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Hydra

Networked Embedded System middleware for
Heterogeneous physical devices in a distributed architecture

D12.10 Ethical considerations in Hydra enabled services and applications

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1. Introduction

1.1 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 ICTs such as those made possible by the application of the Hydra middleware platform.

Ethical problems may be far away from the developer's mind 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 ICT applications and devices. This deliverable will therefore also describe why ethics are important and the kind of legal and social issues ICTs may raise.

The framework offered here consists of three steps: 1) an introduction to ethics, 2) definition and identification of ethical issues in ICTs focusing on ICTs in healthcare, and 3) a case study. The case study is intended to illustrate the kind of ethical issues at stake at the end-user stage by using probing questions that help to not only identify the ethical issues but also whether these have been satisfactorily addressed in the development and design process of a given technology.

This training document is intended as a text-based training document (manual) for the individual developer(s), however, the case study and questions presented here can also be used at ethics training workshops. These workshops can be held for developers only or include the different stakeholders as this will give an even wider perspective on the ethical issues at hand.

This deliverable thus aims to:

- give the developer 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
- provide the developer with a method of how one may identify ethical problems embedded in new ICTs.

1.2 Structure of this deliverable

Chapter 3 describes the aims and objectives of this training manual, and how it is intended to be used. The Hydra project is also introduced here.

In order to fully understand why ethics in ICTs are important and how we can identify the ethical issues related to healthcare and assistive ICTs, we must first understand what ethics are. This is the purpose of Chapter 4.

Chapter 5 identifies the main ethical issues related to ICTs and offers various examples to illustrate how and why some technologies and their use raise certain ethical problems. The ethical issues dealt with here include: design and usability, privacy and data protection, surveillance and autonomy, and informed consent. A list of questions is presented as a method to identify any ethical problems requiring action or resolution. Finally, important legal documents that affect ICT development and implementation are also mentioned here.

Chapter 6 presents a case study of a diabetes self-management service. We here identify the ethical issues as they occur in the case study and use the questions defined in chapter 5 to illustrate how and why the technologies described raise ethical concerns.

Chapter 7 presents the full list of questions that help to identify if a given technology or ICT enabled service raise any ethical problems that need to be dealt with and solved.

2. Executive Summary

A lot of people will often feel unsure about what constitutes ethics and how they should relate to and not least how – and why – they should incorporate ethics into their work. The material here aims to give the trainee a better understanding of ICT ethics and a tool for analysing the ethical issues embedded in ICTs.

Applicable law, codes of conduct and guidelines/recommendations all have an element of ethics, or ethical principle, but should, however, not be considered as ethical guidelines per se. ICT ethics is a complex field and it is necessary to carefully analyse and define the specific ethical issues embedded in each specific application, device or service and their use from the onset of their development. This way one may avoid that ethical problems, e.g. inadequate data protection measures or exclusive/inaccessible design, actually hinder the deployment of new ICTs. An added benefit of being conscious about potential ethical problems is that it strengthens the focus on the end-user needs and requirements which is so vital for the success of a new ICT product or service.

A good way for developers to determine whether a given technology, application or device raise ethical issues is to simply ask questions related to the ethical issues defined below. This document offers a list of question which is used here in a case study to provide the reader with a tangible example of how to identify the ethical issues. This list can also be used for future reference.

The ethical issues dealt with in this document are:

Design and Usability:

- Design for All is a particular user-centric approach which aims to ensure that technologies are accessible to everyone. This entails ensuring that the users' needs, skills and abilities are addressed through user-centric design, thus avoiding the risk of excluding certain groups of users (e.g. senior citizens, people with disabilities, people who are not confident or "super" IT users).

Data protection and Privacy:

- The right to privacy is protected by The European Convention on Human Rights and Fundamental Freedoms. As our society becomes more and more digitalised, the right to privacy and the protection of private data (including medical data) is crucial. ICT systems that collect, transmit, store, analyse and distribute private data face the ethical challenge of securing the user's privacy.

Surveillance and Autonomy:

- Surveillance technologies raise various ethical dilemmas. The problem is one of consoling the perceived benefits with the intrusion of privacy. For example, 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, have the benefit of being able to prevent someone with dementia from unwanted wandering and as such are for the protection of the dementia patient. However, at the same time, these technologies clearly intrude someone's privacy. In this case it is vital that the user (or his/her relatives/guardians) clearly understand the consequences (including benefits and disadvantages) of these technologies.

Informed Consent:

- Informed Consent is in many ways a means to overcome the ethical problems related to privacy and data protection and surveillance and autonomy. The technology should always have the appropriate security measures built in to ensure that only those granted access by the user has access to the specified information. 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.

Legal Issues:

- There are various important legal directives and guidelines which developers should be familiar with and which are relevant for the ethical issues defined in this document. The most important of these are:
  - **Charter of Fundamental Rights of the European Union** [1]
  - **European Convention for the Protection of Human Rights and Fundamental Freedoms** [14]
  - **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** [16]
  - **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)** [20]
  - **Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data of the Council of Europe of 1 January 1981** [21]

3. Training Methodology

This ethical training material takes the form of a guidebook manual aimed at raising the awareness of the complex ethical issues related to ICT and its applications and services. It is first and foremost aimed at developers who develop and design hydra enabled services and applications. They will benefit from incorporating an ethical awareness into their work as ethical awareness and compliance with fundamental ethical principles are basic requirements for getting research project approved by the EC, e.g. under FP7. Moreover, ensuring that a new technology, application or service is ethically sound is a prerequisite for successful marketing and deployment.

3.1 Introduction to Hydra

The Hydra project develops middleware for networked embedded systems that allows developers to create ambient intelligence applications. System developers are thus provided with tools for easily and securely integrating heterogeneous physical devices into interoperable distributed systems.

The middleware includes support for distributed as well as centralised architectures, cognition and context awareness, security and trust, and will be deployable on both new and existing networks of distributed wireless and wired devices that typically are resource constrained in terms of computing power, energy and memory. Hydra provides interoperable access to data, information and knowledge across heterogeneous platforms, including web services, and support true ambient intelligence for ubiquitous networked devices.

Hydra middleware is based on a Service Oriented Architecture to which the underlying communication layer is transparent. The embedded and mobile Service-oriented Architecture will provide interoperable access to data, information and knowledge across heterogeneous platforms, including web services, and support ambient intelligence for ubiquitous networked devices.

The main outcome of the Hydra project will be the Hydra SDK (Software Development Kit) which will be used by developers to develop innovative Model-Driven applications with embedded ambient intelligence using the Hydra middleware. Furthermore a Device Development Kit (DDK) will be provided that enables device manufacturers to produce Hydra-enabled devices. Finally, an Integrated Development Environment (IDE) will be provided.

The Hydra project is being evaluated and validated in three distinct domains: healthcare, building automation and agriculture. In relation to healthcare, Hydra enabled services and applications can e.g. assist patients with chronic diseases to effectively manage and control their condition, thus enabling them to live as normally and independently as possible. In building automation, remote control, for example and management can greatly optimise services and the interoperability of systems, and in agriculture food tracking systems can help promote food safety.

Thus, the Hydra middleware promises to enable truly innovative ICT services and applications which will benefit producers, users and consumers. However, the very possibilities the Hydra middleware offers may raise various ethical issues that should be considered carefully when developing Hydra enabled applications and services.

Although it is not the Hydra middleware itself that is unethical, the functionalities of new applications and services based upon the Hydra middleware may cause ethical problems. For example, the very notion ubiquitous networked devices implies that users (or those subject to their use) do not notice or are unaware of (or don't fully understand) what these applications do or possibly that they are even installed. Consider for example a surveillance and monitoring system in a nursing home designed to prevent a dement person from wandering off the premises. This raises the serious ethical issues of informed consent, protection of privacy and private data, and surveillance and autonomy.

Another important ethical issue is related to the design, usability and accessibility of applications, devices and services enabled by the Hydra middleware. Here developers need to consider carefully the end-users' capabilities, needs and desires; poor design may effectively exclude certain end-user groups or be rejected by the target end-user group because it fails to accommodate their capabilities

(e.g. too complex to use or poorly designed user interfaces). The design of Hydra enabled devices and applications should be flexible so that it is easy to accommodate for special requirement or make changes. Taking this under consideration at the earliest stage possible can help ensure a successful product, plus prevent having to make extensive and expensive modifications at a later stage.

3.2 Aims and objectives of the training

The methodology used here is text based, allowing the reader to first of all get an insight at what ethics are before moving on to more concrete examples of different ethical issues. Through a description of the main ethical issues related to ICTs, the trainee should also come to understand why certain issues are of ethical nature rather than e.g. simply constituting a practical problem or challenge.

The objective here is **not** to identify all the ethical issues related to the three user domains or to all the potential applications and services enabled by the Hydra middleware. Rather, the objective is to create an ethical awareness and train the developer to think ethically, i.e. to be able to identify the ethical issues at stake independently of the specific user domain, application or service.

The case study presented here is precisely intended to provide the trainee with an example of how to think ethically, i.e. looking at the technologies in question from an ethical perspective in order to identify why and how the technologies raise certain ethical issues.

For simplicity, we have chosen to focus on only one of Hydra's user domains, namely healthcare. Focusing on only one user domain will help to keep the otherwise very complex field of ethics on a practical and intelligible level.

Although ethics is a complex field and a field that is constantly changing (i.e. new and different ethical issues arise) as new technologies are being developed, this training material will provide the trainee with a relatively simple tool, i.e. a list of questions to identify potential ethical problems, to help them incorporate ethics into ICT development and research. Another advantage of using questions is that it works as a way to trigger a reflection of the ethical issues at stake. Being able to identify and consider potential ethical problems is a first step in solving, or even avoiding, these and thus secure the development of ethically sound and successful hydra enabled devices and applications.

4. 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 [1] 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.

4.1 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) [2]

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. [3]

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. [6]

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."

Also, in the context of the Seventh Framework Programme (FP7), Article 6 Ethical Principles (§1) states: "All the research activities carried out under the Seventh Framework Programme shall be in compliance with fundamental ethical principles". [7] Not only compliance with ethical principles but also an acute awareness of the ethical aspects of a project or in relation to the development of new ICTs is a prerequisite and good practice.

It may not always be the case of the technology per se, but how it is used that cause ethical problems [8]. 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.

4.2 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 [9]. 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 ICT

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.

5.1 Design and usability

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. Consider this statement from an expert in ubiquitous computing: "I know how to sit in a chair. I can see it at first inspection. I have to be pretty cognitively impaired before I can't see what a chair is or figure out how to use it at first inspection…technology should be designed to that standard." [10]

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 [11].

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. This approach to design has been described as Value Sensitive Design [12].

Value Sensitive Design and Design for All principles are very useful to consider in the very first stage of ICT development as it may help to avoid ethical problems that in effect can hinder a product's success on the market. The European Commission has placed great emphasis on the value and promoting of DfA principles in order to promote e-inclusion and has supported various projects that have adopted the DfA approach. Three strategies have been defined to illustrate the core principles of DfA [13]:

- Design of IST products, services and applications which are demonstrably suitable for most of the potential users without any modifications
- Design of products which are easily adaptable to different users (e.g. by incorporating adaptable or customisable user interfaces)
- Design of products which have standardised interfaces, capable of being accessed by specialised user interaction devices (assistive technologies).

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.

The SENIOR project (Social, ethical and privacy needs in ICT for older people: A dialogue roadmap) which was funded by PF7 programme has defined a list of ethical question which is very useful. [12]

In relation to design and usability we may thus ask:

- 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? [12]

5.2 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." [14].

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." [1]

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. [15] Also, Article 6 of the EU's Data Protection Directive says that personal data must be accurate and, where necessary, kept up to date. [16]

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.[17]

Asking the following question will help to put focus on the ethical issues at stake:

- Is information collected in ways of which the data subject is unaware?
- For how long will the information be retained?
- Will the information be deleted when it is no longer needed for the purpose for which it was collected?
- Who will have access to or use of the data collected?
- Will the data be transferred to or shared with others?
- Has the project taken steps to ensure that persons cannot be identified from the data to be collected?
- How will the system/service determine what constitutes the minimum amount of personal data to be collected?
- What assurances exist that the information collected is true and accurate?
- Has the project taken measures to ensure protection of personal data, e.g., by means of encryption and/or access control? If so, what are they?
- Have measures been put in place to facilitate the person's access to his or her personal data?
- Can the person whose data are collected rectify easily errors in personal data? What procedures are in place for doing so? [12]

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.

We may thus consider the following questions:

- Does the project involve surveillance of individuals or groups of people?
- How and for how long will images or data be retained?
- Who will authorise the surveillance practice, whether in private homes, assisted living residences or public places such as city streets or banks? [12]

5.4 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.[1]

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.* [18]

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.

Ethical questions in relation to informed consent include:

- Has the person been informed of the nature, significance, implications and risks of the technology in question?
- Are people aware that personal data may be collected? Are they aware of who is collecting it and why?
- Does the consent outline the use for which data are to be collected, how the data are to be collected, instructions on how to obtain a copy of the data, a description of the mechanism to correct any erroneous data, and details of who will have access to the data?
- Has the person consented to collection of his personal data?
- If the individual is not able to give informed consent (because, for example, the person suffers from dementia) to participate in a project or to use of a technology, have the project representatives consulted with close relatives, a guardian with powers over the person's welfare or professional carers? Has written consent been obtained from the patient's legal representative and his doctor?
- It is clear where the responsibility lies for liability and accountability? [12]

5.5 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.

In this section we will mention some of the most important EU legal documents that producers and developers ought to familiarise themselves with. However, keeping in mind that applicable law changes over time it is necessary to be kept informed and up to date on current legislative rules. We

[1] This leads us to another dimension of informed consent which is less relevant for soft and hardware developers but nevertheless worth mentioning, namely that the user should have to option of opt out from using a specific ICT service without loosing the right to healthcare; there must always be alternatives available.

may also safely assume that as new ICTs are developed they will raise new legal (and ethical) issues which may result in modifications of existing applicable laws.

- **Charter of Fundamental Rights of the European Union [1]**

  Article 7 and 8 of the Charter are especially important regarding privacy and data protection:

  Article 7 Respect for private and family life:

  Everyone has the right to respect for his or her private and family life, home and communications

  Article 8 Protection of personal data:

  1. Everyone has the right to the protection of personal data concerning him or her.

  2. Such data must be processed fairly for specified purposes and on the basis of the consent of the person concerned or some other legitimate basis laid down by law. Everyone has the right of access to data which has been collected concerning him or her, and the right to have it rectified.

  3. Compliance with these rules shall be subject to control by an independent authority.

- **European Convention for the Protection of Human Rights and Fundamental Freedoms** [14]

  The European Convention for the protection of Human Rights and Fundamental Freedoms (ECHR) of 1950 which formed the European Court of Human Rights provides a very high protection of the individual. Article 8 of the ECHR, on privacy, is very relevant for healthcare ICTs, e.g. regarding protection of personal data. The ECHR provides the legal background for the development of specific legislation to protect the interest of the citizen when ICT is used in healthcare. [19]

- **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** [16]

  The Directive identifies a set of fair information practices or principles which are important in any consideration of ethical issues that might arise in matters affecting privacy and data protection. The Directive is important in relation to ICTs. For example, Article 14 reads: ”Whereas, given the importance of the developments under way, in the framework of the information society, of the techniques used to capture, transmit, manipulate, record, store or communicate sound and image data relation to natural persons, this Directive should be applicable to processing involving 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)** [20]

  This Directive refers back to the Charter of fundamental rights of the European Union, stating that it ”seeks to ensure full respect for the rights set out in Articles 7 and 8 of that Charter.” The Directive aims to ensure "…in particular the right to privacy, with respect to the processing of personal data in the electronic communication sector and to ensure the free movement of such data and of electronic communication equipment and services in the Community.

- **Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data of the Council of Europe of 1 January 1981** [21]

  The objective of the convention is "to strengthen data protection, i.e. the legal protection of individuals with regard to automatic processing of personal information relating to them. There is a need for such legal rules in view of the increasing use

made of computers for administrative purposes. Compared with manual files, automated files have a vastly superior storage capability and offer possibilities for a much wider variety of transactions, which they can perform at high speed. Further growth of automatic data processing in the administrative field is expected in the coming years inter alia as a result of the lowering of data processing costs, the availability of "intelligent" data processing devices and the establishment of new telecommunication facilities for data transmission." The convention also takes the increasing transborder flow of personal data into account.

6. Case study

We will here present a case study scenario related to health care ICTs. The objective is to train the reader in identifying what kind of ethical issues the case studies raise. For this purpose we have highlighted the text where the relevant technologies are described. This is followed by boxes of relevant questions to ask in order to identify any ethical issues or problems concerning the technology in question. Please note that the list of questions is not meant to be exhaustive but it serves to identify the main ethical issues at stake.

The case study describes the end use/implementation of different technologies and services, which is done intentionally in order to emphasise how the development and design – and the related ethical issues – of ICTs must be considered with the end-use and end-user in mind.

The case study is taken from *D2.1 Scenarios for usage of HYDRA in 3 different domains* and thus does not represent a "real life" case study, but a probable future scenario.

6.1 Joining Hands: A case study of a diabetes self-management system

Jean-Claude, a 31-year old male, has recently being diagnosed with diabetes I (Insulin-Dependent Diabetes Mellitus - IDDM). Jean-Claude is employed as an account executive in a manufacturing company in Louvain, south of Brussels. His work is demanding and Jean-Claude usually works long hours and commutes frequently between the company's headquarters in Louvain and the manufacturing plant in Antwerp. A large part of his job is about meeting with key clients. He travels approximately 80 days a year, mostly in Europe but occasionally to the Far East. He also entertains clients visiting the company in Louvain or Antwerp.

Jean-Claude gets a lot of satisfaction from his job but he is very strict on taking time off frequently, to recharge and find new inspiration. He tries twice a year to take two full weeks vacation and makes sure that nothing disturbs him. He and his girlfriend Sandra often go on a week-long canoeing trip in Sweden or they go hiking in the Alps. **Jean-Claude wishes that his disease should interfere minimally on his private and professional life and it should not be limiting his ability to carry out his present work and not adversely affect his overall career plans and future job opportunities.**

The ethical issues here relate to design and usability, thus we need to ask:

- *Does the technology, service, application or device empower users?*
- *Is the technology, service, application or device being designed taking into account values such as human well being, dignity, human rights, and welfare?*

When Jean-Claude's diabetes is controlled, it will help prevent serious complications such as infections, kidney damage, eye damage, nerve damage to feet and heart disease. Controlling diabetes is thus very important and is normally supervised by a medical doctor. However, the Wallonia region's new self-management programme gives Jean-Claude the possibility to take much greater control of his own disease and yet still be under strict supervision by medical professionals using the automatic supervision facilities in the new mobile quality healthcare system (SMSQ - Système Mobilier de la Sante Qualité). After consulting with his family doctor, he decides to enrol in the self-management programme.

At the first meeting with the regional diabetes centre, Jean-Claude is given a detailed explanation of his disease, its cause, its symptoms and how he can control it through monitoring, medication, exercise and a proper diet.

The doctor then creates a personal self-management profile in the SMSQ system to allow it to interact with Jean-Claude's Electronic Patient Record (EPR) and to set up learning, monitoring and feedback schemes for him. The doctor then creates a dedicated e-learning environment for Jean-Claude. **The SMSQ system reads the diagnosis and pertinent data about Jean-Claude from the EPR.**

Informed consent:

- *Has the person been informed of the nature, significance, implications and risks of the technology in question?*
- *Is the person aware that personal data may be collected? Is he/she aware of who is collecting it and why?*
- *Does the consent outline the use for which data are to be collected, how the data are to be collected, instructions on how to obtain a copy of the data, a description of the mechanism to correct any erroneous data, and details of who will have access to the data?*
- *Has the person consented to collection of his/her personal data?*

Privacy and data protection:

- *Who will have access to or use of the data collected?*
- *Will the data be transferred to or shared with others?*
- *How will the system/service determine what constitutes the minimum amount of personal data to be collected?*
- *Is information collected in ways of which the data subject is unaware?*
- *For how long will the information be retained?*
- *Will the information be deleted when it is no longer needed for the purpose for which it was collected?*
- *What assurances exist that the information collected is true and accurate?*
- *What assurances exist that the information collected is true and accurate?*
- *Have measures been put in place to facilitate the person's access to his or her personal data?*
- *Can the person whose data are collected rectify easily errors in personal data? What procedures are in place for doing so?*
- *Has the project taken steps to ensure that persons cannot be identified from the data to be collected?*

The SMSQ Content Compiler assembles a complete e-learning package for Jean-Claude including descriptive literature, multimedia presentations and interactive learning programme.

Design and usability:

- *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?*

The learning package also includes additional customised information from internet resources using semantic search capabilities.

Design and usability:

- *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?*

The learning package is available both for PC and PDA viewing thus allowing Jean-Claude to access the learning material at any time. Further, the doctor creates a specific clinical pathway for Jean-Claude in the EPR. It contains information about which in-vivo parameters should be monitored at regular intervals, their threshold values and measurable milestones to be reached at specific dates. For Jean-Claude, the doctor decides to monitor the following parameters: weight, blood glucose level, blood pressure, and urine ketones.

Jean-Claude now needs the instrumentation to perform the monitoring. First he gets an electronic scale so he can measure his weight twice weekly. **He is also supplied with wearable miniature sensors for automatic monitoring of blood pressure and blood glucose 4 times a day.**

Design and usability:

- *Does the technology, service, application or device empower users?*
- *Does the technology, service, application or device comprise or violate human dignity?*

Privacy and data protection:

- *Has the project taken steps to ensure that persons cannot be identified from the data to be collected?*
- *What assurances exist that the information collected is true and accurate?*

Surveillance and autonomy:

- *Does the project involve surveillance of individuals or groups of people?*
- *How and for how long will images or data be retained?*

To supplement the SMBG, Jean-Claude is also instructed to test his urine for ketones with a testing pen when his blood sugar level is above 200 mg. Ketones in the urine is a warning sign of a low insulin level that requires quick action. The connection and pairing of medical devices is automatic and the result is send to the SMSQ system, which controls the total number of devices. **Each device is uniquely linked to the patient by the combination of device ID and the gateway ID. All the sensors communicate securely via a wireless body network with an available gateway in range. It could be his mobile phone, car radio or just a service gateway that he passes on his way.**

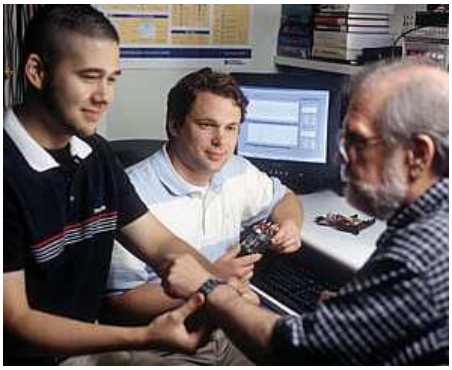
Privacy and data protection:

- *Has steps been taken to ensure that persons cannot be identified from the data to be collected?*
- *Has measures been taken to ensure protection of personal data, e.g., by means of encryption and/or access control? If so, what are they?*
- *Who will have access to or use of the data collected?*

Informed consent:

- *Has the person consented to collection of his personal data?*
- *Has the person been informed of the nature, significance, implications and risks of the technology in question?*
- *Are people aware that personal data may be collected? Are they aware of who is collecting it and why?*

The diabetes centre then creates a role for Jean-Claude's family doctor as the supervisor of Jean-Claude's self-management program and simultaneously **enables the electronic billing system that collects information about the supervisor's transactions, which in turn is used for automatically calculating his provider fee. During a subsequent consultation with his own GP, the doctor logs in to the SMSQ website and accesses Jean-Claude's monitoring scheme.**



Privacy and data protection:

- *Who will have access to or use of the data collected?*
- *Will the data be transferred to or shared with others?*
- *What assurances exist that the information collected is true and accurate?*

He asks for a default monitoring scheme for blood glucose level and adjusts the maximum thresholds to 150 mg before a meal and 200 mg after a meal. The minimum threshold is kept at 50 mg. He asks to be informed by email if measured levels are within 10% of the threshold and by voicemail if they are over the threshold.

In addition, he sets up a feedback alarm scheme that instructs Jean-Claude with a beeper if he needs to do a urine ketones test. If Jean-Claude does not respond with a new measurement within 40 minutes, an emergency is declared. The doctor also sets up **a**

scheme for reading Jean-Claude's weight every Monday and Thursday and his latest blood pressure every Tuesday and Saturday. Especially the weight is interesting to follow at the moment, because Jean-Claude needs to loose 8 kg over the coming 8 months. Finally, the doctor sets up **a PDA based feedback dialog session to be used in case of abnormal measurements or measurements outside the pre-set limits.**

Privacy and data protection:

- *Who will have access to or use of the data collected?*
- *Will the data be transferred to or shared with others?*
- *Have measures been put in place to facilitate the person's access to his or her personal data?*
- *What assurances exist that the information collected is true and accurate?*
- *Has steps been taken to ensure that persons cannot be identified from the data to be collected?*
- *Has the project taken measures to ensure protection of personal data, e.g., by means of encryption and/or access control? If so, what are they?*

Informed consent:

- *Is the person aware that personal data may be collected? Is he/she aware of who is collecting it and why?*
- *Has the person consented to collection of his personal data?*
- *Has the person been informed of the nature, significance, implications and risks of the technology in question?*
- *It is clear where the responsibility lies for liability and accountability?*

Design and usability:

- *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?*

When Jean-Claude returns to home, he first attends to the e-learning programme setup by the diabetes centre. **He decides to download two training animations for blood pressure and glucose measurements (including tips and tricks) to his PDA,** so he can carry it with him when he travels.

Design and usability:

- *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?*

He then performs some test measurement. **The data are uploaded to the EPR system via the SMSQ system and Jean-Claude's doctor is notified to log-in to the EPR to check the data for consistency and calibration. When he has approved the data, all subsequent data are automatically transferred to the EPR. The SMSQ system monitors all data traffic and performs the alert services according to the monitoring schemes created by the doctor.**

Informed consent:

- *Is the person aware that personal data may be collected? Is he/she aware of who is collecting it and why?*
- *Has the person consented to collection of his personal data?*
- *Has the person been informed of the nature, significance, implications and risks of the technology in question?*
- *It is clear where the responsibility lies for liability and accountability?*

Privacy and data protection

- *Who will have access to or use of the data collected?*
- *Will the data be transferred to or shared with others?*
- *How will the system/service determine what constitutes the minimum amount of personal data to be collected?*
- *What assurances exist that the information collected is true and accurate?*

Measuring the various parameters on a daily and weekly basis quickly becomes routine for Jean-Claude. He is still subscribing to "pre-alert by SMS" scheme to let him know when and how he should perform the measurements, but he is considering moving over to a pure monitoring scheme, which only warns him in case the expected measurements are not being received by the SMSQ.

Based on his normal weekly routine measurements, the **SMSQ system monitors the progress according to the thresholds and limits set up by his family doctor. Data are stored in his EPR and the SMSQ constantly monitors for deviations from the clinical pathway. Any deviation exceeding the allowable bands will trigger the system to send a request for further explanation from Jean-Claude, either via SMSQ or via PC.**

Surveillance and autonomy:

- Do*es the project involve surveillance of individuals or groups of people?*
- *How and for how long will images or data be retained?*
- *Who will authorise the surveillance practice, whether in private homes, assisted living residences or public places such as city streets or banks?*
- *What assurances exist that the information collected is true and accurate?*

Informed consent:

- *It is clear where the responsibility lies for liability and accountability?*
- *Has the person been informed of the nature, significance, implications and risks of the technology in question?*

Privacy and data protection:

- *Who will have access to or use of the data collected?*
- *Will the data be transferred to or shared with others?*
- *How will the system/service determine what constitutes the minimum amount of personal data to be collected?*

At the same time, the **SMSQ system assembles a revised learning package for Jean-Claude with emphasis in the consequences of changes in his disease control.**

Design and usability:

- *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?*
- *Does the technology, service, application or device empower users?*

Tuesday morning at 11:30, **the SMSQ sends an SMS to Jean-Claude that the last blood glucose measurement measured his glucose level to 215 mg. The message instructs him to test his ketones level as soon as possible.** Jean-Claude is in an important client meeting that is running longer than planned and he cannot leave the room. At 11:45, he receives **a new SMS warning** him that he must perform his ketones test within 5 minutes. At 11:48 Jean-Claude leaves the meeting and quickly goes to the toilet. **Using his pen ketones meter he measures the level and the data are instantaneously uploaded to the SMSQ system. Within 2 seconds he receives an SMS informing him that his ketones level was only slightly elevated and he is instructed to take a normal dose of insulin.**

Design and usability:

- *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?*
- *Does the technology, service, application or device empower users?*
- *Does the technology, service, application or device comprise or violate human dignity?*

Informed consent:

- *Has the person been informed of the nature, significance, implications and risks of the technology in question?*
- *It is clear where the responsibility lies for liability and accountability?*

Privacy and data protection

- *What assurances exist that the information collected is true and accurate?*
- *Who will authorise the surveillance practice, whether in private homes, assisted living residences or public places such as city streets or banks?*

Surveillance and autonomy:

- *Does the project involve surveillance of individuals or groups of people?*
- *How and for how long will images or data be retained?*
- *What assurances exist that the information collected is true and accurate?*

7. List of questions to identify ethical issues

This chapter presents a complied list of the questions asked in chapter 5. It is intended as a list of reference with can be used to identify and define the ethical issues embedded ICT applications, devices or services. It will help developers to think ahead, i.e. to keep the end-users, their needs and capabilities in mind as they develop and design new ICTs, thus ensuring that the product complies with the applicable ethical principles. This list of question is by no means exhaustive but stands as a basic guideline and point of reference.

Design, usability and accessibility:

- 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?

Privacy and data protection:

- Is information collected in ways of which the data subject is unaware?
- For how long will the information be retained?
- Will the information be deleted when it is no longer needed for the purpose for which it was collected?
- Who will have access to or use of the data collected?
- Will the data be transferred to or shared with others?
- Has the project taken steps to ensure that persons cannot be identified from the data to be collected?
- How will the system/service determine what constitutes the minimum amount of personal data to be collected?
- What assurances exist that the information collected is true and accurate?
- Has the project taken measures to ensure protection of personal data, e.g., by means of encryption and/or access control? If so, what are they?
- Have measures been put in place to facilitate the person's access to his or her personal data?
- Can the person whose data are collected rectify easily errors in personal data? What procedures are in place for doing so?

Surveillance and autonomy:

- Does the project involve surveillance of individuals or groups of people?

- How and for how long will images or data be retained?
- Who will authorise the surveillance practice, whether in private homes, assisted living residences or public places such as city streets or banks?

Informed consent:

- Has the person been informed of the nature, significance, implications and risks of the technology in question?
- Are people aware that personal data may be collected? Are they aware of who is collecting it and why?
- Does the consent outline the use for which data are to be collected, how the data are to be collected, instructions on how to obtain a copy of the data, a description of the mechanism to correct any erroneous data, and details of who will have access to the data?
- Has the person consented to collection of his personal data?
- If the individual is not able to give informed consent (because, for example, the person suffers from dementia) to participate in a project or to use of a technology, have the project representatives consulted with close relatives, a guardian with powers over the person's welfare or professional carers? Has written consent been obtained from the patient's legal representative and his doctor?
- It is clear where the responsibility lies for liability and accountability?

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