”, which describes the methodology and the plan for collecting end-users‘ perspective on the digital coach, according to the User Centered Design approach”

D4.1 “Field study design” which describes the methodology and the contents of the field trials aimed at testing the impact of the digital coach on older adults near to retirement and on older workers‘ wellbeing”.

1.2 DOCUMENT STRUCTURE

This document provides international and national guidelines on ethics issues and their implications relating to the AgeWell project and the methodologies used (chapter 2). Then it enters on the European and individual country regulations applicable to and addressed by the

project and in particular in the field experimentation and trials (chap 3.1 and 3.2). It also clarifies the issues of respect for the privacy and intimacy of the involved end users (chapter 3.3) and how personal data will be transmitted externally (chapter 3.4). It therefore focuses on ethics issues that specifically concern the security (chap 3.5) and acceptability of e-health technologies among adults (chap 3.6). Finally, the approval procedures of the individual ethics committees of the countries involved in AgeWell are described (chapter 4).

2 ETHICS ISSUES AND AGEWELL STUDY

2.1 GENERAL ETHICS CONSIDERATIONS

Research activities, in any way related to or performed on humans, open important ethical questions and need thorough consideration before and during their planning and conduction. Also, these aspects are not to be neglected on the level of implementation of results. Additionally, the project dimensions related to ethical issues involve consideration of EU regulation and national law regarding research on humans. Risk in research is “often defined by reference to the potential physical or psychological harm, discomfort or stress to human participants that a research project might generate. This is especially pertinent in the context of health-related research.” (The Charter of Fundamental Rights of the EU, Strasbourg, Dec 7, 2000). Furthermore, the use of technology takes additional ethics issues in terms of security and risk of stigma.

2.2 AGEWELL OBJECTIVES AND ETHICS IMPLICATIONS

In this respect, the AgeWell project is a 36-month research project aimed at designing a digital coach for older workers and retirees supporting them through their transition from work to retirement. AgeWell stands on two pillars: a) the technology design and b) the technology test for which it involves human beings but to the only purpose of capturing their perspective on the use of technology and the digital coach. The digital coach indeed, is designed following the User Centred Design (UCD) approach. According to the latter focus-groups involving older workers, retirees and their family members and/or colleagues were carried out in three waves, in Austria, Italy and the Netherlands, as described in D2.1.

The outcomes of the focus-groups give inputs and insights to the development of the AgeWell digital coach technical requirements. Once the virtual coach is developed, its impact on older workers and retirees‘ wellbeing is tested by means of a trial involving 100 older adult individuals near to retirement (50 in Italy and 50 in the Netherlands). The trial procedure, research tools and methodology are fully described in D4.1.

Therefore, in general terms, this study does not involve any pharmacological intervention. All the countries involved in the study ensure compliance with all national and EU regulations which are in force for all legal, ethical and research aspects of the project.

3 ETHICAL RESEARCH PRINCIPLES IN THE AGEWELL STUDY

The study will be carried out according to the general ethical requirements stipulated in the Helsinki Declaration and will be conducted in accordance with the principal international documents and provisions relating to human research such as charters, conventions,

declarations, international and national laws, regulations and recommendations constituting the grounds for ethics issues management for research. In addition, national ethical and legal requirements will be met in full in respect of the participating countries where the study sites are located. Prior to field work to start, the study protocol, developed by the Consortium will be submitted to the competent local Ethical Committees for approval (in line with national and applicable law). Each country partner is responsible for the communication with the local Ethical Committee and obtaining final ethics approval before the field study. An approval must be obtained before the study starts.

3.1 INTERNATIONAL AND EUROPEAN REGULATIONS

The relevant international and EU guidance that will govern the AgeWell project will be, among the others:

The Charter of Fundamental Rights of the EU (Strasbourg, Dec 7, 2000): article 3 of Chapter 1 (dealing with free and informed consent according to procedures laid down by the law), article 8 of Chapter 2 (dealing with protection of personal data) and article 25 of Chapter 3 (dealing with the rights of older people to dignity and independence);

The Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects. The current revision of the Declaration of Helsinki (as updated during 64th WMA General Assembly in Fortaleza, Brazil, October 2013) is the accepted basis for clinical study ethics, and must be fully followed and respected by all engaged in research on human beings. Any exceptions must be justified and stated in the protocol. Independent assurance that subjects are protected can only be provided by an Ethical Committee and freely-obtained informed consent;

The General Data Protection Regulation (GDPR, Regulation EU, 2016/679): dealing with the protection of persons in relation to the management of personal data and the transfer of those data.

3.2 NATIONAL REGULATIONS

3.2.1 Austria

In general, research in Austria follows:

- The Charter of Fundamental Rights of the EU (2000/c 364/01),
- REGULATION (EU) 2016/679 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation)[1],

[1]

- The reform of the data protection rules that was launched on January 2012 is not in force yet, but we will consider it and apply once it will be in force,
- Directive 2001/20/EC of 4 April 2001 on clinical good practice,
- Directive 98/44/EC of the European Parliament and of the Council of 6 July 1998 on the legal protection of biotechnological inventions,
- Opinions of the European Group on Ethics in Science and New technologies including in particular:
    - Opinion of the European group on ethics in science and new technologies to the European commission, number 7, 21st of May, 1996
    - Opinions of the European Group on Ethics in Science and New technologies (as from 1998)
- Helsinki Declaration in its latest version.

Additionally, in Austria it is distinguished between areas you have to consult an ethics committee and areas where you can do this on a voluntary basis[2]. Mandatory areas of application are clinical tests of drugs and medical products and the use of new medical methods as well as applied medical research with humans. For all other research it is necessary to find a (voluntary) ethics committee or board which is willing to evaluate the research. Many ethics committees specialized on medical topics declare that they are not responsible for AAL topics. Thus, a medical or voluntary ethics committee or board has to be found in order to get an ethics vote for AAL activities. Voluntary ethics committees or boards in Austria rely on *The European Charter for Researchers*[3].

With respect to the Austrian user involvement parts of AgeWell (focus groups and pre-trials) the ethics board of the University of Applied Sciences Wiener Neustadt will be contacted.

3.2.2 Italy

The national requirements for privacy and data protection, also in relation to sensitive data (e.g., health status), are described herein.

REGULATION (EU) 2016/679 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 27 April 2016, source: http://ec.europa.eu/justice/data-protection/reform/files/regulation_oj_en.pdf

[2] Austrian Federal Ministry of Education, Science and Research – Ethics committees: https://www.bmbwf.gv.at/Themen/Hochschule-und-Universit%C3%A4t/Hochschulgremien-und-akteur-innen/Ethikkommissionen.html, 25.06.2020

[3] The European Charter for Researchers: https://cdn2.euraxess.org/sites/default/files/brochures/eur_21620_de-en.pdf, 25.06.2020

INRCA will carry out the study in accordance to the Italian Laws on privacy and data protection, the Legislative Decree n. 196 of 30th June 2003- Personal data protection code.

This law ensures that personal data are processed by respecting data subjects' rights, fundamental freedoms and dignity, particularly with regard to confidentiality, personal identity and the right to personal data protection.

The processing of personal data shall be regulated by affording a high level of protection for the rights and freedoms in compliance with the principles of simplification, harmonisation and effectiveness of the mechanisms by which data subjects can exercise such rights and data controllers can fulfil the relevant obligations.

A data subject shall have the right to be informed:

a) of the source of the personal data;

b) of the purposes and methods of the processing;

c) of the logic applied to the processing, if the latter is carried out with the help of electronic means;

d) of the identification data concerning data controller, data processors and the representative designated;

e) of the entities or categories of entity to whom or which the personal data may be communicated and who or which may get to know said data in their capacity as designated representative(s) in the State's territory, data processor(s) or person(s) in charge of the processing.

Personal data concerning health status are deemed "sensitive". These kinds of data shall be kept separate from any other personal data that is processed for purposes for which they are not required. These data shall be processed in accordance with the provisions foreseen by the same law also if they are contained in lists, registers or data banks that are kept without the help of electronic means.

The Code of ethical conduct and professional practice applying to processing of personal data for statistical and scientific purposes (Provvedimento del Garante n. 2 del 16 giugno 2004, Gazzetta Ufficiale 14 agosto 2004, n. 190) is adopted according to the Section 106 of Legislative Decree no. 196 of June 30, 2003 containing the personal data protection Code (hereinafter referred to as the "decree"), on the basis of the following premises:

1) The provisions of this Code of conduct and professional practice are aimed at reconciling the individual's fundamental rights and freedoms, in particular the right to personal data protection and the right to privacy, with the requirements of statistics and scientific research as deriving from the principle of freedom of research set forth in the Constitution, which is a precondition for scientific development, improvement of individuals' life-styles, and the growth of a democratic society;

2) Researchers working, whether alone or jointly with others, within universities, research bodies and institutions, and scientific societies, shall abide by this Code in all stages of

processing personal data for statistical and/or scientific purposes regardless of whether the respective bodies and scientific societies have undersigned this Code.

This Code shall apply to all the processing operations carried out for statistical and scientific purposes - pursuant to the relevant sector-related methodological standards - in respect of which universities, other research bodies or institutions, and scientific societies, as well as researchers working within the framework of said universities and research bodies and institutions, and members of said scientific societies, act as data controllers.

Any research shall be carried out on the basis of a project to be drawn up according to the relevant sector-related methodological standards, also in order to prove that the processing is performed for suitable, actual statistical or scientific purposes.

According to the Law, in the treatment of data disclosing health status, Italian research institutions delivering the study, will observe the rules of confidentiality and security required to all health professions and operators, and comparable rules of confidentiality and safety.

Italian Organisations carrying out the AgeWell study will respect the prerequisites for the processing and measures to be adopted for providing information notices, communication and dissemination regulated by the Code.

In this respect, at article 11. Provisions Applying Specifically to Medical, Bio-Medical, and Epidemiological Research, the Codes states that medical, bio-medical, and epidemiological research shall be carried out in compliance with international and Community guidelines and provisions applying to this subject matter, such as the Convention on Human Rights and Biomedicine of 4 April 1957, as ratified by Act no. 145 of 28 March 2001, Council of Europe's Recommendation No. R(97)5 adopted on 13 February 1997, on the protection of medical data, and the World Medical Association Helsinki Declaration on the principles for medical research involving human subjects.

Security and rules of conduct are also regulated by the Code, in terms of selection of professionals belonging to the research team, data collection and retention procedures, security measures and exercise of data subjects' rights.

3.2.3 The Netherlands

The same general EU regulations apply in the Netherlands as stated in paragraph 3.1. Regarding the GDPR there is ongoing work to revise Code of Conduct for the use of data in health research which has lead to the COREON statement 'further use' of personal data for scientific research, which states that further data processing for scientific research or statistical purposes is not incompatible with the original purpose, and the COREON statement Scientific research which elaborates on the definition of the term scientific research (https://www.federa.org/codes-conduct).

Furthermore, there is a national law 'Medical Research Involving Human Subjects Act' (WMO, Wet medisch-wetenschappelijk onderzoek met mensen, https://wetten.overheid.nl/BWBR0009408/2020-01-01), which states that if a study 1. Concerns medical scientific research AND 2. Participants are subject to procedures or are required to follow rules of behaviour, then it must undergo a review by an accredited MREC or the CCMO (https://english.ccmo.nl/investigators/legal-framework-for-medical-scientific-

research/your-research-is-it-subject-to-the-wmo-or-not). The WMO does not offer a definition of the term medical-scientific research. As a result, it is not always clear if the research protocol must be submitted for review by law. In general research which only involves filing in a questionnaire does not fall under this law, however if the questions are taxing for a participant, asks intimate questions or if it takes a lot of time and effort to participate it might be (https://www.ccmo.nl/onderzoekers/soorten-onderzoek/overig-onderzoek/vragenlijstonderzoek). If in doubt, there is a procedure to check if the study falls under the WMO. For social science research there are further guidelines to decide whether a study falls under WMO regulations (https://www.ccmo.nl/onderzoekers/publicaties/publicaties/2001/12/01/ccmo-notitie-gedragswetenschappelijk-onderzoek-en-de-wmo-enkele-conclusies), however they are inconclusive regarding so called grey area research. Therefore, it is necessary to check with the local MREC if the study falls under the WMO or not.

3.3 RESPECT PRIVACY AND INTIMACY OF THE INVOLVED END USERS

Each person enrolled in AgeWell will be included in the study on a voluntary basis and after signing an informed consent form and Information Sheets that will have been approved by the Ethical Committee at each study site before the start of the study and signed before enrolment by each individual. All individuals included in the study will be provided with:

- Questionnaire in three versions (baseline, mid-term and post intervention)
- Informed Consent Forms including the Information Sheets

The documents above will be approved by the Ethical Committee at each study site before the start of the study, i.e. enrolment of the first participant.

AgeWell will not involve vulnerable groups needing special consent to attend by legal tutors or family carers.

It is the responsibility of the investigators to conduct the study according to the protocol and to ensure that (s)he has the subject availability to conduct the study within the period defined in the study protocol. The Responsible Investigator of any given recruiting centre will be personally responsible for the implementation of ethical requirements.

The local Ethical Committees from participating sites will approve the study protocols related to activities with end users (older workers and retirees).

3.4 ENSURE THE CONFIDENTIALITY OF PERSONAL DATA TRANSMITTED TO EXTERNAL SERVICES

The AgeWell project will collect personal data concerning older adults guaranteeing their secure storage and treatment, as well as the anonymity of published results. Only relevant data will be collected (as listed in the study protocol, D4.1) and this will not be more than what is needed for the research study. In terms of data protection, the proper use of personal data will be monitored and certified throughout the project and researchers will use internationally recognized and globally accepted standards and on the legal environment of each country where the research will take place. The confidentiality of the participants and data protection

will be assured according to the relevant standards in EU countries, including compliance with the General Data Protection Regulation (EU) 2016/679 (GDPR). Data storage, process and treatment will be a centralized task for the coordinator.

AgeWell will collect sensitive data on health, wellbeing, lifestyle and other key demographic aspects. Appropriate additional measures for data security and protection will be put in place. Identification codes will be used to uniquely identify each person involved and related data; the list associating involved individuals and respective identification codes will be stored separately by each partner responsible for national data collection, and made available only to ethics committees or relevant authorities upon request.

All information and documentation concerning the ethics and recruitment process will be stored safely and kept by each partner responsible for the national trial according to national legislation and EU regulation, in line with the data management plan (D1.2 Data protection and privacy). Copies of such information and documentation will be submitted to the European Commission and relevant authorities on request.

Furthermore, the following details and information will be produced and provided to the European Commission as soon as they will become available during the project:

- the procedures and criteria that will be used to identify/recruit research participants;
- the informed consent procedures that will be implemented for the participation of humans, including details on incidental findings policy;
- the measures taken to prevent the risk of enhancing vulnerability/stigmatisation of individuals/groups.

3.5 ACHIEVE A HIGH LEVEL OF SECURITY REGARDING POTENTIAL RISKS WITH RESPECT TO THE AGEWELL COMPONENTS

Details on how the consortium deals with security and privacy in the project can be found in D3.2 AgeWell Security and privacy concept and implementation.

3.6 ETHICAL ACCEPTABILITY OF E-HEALTH TECHNOLOGIES AMONG OLDER ADULTS

Advancements in Information and Communication Technologies (ICTs) have enabled the creation of artifacts to cope with the escalating needs of the population ageing. Every day, these devices support healthcare for clinical purposes and gather, transmit, curate, label, store and analyze personal data. Despite the great opportunities offer by the ICTs advancements, several ethical considerations are reaching the interest and concerns of the relevant literature. For example, the **privacy and intrusiveness** appear to be the most cited complains in researches on the field of e-health for older adults [1-2].

The debate about the values that should underline the development and integration of social robots as well as virtual personal assistant like AgeWell virtual coach, into the homes of older

people as well as older adults, can provide a 'presence' in the home that other technology cannot. In this way, the user is assisted by fetching and carrying, by keeping track of his or her preferred routine. In the same way, the robot or the avatar can sometimes be intrusive, collect and communicate data potentially at variance with the user's wishes, and help to connect the user to an outside world that can present dangers [3]. In this respect, the **individual's right to control the access of personal data**, physical and personal space as well as the act of respecting the decision of sharing this sensitive information, represents a significant challenge associated with new technological development.

Another significant ethical concern is the **stigma** effect that refers to the association of a subject with the disease or health condition and the related impact in the user's sense of identity. These ethical issues can be considered severe hindrances to the uptake of technologies in favor of older adults.

Unfortunately, there is a relatively small body of literature that is concerned with perceptions toward ethical issues from real users or predictors of ethical acceptance in the e-health research field. To cover this gap, the AgeWell study foresaw the risk for stigma during the process of the user centred design (UCD) in order to mitigate such a risk as much as possible. Moreover, the AgeWell data collection tool also included questions on privacy and stigma to monitor these aspects during the experimentation.

Nevertheless, significant countermeasures can be considered to manage the ethical acceptance.
Firstly, **older adults need to be informed** and reassured in order to avoid misperceptions, fears, doubts or negative perspective about smart home health technologies [4]. For example, the use of effective information sheet, written informed consent and the support of a researcher in touch with the participants can both ensure voluntary participation and improve ethical acceptance of technologies.
Secondly, if technology meets the users' **expected benefits**, ethical concerns are no longer important issues [4]. Literature shows that in some cases participants seemed aware to choose the health monitoring benefit driven by technology over risks related to sharing personal data. As a result, during information exchange, negative consequences were rationally weight against goals and possible outcomes, aiming to maximize benefits and minimize the future privacy risks [5]. Hence, subjects' intentions and behaviors were positively influenced by expected benefits.
These two points demonstrate the importance to spread awareness and knowledge among end users about technology's benefit and utility. Many older adults have no understanding of how technology can influence their day-to-day's activities but through meaningful learning and training, they can rationally weight benefits against risks.

The AgeWell consortium tried to address the two issues above by writing clear but short and understandable information sheet for the individuals included in the study, where also potential benefits of the technology were explained (e.g. stimulation, motivation, healthy life style, etc).

4 PROCEDURES OF APPLICATION TO NATIONAL/LOCAL ETHICS COMMITTEES

4.1 AUSTRIA

As described in Section 3.2.1, in Austria it is distinguished obligatory and non-obligatory areas when it comes to the consultation of an ethics committee/board. If an AAL service/product is not a medial product or does not deal with clinical tests of drugs the consultation of an ethics committee is voluntary. Nevertheless, the Austrian partners decided to consult the ethics board of University of Applied Sciences Wiener Neustadt.

Following documents have to be provided to the ethics board:

- Application for assessment
- Study protocol
- Information letter and informed consent

4.2 ITALY

In Italy, the INRCA Bioethics Committee is composed of President Dr. Marco Giulioni; Secretary Dott.ssa Dott.ssa Anna Rita Bonfigli, E-mail: committeeetico@inrca.it, tel Tel. 0718003500 - 3719

The Principal Investigator of every research study of whatever kind i.e. Randomised Controlled Trial, Observational, Pharmaceutical or Behavioural is required to provide the EC with the following documents:

- the study synopsis (a brief presentation of the project's objectives, materials and methods),
- the data collection tools e.g. topic-guide interview, questionnaires including all scales and measures which will be adopted during the study
- the information letter for the subject participating in the study
- the informed consent

Moreover, the following specific forms are also required, signed by the project manager:

- Transmission letter requesting the opinion of the committee and the company authorization

- DECLARATION OF CONFORMITY TO THE MINISTRY OF HEALTH DECREE 17/12/2004

- MODEL OF PUBLIC DECLARATION ON THE CONFLICT OF INTERESTS OF THE EXPERIMENT

Lastly, the updated curriculum in European format of the PI is required.

The committee meets about 2 times in a month and the documents to be submitted to its attention must be prepared at least a week before, to allow an adequate vision. Generally, the evaluation and response time does not exceed 3 months, therefore it is necessary to move well in advance.

The illustrated trial protocol was drawn up in accordance with the European Union's Standards of Good Clinical Practice and the current revision of the Helsinki Declaration, and has been submitted for approval by the Bioethics Committee of this Institute.

4.3 THE NETHERLANDS

In the Netherlands social science research which is "standard" and conforms to the guidelines below, don't need further review by the Medical Research Ethics Committee (MREC, https://english.ccmo.nl/investigators/legal-framework-for-medical-scientific-research/your-research-is-it-subject-to-the-wmo-or-not).

In "standard" research:

- No harm is envisaged for the participants or the population from which participants have been drawn
- Participants receive complete and accurate information about the goals of the research before they participate
- Participants give active consent for participation in the research
- Participants are not deceived without being thoroughly debriefed
- Participants are healthy adults who are not in a vulnerable position
- Personal and sensitive data are kept confidential and are stored in a secure environment.

In order to obtain an official waver for ethics approval in The Netherlands Gouden Dagen will apply at the Medical Ethical Committee in Utrecht for a wave of full ethics approval.

When a waver for Medical Ethical approval is given then the so called WMO-law does not apply. Gouden Dagen is responsible for following the General Data Protection Regulation (GDPR) and making sure the list above is followed during the study in the Netherlands. Gouden Dagen will follow the AgeWell field trial research protocol. Procedures for informed consent and data handling will be the same in Italy and the Netherlands. Participants will receive the Dutch version of the information letter and informed consent form.

5 CONCLUSIONS

This deliverable reported laws regulating the ethics in the research involving human beings and the procedures that the partners which will carry out the trial will need to observe to apply for the local ethics committee. The application to the latter will represent the next step towards the pilot-study due to September 2020 and the experimentation of the AgeWell digital coach whose beginning is planned for November 2020. The feedback from the ethics committees will give inputs and insights for fine-tuning the protocol, the information sheet and the informed consent such that the AgeWell trial will fully address all the foreseen ethics issues and will be respectful of participants' rights to be informed on the project and to be sure that their data will be treated confidentially.

6 REFERENCES

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