Adaptive Ambient Empowerment of the Elderly

# Deliverable 3.2

# Ethical and legal requirements

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# 1 Purpose and context of this deliverable

The purpose of this document is to provide a framework for assessing the various ethical issues related to the development, design, implementation and adaptation of $A^2E^2$ solution. Ethical problems are typically not processed in development departments and often the ethical problems only become apparent once a certain technology, application or device is put on the market or to use.

Awareness and reflection of existing and potential ethical issues should be an integral part of the development process of new software applications. This deliverable will therefore also describe why ethics are important and the kind of legal and social issues ICTs may raise.

This deliverable thus aims to:

- give the project participants an overview of what ethics are and why ethics in ICT are important
- define the main ethical problems related to ICT development, especially in relation to healthcare and assistive ICTs

As a special thanks, Fraunhofer FIT Hydra project's material was used as reference for this ethical document.

## 2 What is ethics?

To put it simply, ethics is the philosophical study of right and wrong. However, one need not be a philosopher to discuss ethics or to have an understanding of what ethics are or whether something is ethically correct (or safe) or not. Yet, ethics is a subject that leaves most of us confused as to how to define what exactly it is, how to take it into account and how it may impact our work and products.

Generally, in all areas of life we all have some idea of what may be deemed ethical or unethical. These ideas are socially and culturally determined and as such subject to interpretation, but we may nevertheless talk about dominant (i.e. socially accepted and agreed upon) customs, values, practices and rules which indirectly and/or directly determines our social actions and behaviours, and what we deem as acceptable and ethical. For example, the Charter of Fundamental Rights of the European Union defines certain shared values and as such serve as formal ethical guidelines.

In other words, ethics are close to morals; whereas the concept of ethics may leave most people with the impression of something very philosophical, theoretical and to an extent intangible, the concept of morals may be easier to grasp as morals take on a more practical and tangible meaning for most people. Ethics and morals are thus closely interconnected and we may thus define ethics as the moral standards that help guide behaviour, actions, and choices.

In a business context, we often find that companies have a code of conduct, which in essence defines the company's ethics or moral standards in relation to internal and external practices.

## 3 Ethics and ICT

The field of ethics in relation to ICT is more commonly known as computer ethics. Computer ethics may be defined as "the analysis of the nature and social impact of computer technology and the corresponding formulation and justification of policies for the ethical use of such technology." (Moor, 1985)

The creation of the field of computer ethics is generally credited to Norbert Wiener dating back to the 1940s. However, it was not until 1985 that the field really took off with the creation of various journals, textbooks, university courses and degree programmes, conferences and websites etc. As computer technology has continued to develop, so too there now exists a number of subfields of computer ethics, such as cyborg ethics, "agent" (robots) ethics, global information ethics, information technology and genetics, computing and terrorism etc.

What are the social and ethical impacts of ICTs on our society? There is no straightforward answer to this question as it is very much context dependent, i.e. what kind of ICT are we talking about, how is it used, by whom and why etc. In this sense, we are dealing with applied ethics as we wish to define the impact the possibilities of ICTs have on our lives, health, security and opportunities ect.

In the European context, some important documents related to ethics and ICT are the Riga Declaration [4], Aging well in the Information Society [5] and i2010.

These documents call for an increased ethical awareness in relation to ICTs, particularly in the context of e-inclusion, assistive technologies in healthcare, and the aging population. For example, the Bled Report states "ICT ethics demand that we look beyond legal compliance to moral requirements when planning, developing and implementing ICT systems."

Overall, it should be safe to say that ICTs are developed with the aim to provide some sort of benefit to society and individuals, whether it be more effective work procedures, assisting the ageing or people with chronic diseases, optimising existing services etc. The problem is that it is crucial to look beyond the instant obvious benefit a technology is meant to offer and look at it in the context of "the big picture". Only by doing so, is it possible to analyse and define the ethical issues embedded in the technology and its use.

For example, a surveillance system which can monitor and track a person with Alzheimer disease, in order to avoid the person from wandering and potentially getting lost or come to other harm, has clear benefits. However, at the same time it raises the ethical issue of the right to privacy. If the technology is used without the informed consent of the person who is being monitored, the real ethical problem is not the technology per se, but how it is being used. However, this problem could be avoided if proper security and privacy measures are built into the technology so that

informed consent is a prerequisite for the system to be activated. This is why it is so important to think ethics into the first stage of ICT development, i.e. training developers to think about ethics, as this can effectively prevent misuse and ethical problems.

As the above example demonstrate, healthcare ICTs (including assistive technologies) can be particularly tricky ethically speaking. They often require a careful analysis and evaluation of the pros and cons, or in other words, a careful ethical assessment. As such, healthcare technologies are especially good for our purposes here and will thus be our main focus area in this deliverable.

## 4 Why is ethics important

Compliance with legal requirements and codes of conduct is obviously a must. Failure to do so will hinder the deployment of any new ICT services or appliances on the market. As pointed out above, legal guidelines have a certain ethical element to them but they cannot be substituted with properly defined ethical guidelines. Nor do they specify the particular ethical issues at stake for specific ICTs or how to resolves these. In fact, it would be impossible to define a full list of all the ethical issues embedded in ICTs or how to resolve these because as technology continues to develop and new systems, services, devices and appliances are realised, so will new and/or different ethical issues arise.

Being aware of the potential ethical dilemmas is the very first step in addressing and solving these, ideally before they become a reality, i.e. before a system or application is put on the market or implemented. This is particularly important as it can prevent the market failure of a system or application due to unforeseen ethical problems that cause end-users or producers to reject it. Also, having to readjust or redesign a technology in order to meet ethical requirements is often very complicated and expensive and may simply not be feasible thus also causing the product to be rejected.

Another advantage is that awareness of ethics offers us a way to focus on the needs of the end-user. As mentioned in the previous section, ethics ought to be considered at the onset in order to prevent future misuse and here we see that this point also has a very practical marketing aspect as well.

5. Ethical issues in software

In this section we will take a closer look at some of the main ethical problems there are likely to arise in relation to ICT. The main focus will be on healthcare and assistive technology where the end-user is typically an elderly person and/or someone with a chronic disease/condition or disability.

Design and usability are intrinsically linked. For example, in relation to the design of a user interface; poor design will render a system, application or device difficult and complicated to use, thereby hindering a successful deployment and uptake of the product. In essence, a user-interface should be designed in a way so that the user will have no doubt as to how to use it at first sight.

It is crucial that developers consider the design carefully because it may ultimately determine the failure or success of a product. The approach to design should be user-centric, i.e. designing with the end-users' needs and abilities in mind. This may not be "breaking news" but when considering the ethical aspect of design and usability this approach takes on an even further urgency because it is a serious ethical problem if the design effectively excludes certain people from being able to use a particular technology.

This user-centric approach to design is generally referred to as Design for All (DfA) which focuses on information services and products. The main principle underlying the idea of a DfA is that new technologies should be designed in a way that makes them accessible to everyone. This does not mean that one single design can accommodate for all users' needs and abilities, but it means that these needs and abilities must be addressed within the design process. It also means that development of new technologies should not just be aimed at the desires and needs of certain groups of users. It has to be possible to easily adapt ICT products to each user's specific abilities, skills, requirements, preferences and needs.

For example, many senior citizens would benefit from interfaces that consider decreased visual and auditory sensitivity, weakened motor abilities, slow down in the processing of information, reduction of problem-solving performance and working memory capacity, increase of the reaction time etc. In practice, such interface considerations or alternatives could include larger text size, spoken output of screen text, navigating web site wit the keyboard instead of with the mouse, multi-touch screens and so on. By addressing and accommodating senior citizens' abilities and needs more would be able to fully enjoy and benefit from ICTs and the risk of excluding this group of citizens on the basis of design and usability would be greatly minimized.

With this in mind it becomes quite obvious that designing for the techno-savvy teenager is not the same as designing for the elderly. A vital element of the DfA approach is precisely to first of all clearly define who the end-users for a given system or application are, and secondly to involve the end-users in the design process, i.e. through consultations, workshops, questionnaires etc., in order to find out what their specific needs are. Doing this thoroughly is effectively a way to integrate an ethical perspective and awareness into the development process; the ethical problem of exclusion can subsequently be avoided.

Another important ethical issue that is related to design is dignity. Dignity is a general ideal or principle, which is recognised as a human right and protected by various legislatures, e.g. the Charter of Fundamental Rights of the European Union [1] and UN's Universal Declaration of Human Rights. Dignity can be defined as being respected, protected and valued. People who need some form of assistance in their daily lives whether they live at home or in assistive living residencies, should not as a consequence of their required assistance/care loose their right to dignity. When we apply this principle to health care technologies it means that a given technology or device should be designed in the least obtrusive way, both aesthetically and practically speaking. The significance of appearance in our society should not be underestimated, and a device which signals "inability" loud and clear risks stigmatising the individual unnecessarily. Also, a smart, aesthetic and unobtrusive design will appear more appealing to the user thus promoting user acceptance.

Keeping these three core principles in mind when designing and developing new technologies is not only a good way to ensure a new product's usability and accessibility, it is also a means to incorporate an ethical perspective in the development and design process. To help this process along, it is also very useful to consider different ethical questions throughout the process. In some ways, this may be a more tangible way to define and assess the ethical issues.

Thus following questions are used to evaluate ethicality of $A^2E^2$ functionality:

- Does the new technology, service, application or device expect a certain level of knowledge of computers and the Internet that some people may not have?
- Is the technology, service, application or device being designed to be accessible and easy to use for senior citizens and/or citizens with disabilities?
- Is the technology, service, application or device being designed taking into account values such as human well being, dignity, human rights, and welfare?
- Does the technology, service, application or device empower users?
- Does the technology, service, application or device comprise or violate human
- dignity?
- Are some services being transferred to the Internet only, so that a service is effectively no longer available to people who do not (know how to) use computers or the Internet?

## 5 Privacy and Data Protection

The right to privacy is a human right and is protected by legislation. Article 8 of the European Convention for the Protection of Human Rights and Fundamental Freedoms states that:

1) Everyone has the right to respect for his private and family life, his home and his correspondence.
2) There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.".

Also, Article 8, no 1, of the Charter of Fundamental Rights of the European says that: "Everyone has
the right to the protection of personal data concerning him or her."

Another related issue is the right to check the accuracy on one's personal data. In this regard, the OECD guidelines say that personal data should be accurate, complete and kept up-to date. Also, Article 6 of the EU's Data Protection Directive says that personal data must be accurate and, where necessary, kept up to date.

As we see here, privacy and the protection of data are closely linked. Furthermore, the right to privacy includes the right to control our personal information, i.e. to control who has access to our personal information and what kind of information others have access to. It is crucial to ensure that ICTs will not violate human rights such as the right to privacy. The importance of this cannot be stressed enough in the light of the fact that our lives are becoming more and more online. Privacy and the protection hereof, have taken on a digital dimension, especially as ICTs are increasingly used to collect, store, analyse and distribute personal data. This raises the ethical issue of how to secure that the individual maintains the power to control and protect his own personal data.

With respect to the data protection, technical and policy provisions should be developed to protect the confidentiality of the processed data, while simultaneously enabling efficient access to the information for e.g. diagnostic and therapeutic purposes. Some of the main data protection issues are what information is collected by the system, controlled (not excessive) use, for what purpose the information is used, to whom it may be transferred, user's access to information and the possibility to correct personal information, storage, archiving and destruction of information obtained, user information, proportional use, communication of information to third parties, and security measures embedded in ubiquitous applications to avoid data leakages, alteration of information or 'cloning' of the captured information.

## 5.3 Surveillance and Autonomy

Surveillance technologies raise various ethical dilemmas. The problem is one of consoling the perceived benefits with intrusion of privacy. In the context of healthcare ICTs, e.g. assistive technologies, we can take the example of remote monitoring and surveillance. The obvious benefits include improved control and management of chronic conditions, allowing people to stay at home for longer (including allowing "hospitalisation at home"), and making healthcare services more efficient. There are also explicit surveillance technologies that are designed to track the movement of an individual, e.g. sensors in exit doors in care homes that warn staff when someone is leaving. The rationale behind the use of this is obvious to prevent for example someone with dementia from unwanted wandering and as such is for the protection of the dementia patient.

However, it still raises serious ethical problems in relation to protection of this person's privacy. All these services rely on the transmittance of personal medical data and on a certain degree of surveillance of the individual. The ethical problem is how one can ensure that monitoring and surveillance technologies do not violate the individual's right to privacy or in any way endangers the protection of personal data.

Another related issue is the issue of autonomy. Surveillance technologies may threaten the person's autonomy in the sense that he/she begins to exercise self-censorship and/or simply loosing the feeling of autonomy as a consequence of being constantly observed and monitored.

Autonomy includes having control of the system, i.e. that the (informed) user is able to switch it on or off. One may here ask what is the point then if users can freely switch the system on or off? However, the issue is in reality not different from the traditional healthcare setting where the patient may choose whether or not to follow the doctor's orders. The ethical requirement here is that the patient is made fully aware of the consequences of non-compliance.

Likewise with assistive and healthcare technology, although here the patient also need to be made fully aware of the consequences of the use of and compliance with these technologies, e.g. the impact on/invasion of privacy.

Assistive technologies should always remain 'assistive' in the sense that they should not take control over someone's life. Take the example of ubiquitous ICTs in the context of ambient assisted living systems. The constant and ubiquitous recording of the user's compliance with medical advice and/or medication, may threaten the user's autonomy and agency as compliance or non-compliance per se ceases to be an option. Moreover, ubiquitous communication technologies may cause an erosion of privacy; the user (or his/her family) may be forced to compromise between privacy and security, e.g. created by monitoring and surveillance healthcare systems. The freedom to choose, to have active control over one's life, is greatly diminished as reliance and dependence on technology increases.

### 5.4 Ethical issues in Amsta

In Amsta the Ethical regulations are related to the four core values of Amsta: Professional, Personal, Practical and Loving. These values are the guideline throughout ethical and moral issues. For example  about safety, quality of care, cultural habits, relationships and clients or personals behavior.

The Ethical committee aims stimulation of consciousness of ethical dilemma's. The committee will provide the process, motivates personal and facilitates communication within the organization and advices the Board.

Different tasks are p.e. consultation, try out practice and science in a moral deliberation, education and policy making.
The committee contains members who are selected out of different medical and non medical backgrounds according to Amsta's target groups: independently living elderly, elderly living in elderly homes and nursing homes and mental disabled people.

In a regulated procedure ethical issues are brought in written in by the board. Advices will be brought out to the board and organization. Decision-making, secrecy and reporting are regulated.

This regulation has been reviewed recently.

## 6 Informed Consent

In the context of healthcare technologies as exemplified above, an important step to overcome the ethical problems related to privacy and data protection and surveillance and autonomy is informed consent. Informed consent allows the user/patient to exercise control over his/hers personal data by determining who has access to what information and when.

It is here vital that the user fully understands the technology and its use in order to understand the implications of either the granted or the denied access to his/her personal information. Thus, it is crucial that ICT manufacturers recognise the importance – and their responsibilities – in providing coherent and accurate information about how the technology works, including how data is gathered, processed, stored etc., and what risks are involved with using the technology.

Moreover, in order for informed consent to have any real effect, it is also necessary that the technology itself has the appropriate security measures built in to ensure that only those granted access by the user has access to the specified information. The technology should also be designed in a way that takes into account that not all users will grant the same level of access to their personal information. This will obviously affect the nature of the service on offer which the technology should be able to support and subsequently adapt to.

One of the key conclusions from the "Bled Exploration of issues and guidance" on Ethics and e-Inclusion: Contribution to the European e-Inclusion Initiative:
Informed consent is vital, choices available must be understandable and transparent. They should be adapted to match the comprehension level of the recipient. Consideration needs to be given to the right not to know.

It is also important that users are informed of any potential risks by using a certain technology. However, informed consent from the user does not cancel out the issue of reliability or liability; it should be clearly stated who is liable if technology enabled service, e.g. a self-management system, monitoring or surveillance technologies etc., fails partly or completely. In relation to healthcare and/or assistive technology one may envision cases where the user/patient is unable to give informed consent. Take the example of people with dementia who are unlike to fully understand how a monitoring system capture and transmit information and the kind of information in question. If users cannot fully understand, or are unaware of, how a system or devices function, they may also not understand or be fully aware of how their privacy might be affected. Informed consent must then be given by the user/patient's guardian or other trustee.

# 7 Legal Issues

There are various legal directives and guidelines which are relevant to ICT ethics. Compliance with the legal requirements and guidelines is not only a legal issue; it is also an ethical issue. It would be unethical to consciously ignore or to be simply unaware of the legal requirements when developing new ICTs, not to mention that it would simple also be a very bad and unsustainable marketing/commercial approach.

The most important of these are:

- Charter of Fundamental Rights of the European Union
- European Convention for the Protection of Human Rights and Fundamental Freedoms
- Directive 95/46/EC on the protection of individuals with regard to the processing of personal data and on the free movement of such data
- Directive 2000/58/EC concerning the processing of personal data and the protection of privacy in the electronic communications sector (Directive on privacy and electronic communications)
- Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data of the Council of Europe of 1 January 1981