

AMBIENT ASSISTED LIVING (AAL)  
JOINT PROGRAMME

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

**D1.3 Ethical project guidelines**

Project acronym: **ActGo-Gate**

Project full title: **Active Retiree and Golden Workers Gate**

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## CHANGE HISTORY

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1.0	Philipp Menschner	19.01.2015	Updating of existing material
1.1	Philipp Menschner	27.02.2015	V1 completed

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## **TERMINOLOGY & ABBREVIATIONS**

To assure coherent terminology and abbreviations across all documents inside the project, the specific terminology and abbreviations for this deliverable should be written here.

E.g. .... Example given

## EXECUTIVE SUMMARY

These ethical project guidelines are intended for the research and development project ActGo-Gate. Throughout the ActGo-Gate project, many ethical, privacy, and usage issues related to the end user may occur. It is the responsibility of the partners involved to identify and integrate ethical standards from the very beginning. It is important to ensure that these issues are addressed in a professional manner and do not overlook the importance to maintain these ethical standards throughout all work.

As defined within Task T1.2, this deliverable serves to provide the necessary guidelines in approaching the pilot studies for the execution of ActGo-Gate project. Pilot studies and the technical components designed/developed during the project will adhere to these guidelines to ensure that the necessary ethical considerations are met. There are two main objectives to be met through this deliverable:

- (1) Respect the privacy and intimacy of end users involved, in particular end users and
- (2) Ensure the confidentiality of personal data that will be transmitted to any organisation.

More specifically, all partners of the ActGo-Gate project will cooperate to ensure that all concepts developed in WP2 and the technical components developed and tested during the project (WP3 and WP4) will be subject of ethical supervision by the project coordinator.

This document is the Ethical Project Guidelines for the ActGo-Gate project, Deliverable 1.3. Based on international and national standards, it categorizes two areas of ethical concern within the execution of the project: privacy of end users, and confidentiality of personal data. These ethical issues are addressed and methods of prevention are provided.

# 1 INTRODUCTION

The vision of the ActGo-Gate project is to inspire and enable people to get involved in social activities, voluntary work and micro-tasks by providing them with easy-to-use ICT-supported solutions. In doing so, the ActGo-Gate project increases transparency of demands and offerings in social marketplaces, allowing for flexible and self-determined participation. The purpose is to strengthen social ties and mutual support as well as to improve quality of life.

The purpose of the following ethical project guidelines is to increase the mutual trust between the ActGo-Gate project and all external subjects involved, in particular potential participants and strengthen the trust among the involved project partners. Furthermore these ethical project guidelines aim to make scientists and end user organisations aware of their responsibility regarding their research work and possible impacts of the outcome.

An analysis of the literature suggests that user involvement has generally positive effects, especially on user satisfaction, and some evidence exists to suggest that taking users as a primary information source is an effective means of requirements capture.

However, the role of users must be carefully considered and more cost-efficient practices are needed for gathering users' implicit needs and requirements in real product and software development contexts.

User involvement is a widely accepted principle in development of usable systems. However, it is vague concept covering many approaches. The ethical project guidelines first clarify general principles for the ActGo-Gate project, and secondly review the relevant legal basis for the project countries and other instances. Third, information will be defined that ensure that potential participants are fully informed about the research project.

## 2 GENERAL PRINCIPLES FOR THE PROJECT

The goal of the ActGo-Gate project is to develop a service platform that will inspire and enable people to get involved in social activities, voluntary work and micro-tasks by providing them with easy-to-use ICT-supported solutions. In doing so, the platform should increase transparency of demands and offerings in social marketplaces, allowing for flexible and self-determined participation. The efforts aim is strengthening social ties and mutual support as well as improving quality of life.

The target groups of the platform are golden workers and active retirees which are people between 50 and 75 years old. Ethical aspects will not only affect the end-users participating in the project, but will also be considered relevant for the people and organisations participating in the project, and in general terms, will cover the limitations and regulations that must be applied to every project activity: research, development, testing, evaluation and dissemination.

As a basis for action in this research project principles are needed that can ensure proper development and implementation of a technical solution that will facilitate the success of the research project. People and organisations participating in the project will guide their activities by means of the following four principles (Beauchamp & Childress, 2013):

- Respect for autonomy. With the general aim of promoting the participants' cognitive and functional abilities, participation in the project and in the general operation of its outcome should be based upon a process of informed consent, and the participants right to control his or her personal information will be respected at all times (this includes issues of confidentiality and data security).
- Non maleficence. The project and the operation of its outcome should not harm the participant, or put him or her under unacceptable risk (this includes risks to privacy).
- Beneficence. The project and the operation of its outcome should benefit the participant according to his or her own conception of the good (this is a nonpaternalistic interpretation of the principle, and includes ensuring that participants hold authentically those conceptions).
- Justice. The project and the operation of its outcome 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 user trials). Benefits of the study will be shared with the involved communities (this includes publication of the results of the project).

These principles should be respected by all project partners in the ActGo-Gate project and be observed over the entire project duration and beyond if information, knowledge, and outcome that have been gained in the project are also used thereafter.

### 3 RELEVANT LEGAL BASIS

In addition to the previously defined general principles this chapter will show the central international and national laws, directions, and legal documents that are key documents for the ActGo-Gate partners. The partners were recommended to review and study the documents prior to arranging research activities with potential participants or users. Listed below are also national committee, agencies and organizations that can provide further assistance in conducting ethically sound research.

#### 3.1 European Union

Due to the public funding of ActGo-Gate project by the AAL JP legal foundations for ethics and privacy for the ActGo gate project is an essential basis. EU regulations, especially such that address data protection and privacy, are implemented by the EU Members.

- In 2012 the European Commission proposed a reform of the EU's data protection rules to make them fit for the 21st century. The reform consists of a draft Regulation setting out a general EU framework for data protection and a draft Directive on protecting personal data processed for the purposes of prevention, detection, investigation or prosecution of criminal offences and related judicial activities. This process, leading into a new Data Protection Regulation is expected to be finished in 2015. Prior to the first preparation of this document, the new reform has not yet come into force. Once the new reform comes into force, this document should be revised and adapted
- Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data.
- Directive 2002/58/EC of the European Parliament and of the Council of 12 July 2002 concerning the processing of personal data and the protection of privacy in the electronic communications sector (Directive on privacy and electronic communications).
- Directive 97/66/EC of the European Parliament and of the Council of 15 December 1997 concerning the processing of personal data and the protection of privacy in the telecommunications sector.

#### 3.2 Switzerland

- Federal Act on Data Protection (FADP) of 19 June 1992 (Status as of 1 January 2014).
- Ordinance to the Federal Act on Data Protection of 14 June 1993 (Status as at 1 December 2010)



- In addition, further data protection statutes are also found at individual canton levels. Each canton in Switzerland has a cantonal data protection act in place. These cantonal acts are directed to cantonal governmental bodies as data controllers.

Switzerland, not being a member of the EU, applies its own federal law which is outside of the scope of DP Directive. However, the Swiss law follows the same approach as the DP Directive and the law was also recognized as providing adequate data protection for the purposes of transfer of personal data outside of EU/EEA. The European Commission has taken a Decision pursuant to Directive 95/46/EC stating that the level of Data protection is equivalent to that in the EU. That has as a consequence that personal data may be transferred to Switzerland just as if Switzerland was member of the European Union. No additional issues arise therefore from the fact that one of the partners is based in Switzerland.

### 3.3 Germany

- Federal Data Protection Act (*Bundesdatenschutzgesetz*) (BDSG). Aim is to protect personal data from processing and use by federal public authorities and private bodies.
- Additionally, each German state has a data protection law of its own.

### 3.4 Poland

- Act of August 29, 1997 on the Protection of Personal Data (unified text – Journal of Laws of 2014, item 1182, with amendments).
- Constitution of the Republic of Poland (Articles 47 and 51). Resolution of the first Polish Act on the Protection of Personal Data being a manifestation of progressing democratization of public life in Poland and concern for the protection of privacy of every Polish citizen. Article 47 guaranteeing everyone's right to privacy and Article 51 guaranteeing everyone's right to have the information pertaining to him/her protected.

## 4 INFORMATIONS FOR USER

This chapter introduces documents that are necessary for ensuring the adherence to the presented ethical project guidelines. It is important to inform the involved persons about all aspects of the research, their input and the accordant data protection and privacy.

### 4.1 General information policy

The ActGo-Gate project consortium guarantees that no research with the participants will be conducted without assuring and obtaining an informed consent. Informed consent is the process by which a participant will be fully informed about the research that the participant will be involved in. It originates from the legal and ethical right participants have to direct what happens to them and their personal data and from the ethical duty of the investigators to involve the participants in research.

To guide the process of informed consent, a number of forms comprising an information letter, authorization statements and release forms will be prepared and will be employed in all relevant parts of the project. In order to assure that no misinformation and manipulation can occur, only qualified or trained personnel will conduct the studies. For the reason that most of involvement of users does not happen in English but in German all documents that will affect the participants will be translated to the native language of the participants. The responsible researchers will read the documents of the informed consent together with the potential participant. It has to be assured that the participant understands what will be expected before the participant signs the informed consent. This means that the potential test persons:

- Understand the purpose of the project and the consequences of participation
- Can assess their situation
- Can make an independent and voluntary decision whether to participate on the basis of information supplied and their preferences and values
- Voluntary communicate their decision

### 4.2 Information Letter

The information letter will provide all relevant information to the potential participant before signing it and starting the capturing of user requirements, user test or other tasks where participant will provide information to the ActGo-Gate project. For the purpose of full information to the potential participant the following aspects will be included:

- Title of the project and funding body,
- Project goals and purpose of research, expected duration,
- Participation conditions and procedures,
- Possible risks and benefits to the participant or to others which may reasonably be expected from the research,

- Explanations on confidentiality (and limits) of the data,
- Right to decline participation and to withdraw from the research at any time,
- Consent to be invited again for upcoming studies,
- Contact person for questions about the research in general and the specific study

Due to a broad variation of user involving methods applied in the ActGo-Gate project the information letter for the potential participant has to be created initially, reviewed and possibly revised for the different pilot applications within the ActGo-Gate project.

After giving consent to participate in a specific study every test person receives a complete copy of the informed consent document in case of further questions coming up later. If a test person is invited for several studies, e.g. to conduct various iterations of usability tests and to take part in focus groups, s/he has to give consent for every participation again. Former consent does not apply anymore as studies are different and test conditions can differ too.

## **5 AGREEMENT OF THE ACTGO-GATE CONSORTIUM**

People participating in the project or research parts of the project have the right not to have their identities or the organizations to which they belong revealed. Data protection implies informing the participants about who has access to their data and what may be done with their data. It also implies that the project partners handle the collected data with care and according to the general principles for the project and relevant legal basis.

The agreement with respect to these ethical project guidelines is a document that will be signed by all project partners to assure that the recorded data related to the project will only be used for the foreseen project and research objectives.

## 6 CONCLUSION

This deliverable discusses ethical issues concerned with the execution of the ActGo-Gate project and will be updated as necessary. Issues primarily relate to the inclusion of information from participants during various parts of the project, methods of evaluation, and aspects of data and privacy protection and will be addressed within the consortium. Two main topics were identified as respect the privacy and intimacy of end users involved and the confidentiality of personal data transmitted to external services. To address these concerns, ActGo-Gate partners will ensure that all participation is voluntary and informed of the rights available when participating, including informed consent. In addition, safety measures will be taken in the design and function of the platform to protect the data of users with external services and potential risks of unconscious incurred costs.

## REFERENCES

Beauchamp, T. L., & Childress, J. F. (2013). *Principles of Biomedical Ethics*. Oxford University Press.