

# Ethical Dimensions in the Development of CONFIDENCE

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**Abstract:** Information and communication technology (ICT) developments are targeted as a means to reduce the multilevel burdens associated with demographic change. The project Ubiquitous Care System to Support Independent Living or CONFIDENCE, aims at extending the independence of older people beyond what would be possible without technological support. The goal of this paper is to present the ethical issues that appeared relevant at the concept development stage, and during the project. One ethical dimension is directly associated with the technology and must support principles such as human rights, privacy, and dignity. The other ethical dimension is the voluntary contribution of people as participants in research activities. Ethical review of research plans by ethical committees and informed consent of the participants must be observed in this domain. We conclude that observing ethical issues since the inception of concepts and during the research and development process not only adds to the credibility of the results, but also empowers the users to make informed decisions on the acceptance of ICT once it becomes available.

**Keywords:** Ethics; older people; care system, independent living.

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## 1. Introduction

It is well known that the population is growing older and that the dependency ratio is equally increasing. This demographic phenomenon imposes socioeconomic burdens on the older people, their caregivers, and the health and social care systems. Information and communication technology (ICT) developments are considered as important contributors to reduce these multilevel burdens. The project Ubiquitous Care System to Support Independent Living (CONFIDENCE), aims at enabling older people to live in their preferred environment, i.e., their own home, as long as possible with the support of ICT technologies and services. The system will be able to identify harmful situations, such as falls, and anomalous conditions such as reduced functional ability in the performance of activities of daily living (ADL). Wearable radio frequency (RF) sensors and communication channels are the

technologies that support these functions. A more detailed description of the system is presented in [1] and [2], also presented at this conference. The successful development of this system cannot be conceived without adopting the involvement of the users, i.e., the older people, and other relevant stakeholders, as the gravitational center.

The pioneering field in which ethical guidelines appeared was medicine [3]. Other disciplines such as the social and behavioral sciences have followed [4]. These have also provided their associates with codes of conduct and ethical guidelines to ensure that research with human subjects does not use the right to freedom of research beyond the rights of the participating humans. Freedom, respect for life, justice, beneficence, and privacy are the most salient human rights contemplated in ethical guides.

The goal of this paper is to present the ethical issues that appeared relevant at the concept development stage, as well as those which arise during the project. These may be relevant for other projects addressing research and development (R&D) in the areas of ambient assisted living (AAL), ICT and ageing, and eInclusion.

One ethical dimension is directly associated with the technology under development and how this can affect the potential users when it becomes available on the market. The other ethical dimension within the project is the voluntary contribution of people as research participants.

## **2. Ethics in the dimension of ICT development**

Most of the ethical issues related to research with human participants are well grounded. However, when technological innovations are considered, such as in CONFIDENCE, there might be issues difficult to foresee and difficult to handle. At the beginning of the project, we reasoned that the system ought to support principles such as basic human rights, privacy, integrity, and dignity [5]. It also became apparent that the European regulations on personal data processing were relevant [6], [7].

Freedom is the most valuable of the human rights achieved by human kind. The technology employed in this system shall respect the freedom of choice of the user. The user will be able to decide whether to use the system or not. This might seem obvious; of course, one has the right to switch, for example, the TV on and off. However, in the future of interoperable health and care ICT products the freedom to use a certain component or not, e.g. a monitoring device which causes inconvenience to the user, might not be so straightforward.

The system collects and processes information concerning the users, i.e., 3D bodily posture and motor activity acquired through (RF) tags and sensors, see e.g. [8]. The mechanism implemented by CONFIDENCE to comply with data processing regulations has been to assign the role of data controller to the user. That is, the data collected and processed by the system belongs to and is managed by the user. Privacy is also respected because the system does not share or provide data to other systems or services. The information is relevant for detecting falls and other behaviors that may relate to health problems, and to summon help when there is an emergency. The person controls whether an alarm procedure is initiated or not, except when the person is not capable of acknowledging this situation, for example, when the person is unconscious. In the latter case, the system initiates the alarm without the explicit consent of the user at this particular moment.

Information and training to the user before adopting the system should guarantee that the informed consent of the user for this situation has been provided in advance.

### **3. Ethics in the dimension of research with humans**

The project consortium is multidisciplinary and brings together several social and cultural backgrounds. At the beginning of the project, an ethical manual was elaborated [9]. This serves as the common ethical reference upon which the different disciplines and cultures can rely upon in order to deal with the ethical issues that may arise during the R&D process. Several research activities within CONFIDENCE required the participation of older people, health and social care experts, and family members, or others providing care to older people.

Following a pragmatic approach, two of the partners carrying out research with human participants have established internal ethical committees for this project within their organizations. We direct ethical enquiries to the institutional ethical committee of the university. Ethical approval for two needs and requirements elicitation studies has been obtained from the respective ethical committee of each research site.

During the information consent process, the information sheet and the informed consent were offered to the participants. A requisite for participation in the research was to sign the informed consent form. The information sheet indicated that their participation was voluntary and invited them to read the explanation of the studies. This also stated the purpose of the research, the procedures involved, the potential benefits, risks, discomforts, and precautions of the research. It also described the alternative procedures available to them. In our case, it was indicated that no alternative treatments were available, as these studies did not involve treatment to the participants. The right to withdraw from the study at any time without consequences was also stressed. Confidentiality and anonymity of the information they provided was assured. Their identity will not be disclosed in scientific or other publications, or to third parties. The participants were also reminded of their rights concerning the processing of personal data. Another section of the information sheet considered the possibility of obtaining incidental findings. Therefore, the participants were asked how they would like the researchers to handle the findings, i.e., to be informed or not. Finally, information was supplied about the persons they could contact concerning the research and the ethical committee which had approved the research.

One issue raised by these ethical reviews has been the understandability of the information provided to the participants describing the research. Therefore, we modified this information to ensure that the participants understood unequivocally the purpose of the research and their role. Further, research such as usability studies with prototypes of CONFIDENCE will follow similar ethical review procedures to safeguard the rights of the participants.

### **4. Ethical concerns of the research participants**

In the beginning of the project, 23 older people participated in individual semi-structured interviews aimed at collecting information about their needs and requirements for the design of CONFIDENCE. Eighteen of the 23 end users considered that the system could violate their integrity. In a follow up

question, they characterized their answers about integrity as an abstract concept. Some manifested that the relevance of the system to the end user might justify the use of this technology. Quoted, end users thought that the “system does not violate privacy, if the information collected is confidential” and “if obtaining help relies on the technology, it doesn’t violate integrity”. However, they also thought that constant monitoring would violate their privacy.

The participants had positive attitudes towards using tags at home. Twenty respondents would use tags. Similarly, 19 of 23 would accept the presence of tags in clothes.

Semi-structured interviews with end users at another stage of the project involved 10 participants. At this stage, eight participants thought that the system would not violate their privacy or integrity. Eight participants preferred hidden sensors and tags. Our interpretation is that this would help to maintain their dignity. Visible signs of care technology on them could denote weakness, but these would not be perceived by others. The participants had doubts about who could access the information and if it could be possible to misuse it. One participant pointed out that legal aspects should be considered carefully and formulated “who is allowed to investigate the location of the user?”

Additionally, we asked the participants to provide their opinions about the ethical issues that could arise from using CONFIDENCE. Care experts, who participated in focus groups and end users reported that the system seems to respect the rights of the users in terms of privacy, autonomy, integrity, and dignity.

## **5. Possible scenarios of misuse**

We attempt to maximize the ethical compliance of the results of this ICT project. Therefore, we research, explore, and suggest options to prevent possible scenarios of misuse of this technology. This includes issues such as: disclosure of information concerning the functional ability of the users, for example, to relatives without the consent of the user; use of information collected by the system for purposes for which the device was not intended, e.g. by insurance companies to adjust the coverage or the premium; profiling the user by means of the information gathered by the system for purposes such as advertising or selling products or services, which also falls within the realm of using the system for unintended purposes. There will be situations beyond the capacity of the technology to prevent misuse if the users are not aware of the risks involved and the protective actions that they can perform. Furthermore, the users will be likely find new uses for which the system was not conceived. To prevent situations like these, the only precaution possible is to ensure that the user is properly informed about the functions of the system and possible hazards. The technological development will include safety mechanisms such as access keys and data encryption.

## **5. Conclusions**

The CONFIDENCE project continuously considers ethical issues and data processing regulations from the outset. The partners in the consortium are aware of the ethical issues that may appear as a result of the technologies employed in this R&D activity, and as the users interact with the system. Ethical committees review and provide opinions on the research plans involving human participants. Their opinions have been used to improve the understandability of the information presented to the

participants. They cannot make free decisions when the research situation is not completely understood. According to the opinions of research participants, personal data processing, privacy, and dignity do not seem to be at stake within the development of the project. The system, as a commercial product, shall implement each of the available mechanisms to protect the privacy, dignity, and safety of the older people. Misuse of the system shall be prevented through design and information to the users which specifies how they can contribute to maintain their privacy and safety. We trust that our dedication to ethical issues during the project will transfer to ethically compliant and acceptable commercial applications for the benefit of independent older people.

### Acknowledgements

This research has received funding from the European Community's Framework Programme FP7/2007-2013 under grant agreement No 214986. The Finnish older people participating in this research and the interviewers are gratefully acknowledged for their contribution.

CONFIDENCE Consortium: Centro de Estudios e Investigaciones Técnicas de Gipuzkoa, Fraunhofer Institute for Integrated Circuits, Jozef Stefan Institute, IKERLAN-IK4, COOSS Marche, University of Jyväskylä, Umeå Municipality, eDevice, CUP 2000, and ZENON Automation Technologies S.A.

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