Information and Communication Technologies, Society and Human Beings:
Theory and Framework

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Chapter 37
eHealth and Ethics:
Theory, Teaching, and Practice

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ABSTRACT

The use of information and communication technologies (ICT) is increasing rapidly in many spheres of contemporary life in Europe. The ethical use of ICT in all areas of its application is of growing importance. This is especially evident in the field of healthcare. The regional, national, and Europe-wide electronic aspects of health services and systems are related fundamentally to these two developments. This chapter explores the relevance of ethics to eHealth generally. It outlines two main contrasting ideas that have influenced ethical thought: Kantian ethics and consequentialism. It investigates the ways in which teaching and practice for ICT professionals and trainees can be enhanced and extended to increase the awareness of ethical issues in eHealth. It takes as examples two technological applications that are in increasing use in the eHealth field: electronic health records and radio frequency identification devices. The chapter ends with a brief discussion and conclusions about how this ethical awareness can be expanded beyond ICT professionals to other stakeholder groups, and to other eHealth technologies or applications.

INTRODUCTION

eHealth has variously been referred to as medical informatics or medical information systems, clinical informatics or clinical information systems, health informatics or health information systems, or information and communication technologies

(ICT) for health (Duquenoy et al., 2008a). A number of definitions have been outlined in both the academic literature and in policy-related documentation (COM(2004) 356 final; COM(2007) 860 final; Eng (2001); Eysenbach (2001); Oh et al. (2005); Pagliari et al. (2005)). In this paper, we have selected from the text of the eHealth action plan (COM(2004)356, p4) one of the more pragmatic definitions:

[eHealth] describes the application of information and communications technologies across the whole range of functions that affect the health sector.

This paper is written in the context of health as it affects people's daily lives, enhances the overall well-being of Europe's citizens, and influences the continent's social and economic status. We focus on health supported by electronic means.

The paper describes what eHealth is, what ethics is, and how the two relate to each other particularly within a teaching or training context.

It is directed chiefly towards raising ethical awareness about eHealth applications for ICT professionals and for trainee or prospective professionals. Choosing a comprehensive definition of eHealth enables us to explore ICT applications in their variety and richness. Here, however, we concentrate our analytical efforts on radio frequency identification (RFID) devices and electronic health records.

The paper is completed by asking whether, and in what way, this ethical awareness can be extended to the design, implementation and use of other types of eHealth-related applications, and included in the education and training of other stakeholders. While the proposals outlined here limit themselves to the European scene, they can certainly be extended to a wider, international, perspective.

The paper is particularly intended as a complement to the longstanding work of Professor Gunilla Bradley who focused her ideas so keenly on the importance of human needs in relation to ICT, and has always had a profoundly holistic approach to ICT (cf. Bradley, 2009).

EHEALTH IN EUROPE: GENERAL OVERVIEW

eHealth has been under development in Europe for two decades and, elsewhere, for over four.

In the European Union, the early foundations of eHealth were laid in the late 1980s. Pilot studies were co-financed as early as the second stage of the European Union. From an initial funding of €20 million in 1988, investment in this domain of research and development later expanded tenfold during its Sixth Framework Programme (2002 to 2006). The Commission is now co-financing the Seventh Framework Programme that runs from 2007 to 2013. The amount of financing provided by the Commission dedicated to eHealth in this latest Framework Programme over this time-period is expected to be well over €200 million.

Large amounts of co-financing are now being invested in the deployment of eHealth. The research and development commitment of the Commission has been paralleled by work on the practical aspects of eHealth in the Competitiveness and Innovation Framework Programme (CIP) Information and Communication Technologies (ICT) Policy Support Programme (PSP) (more frequently known simply by its abbreviation as the CIP ICT PSP). This scheme supports the practical advance and integration of ICT use in various public sector domains among the Member States. In eHealth, the ministries of health, eHealth competence centres and industry partners in 12 Member States are focusing on electronic health data (health records/medication records or "patient summaries"), and ePrescribing. The first of these areas is one on which we concentrate in this paper.

eHealth also became an area for strong policy development with the formulation of a plan for policy convergence (COM(2004) 356 final). This plan is soon due to be completed and – presumably – also for some form of renewal or update. Although progress has been steady over the plan's seven-year lifetime, many of its accomplishments started to come to fruition – and have even been reinforced by further policy documentation – over its last three years of operation.

In particular, 2008, 2009 and 2010 have been key years for eHealth in Europe. For example, in the specific contexts of patient mobility, cross-

border health services, and eHealth interoperability, a Proposal for a Directive – which has now received even greater support – and a Recommendation were adopted (COM(2008)414 final; COM(2008)3282 final). In 2008, a policy document was also published on telemedicine (COM(2008)489 final).

EHEALTH IN EUROPE: A GROWING COMMITMENT TO DEPLOYMENT

Europe's Member States have committed themselves to collaborate on eHealth[1]. They are currently working together intensively to form a high-level governance framework that will begin to operate formally by the end of 2010. The aim of this governance will be to ensure that health ministries and their high-level leaders and decision-makers cooperate on the key aspects of an eHealth strategy for Europe, working together on eHealth implementation and on monitoring their collective progress[2]. These initiatives are highly likely to incorporate the involvement of a wide range of stakeholders.

There is much current emphasis on the deployment and application of eHealth. eHealth is commonly perceived by policy-makers and decision-makers as a key enabler of good healthcare and as a means of reinforcing the European Union's common values and goals for its health systems. Two-thirds of Europe's Member States believe that their health policy priorities can be supported by eHealth (European Commission, 2007). Every European Member State possesses its own eHealth road map or action plan, and all the States are now building their own initiatives to implement eHealth services, systems, and applications. There are many commonalities among the 27 States. However, there is still considerable disparity among them with regard to their stages of innovation and how they are putting eHealth into practice. This 2007 overview (Ibid) shows that the deployment of the main, common eHealth services in European countries has been motivated by such concerns as the quality of care and access to care for patients/citizens, which both have ethical aspects. A further review is taking place in 2009-2010[3].

The majority of Member States are now introducing, building, and using three technical domains: infrastructure, electronic health records or cards, and interoperability (Ibid, p13-15). The link between Europe's cited policy directions in eHealth and the actual commitment of the Member States to these particular fields is currently becoming clearer.

The co-financing initiatives of the CIP ICT PSP have increased the extent of collaboration among European Member States. Since 2008, two large-scale undertakings have been established: the first, a European-wide pilot project known as epSOS[4] which focuses on eHealth interoperability; the second, a thematic network which supports comprehensive stakeholder engagement in eHealth called CALLIOPE[5]. Several other similar initiatives also illustrate complementary Europe-wide action. An example here is STORK[6], which focuses on information security and the identification and authentication of users in such settings as eHealth.

European and international organisations are showing a renewed interest in eHealth as a market or business. Many elements of the relevant industries are endeavouring to work together on a number of eHealth-related initiatives: one example is the Continua Health Alliance[7]. In late 2007, the European Commission also launched a platform known as the Lead Market Initiative. This initiative emphasises the notion of the public sector as a driver of technological innovation and potential industrial growth – eHealth is one of the six domains to which attention is directed (COM(2007)860 final).

The health sector has always been a field strongly bound up with ethical questions. Here, we offer a brief overview of some key issues that

relate to ethics generally before we apply them in more detail to eHealth.

ETHICS

Ethics is a branch of moral philosophy. It has several schools of thought and action. The consideration of ethics and ethical theory in relation to human behaviour is known as normative ethics. It contrasts with more abstract discussions on morality (i.e. meta-ethics). In the context of this paper, we are interested in normative ethics – the practical application of ethics.

Ethical theories are useful points of departure to enable people to make appropriate choices and to act according to those choices. They provide people with a form of toolkit that can enable them, at any moment in time and in any specific context, to understand the particular moral position taken and the reasoning which underpins a specific moral choice. Each moral choice is complemented by its own criteria and constraints.

In recent years, different ethical theories have been used to assess the ethical implications of ICT. Two of the most common theories used are Kantian ethics and utilitarian ethics.

First, Kantian ethics argues that it is human will that motivates moral action. However, the will can only motivate itself from a rational foundation (Kant, 1981). Rationality implies autonomy (i.e. self-determination); rational argument dictates that all human beings must be equal. Two propositions are the result of this approach. They are, to treat humanity always as an end in itself and never as a means to an end; and, then, in the words of Kant, "Act only on that maxim which you can at the same time will to be a universal law" (Ibid, p421).

Second, utilitarian ethics is located in the field of 'consequentialist' ethics, and is sometimes referred to as consequentialism. Here, the principles of moral actions are considered to be based on their consequences. The principle of utility (the 'utility principle') is that right actions bring the greatest happiness to the greatest number of people. This 'greatest happiness' is determined as being either that which is of the highest value or which does the least harm.

Kantian and utilitarian ethics have led to the taking of two distinct positions. In the first, there is a consideration of human autonomy and respect for others. In the second, a basis is provided for addressing, deciding on, and assessing a specific course of action that is focused on the greatest benefit.

EHEALTH AND ETHICS

High-level, ethical, principles can be brought to bear on specific areas of application. They have been applied to the practice of medicine, the field of health and, more recently, the combined fields of eHealth (i.e., medicine or health and ICT). The more applied the field, the more specific, focused, and contingent are the particular ethical questions. The technologies that are involved in a particular context add yet another layer of complexity.

Codes of ethics often articulate the ethical principles that underpin any given context or setting. These codes provide the ethical foundation for many organisations, and particularly for professional bodies.

The complexity of modern society and communities of work means that the ethics of specific occupations (e.g. their codes of ethics, behaviour, or practice) need to be given careful consideration when two or more such professional or occupational groups collaborate. Challenges might arise: are the professions/occupations similar, do they share the same values, are there any areas of potential conflict among the two (or more) fields, and are there any particular gaps in their thinking/acting?

The ICT industry encompasses a range of disciplines that include electronic engineering, computer science, and information management. The ethical principles of these professions usually

fall into different groupings. However, in general, their codes of practice state that they each protect the public interest, uphold the standards of the specific profession, promote knowledge transfer, and require a commitment to personal integrity.

Of direct relevance in the case of this paper are the rules of conduct for Health Informatics Professionals which were drawn up in the United Kingdom under the auspices of the Health Informatics Committee of the British Computer Society. These rules of conduct recognise the role played by ICT in the field of medicine (Kluge, 2003). Several fundamental ethical principles were laid down in this document. They are the: Principle of Autonomy; Principle of Equality and Justice; Principle of Beneficence; Principle of Non-Malfeasance; and the Principle of Impossibility (the last of these principles relates to the assumption that it must be possible to meet the rights and duties that are expressed by the preceding four). These principles are transposed into concrete and practical uses that are aligned with the responsibilities of Health Informatics Professionals.

Here, the ICT professional has "a duty to ensure that appropriate measures are in place that may reasonably be expected to safeguard: The security of electronic records; The integrity of electronic records; The material quality of electronic records; The usability of electronic records; The accessibility of electronic records." (Ibid, p14).

These five characteristics of electronic health records are regarded by Health Informatics Professionals as important to the provision of healthcare. Each characteristic describes an aspect of the data store that could be compromised by technical mediation. In simple terms, these are the possible crisis-points of technically-mediated patient information.

The effective presentation of patient information can be construed as providing "the correct information at the right time, to the right people"; it is the basis for a strong ethical foundation to eHealth (Duquenoy et al, 2008b). This is not an easy task given the increasingly complex organisational and technical interactions implied by eHealth.

TEACHING ETHICS TO ICT PROFESSIONALS

In this section, we highlight the challenges of teaching ethics in the kind of discipline, such as ICT, where ethics has traditionally been an unfamiliar topic. We advocate the benefits of using examples, cases, and analogies. Whereas we concentrate here on teaching ethics to ICT professionals, using eHealth as our specific example, we later expand our discussions to a more holistic approach of interacting with other stakeholders in the eHealth domain.

In some professions, such as medicine and law, the consideration of ethics forms an inherent part of the particular profession's (and professionals') job. Such an approach has a long history and is well understood; ethics is a traditional component of any training offered to the student, and is likely to be treated in each of the various topics taught to the trainee professional.

This is not, however, the case for students of information systems or informatics. In this field of interest, unfortunately, the ethical implications of technologies were not recognised for a long time. Even today, many ICT practitioners find it hard to associate or reconcile the topic of ethics with their training about technologies.

Teaching ethics to technology students is made difficult in several ways. First, ethics tends to offer an abstract, highly conceptual, and even – at times – ambiguous approach to solving problems. Second, technology students tend to be practically-minded, hands-on problem solvers. Third, technology is usually developed with a focus on a specific task that is isolated from a wider context of use. As a result, using the electronic database of patient records as in our example, it can be difficult for

technology students to see how building such a database has some form of ethical importance.

Ethics must therefore be made relevant to technology students. They need to be shown the direct connection between technology applications and human beings and the impacts – whether beneficial or detrimental – on people's everyday lives. How best to do this?

Ethics is about promoting benefits and reducing harm. While this is a relatively simple message, it can actually be more difficult to assess what might constitute a benefit and what might constitute a harm. These are fundamental elements of ethical discussion, and it is here that reference to different ethical theories can help. Technology students do not necessarily need to be persuaded by the principles of a particular theory (although many students will lean towards one theory rather than another in their personal preferences). They do, however, need to use the principles as a foundation for discussion in order to draw out the key elements of the subject under debate.

These two elements – the connection between technology and people, and the consideration of ethics – can also be brought together quite simply. First, an introduction to a set of ethical principles is needed. Alongside this, one simple approach can be developed by selecting well-chosen case studies (whether hypothetical or real) or by focusing on concrete examples – what can be called eHealth in practice. A much wider range of technologies with pertinence to eHealth could of course be explored.

Here, we consider two technological applications in further detail: patient electronic health records and RFID devices. We cover in particular the issues of justice and equity. There has generally been a trend to examine justice and equity in the domains of eInclusion and eAccessibility[8] rather than in the eHealth field, however, this is becoming increasingly a pressing field of examination.

ELECTRONIC HEALTH RECORDS AND RADIO FREQUENCY IDENTIFICATION DEVICES

For the sake of simplicity, here we look at only two specific forms of technology that have a relevance to the healthcare field. These two applications were explored in detail at the International Federation for Information Processing summer school on "The Future of Identity in the Information Society – Challenges for Privacy and Security" held in the Czech Republic in 2008[9]. The theoretical and empirical background, especially to the field of RFID, was examined in an earlier paper (Whitehouse and Duquenoy, 2009).

We demonstrate how the application of ethics to specific technologies can be handled in a very practical way. The creation of illustrative templates or charts can encourage the consideration of particular ethical issues. At stake are questions that relate to the impacts of the technology on human beings and on information storage and transmission.

We place our discussion of ethics in the framework of the four issues that were raised earlier in relation to the work of Kluge (2003): non-malfeasance, beneficence, autonomy, and justice/equity. However, rather than covering all four of the potential ethical issues at stake, we choose to focus on the specific matter of *justice/equity*. Our preference for the choice of this field relates to the growing importance in Europe of users' rights in relation to technology use[10] and, in parallel, the rise in awareness of patients' engagement and involvement in their own healthcare[11].

Here, we discuss the usefulness of a specific ethical theory or an ethical approach (cf. Kluge, 2003), and how these underlying principles can provide a tool to tease out, identify, and assess ethical issues.

Electronic Health Records

Patients' health records may be held in a computer database either locally or centrally. Locally-held records may be stored at a doctor's premises or in a group practice shared among several general practitioners. Centrally-held records may be stored in a national database at either an institutional or a governmental level. Generally, locally-held data are less likely to be compromised by security issues than are centrally-held data which are transmitted over a network.

Patient data may also be held in a more distributed manner and/or collated from a range of sources. They could eventually be held by the patient him or herself. It is these options which may be increasingly widely explored, especially given the importance of cloud computing and the possibility of shared services (including health, social, and care services – whether public or private or a mix of the two).

In its widest possible context of use, the development of an electronic health-related database could cause many complex situations to arise that have a bearing on ethics. For example, the sharing of patient data among or between different healthcare professionals, departments, and other information systems could affect the confidentiality of a patient's data or it could compromise the integrity and timeliness of the treatment of the data.

There are at least two concerns that relate to the records application itself, and to the information that it holds. First, a lack of understanding of the particular technologies involved could place certain patients at a disadvantage. Second, the digital format of records could allow for the categorisation of patients according to fields such as age, gender, incidence of ill health (e.g., cancer), the geographic location of their home, or type of lifestyle (such as a person's addiction to cigarettes, leisure drugs, or alcohol). The technical and organisational capabilities for sorting these various data fields could impact on equality and equity generally. Such information can of course

be used in ways that reinforce justice and equity positively e.g., by increasing the understanding of the level of good public health in the community, region, or the country generally or by ensuring equal health treatment whatever the person's socio-economic background. On the other hand, the information could be used negatively to reduce the amount of treatment available to the particular individual and the ways in which such treatment is distributed.

A well-recognised approach to justice/equity would indicate that all patients should be able to have electronic records, so that no person (patient/citizen) is discriminated against[12]. The implication is that all patients should be treated equally. The same rationale and basis for information collection would be used, and non-discriminatory judgements would be made in relation to the basis of the information that is collected. All instances of data collection and transmission should be equal and fair for all patients. All patients should be reassured of the material quality of the record and that the record's content can be interpreted appropriately. If devices or records are designed to be used by patients (for example, for people who may have to read data on-screen or who may have to record and change data for themselves), then devices should be designed with a view to ensuring that all patients should be capable of using them easily. If patients are to have access to records, then all patients should have the same kinds of opportunities to access their own records.

Radio Frequency Identification Devices

RFID is based on small devices that can store data (information) which can be communicated to a receiver for some designated purpose. The device is attached to a host (artefact, human, animal). The ethically interesting – and provocative – characteristics of RFID devices are that they are small (possibly even un-seen) forms of ICT; they can be attached in some way to someone or some

object (such as clothing, a piece of equipment, or a badge). They can collect, store, and transmit information using a range of radio frequencies.

To examine the ethical issues that might arise from RFID, we need to consider the fundamentals of the technology and its relationship to the 'ethical entity' which in the case of this paper is a human being. In terms of *the location* of the RFID device, it can matter substantially whether the device is worn externally on a wristband, or is embedded on an internal artefact such as a hip replacement, or is implanted in human tissue. If the device is attached externally, could it cause the patient embarrassment or could it cause them to be discriminated against? If an internal device is deemed to be less discriminating (as well as being beneficial in other important ways), do all comparable patient-cases have the opportunity to benefit from similar technologies? Is there some form of potential interference that could be triggered by a device and cause undue harm to others? Are all patients who carry/use such devices assessed individually in terms of potential harmful effects, i.e., is there an equal interest to assess the needs of each patient? In terms of location, issues arise with regard to complementary or parallel use of other devices and technologies: operationally, is the device likely to interfere with other nearby devices or *vice versa*? Can any radio waves from the device itself, or from one or a combination of nearby devices, affect the patient?

Relating the use of RFID devices to the ethical principles of non-malfeasance, beneficence, autonomy and justice (equity) can help to facilitate ethical decision-making (cf. Kluge, 2003). Thus, very generally, a range of questions would need to be asked when considering the *envisioned use* of the RFID device for a health-related purpose. Specifically, is anyone harmed (such as the patient, or others)? Does the technology promote well-being (does it protect the patient from harm or keep the patient safe)? Is the patient's autonomy respected (i.e. is there respect for the patient's degree of personal choice and independent decision-making)?

Does the use of the device promote justice and equity (or, conversely, does it permit discrimination and inequality)?

Approaching equity/justice in relation to RFID devices might particularly emphasise such issues as: the rationale and basis for use; non-discrimination with regard to the security of the data transmitted; fairness and equality of data collection and transmission; assurances with regard to the data's eventual interpretation; the ease of usability of the devices and equipment; and the access and availability of the devices to all patients on an equitable basis. These kinds of concerns are indeed very similar to those which are also raised in this paper in relation to electronic health records.

RAISING ETHICS AWARENESS IN OTHER AREAS

This paper has focused on raising an awareness of ethics with ICT professionals and trainees. It has used eHealth as a specific example, and has drawn attention to two applications in this domain: electronic health records and RFID devices.

Given the increasing spread of the use of ICT generally, and specifically within the field of eHealth, there are a number of other elements that need to be considered when raising an awareness of ethics.

First, not all ICT professionals enter their profession through the route of higher education – although clearly that entry-point has become more and more the norm. Other levels of education and other professional domains are important.

Second, the debate and discussion strategy used in teaching to bring out the ethical dimensions of technology is equally applicable to other groups, but may need to be conducted in a different context. Forums, or 'spaces for discussion' (Berleur et al. 2000; Berleur et al. 2009) enable participants within a particular domain to explore and gain understanding of different ethical perspectives,

and to relate discussions to personal experiences and situations.

Third, formal training programmes are not necessarily going to be either appropriate or helpful with regard to the relevant education of patients, their carers or their families, and they are unlikely to be a feasible option for these groups. What can be achieved, however, would be a general raising of ethical awareness on the part of those who are outside a conventional institutional setting (e.g., a university; a training centre; a hospital; or a clinic), and yet who are nevertheless direct stakeholders in eHealth.

Fourth, in recent times, technologies have begun to provide opportunities to participate in discussions remotely – for example, discussion spaces started from blogs, or facilitated by social networking sites (Whitehouse, 2009). Some of the benefits of face-to-face interaction may be lost using these means, but gains can be made by virtue of the fact that physical presence is not required. This opportunity could be especially relevant to people who experience constraints, in health terms, in terms of physical presence, geographic mobility, or employment conditions.

Fifth, raising ethical awareness is especially important where technologies are used at-a-distance (e.g. telemedicine or telecare), and where the ethical implications may not be so easily or immediately perceived. For example, a diabetes monitoring aid may send information electronically (e.g. *via* wireless connections) to a remote healthcare practitioner. Would either of the users (patient or healthcare professional) understand the potential for compromising data integrity using this means (Duquenoy 2009)?

DISCUSSION

eHealth by its very definition involves the use of ICT in a field which is likely to involve not only a far wider range of professional personnel than simply ICT professionals but also many other people with a wide range of educational and professional competences.

In the eHealth domain, a wide range of different professions and occupations may need to work together alongside ICT professionals, e.g. administrators, clinicians, insurers, nurses, pharmacists, and researchers. These may also interact with other groups of individuals, e.g. patients, carers, and family members.

The ethical aspects of technology are as valid for healthcare professionals as they are for their ICT counterparts. Healthcare professionals would probably not need to be convinced of the role of ethics within their own professional domain, but they should also know how the introduction of technology could impact on their own ethical practices.

Ethical training is therefore increasingly a multi-lane highway rather than simply being a two-way street. The needs involve: an understanding of ethics on the part of the technologists; an understanding of technology on the part of the healthcare (and other) practitioners; and an understanding of both ethics and technology on the part of people who may be neither ICT nor eHealth specialists, but may simply be concerned about their own health, the health of those close to them, or the health of those for whom they care or with whom they work.

Key challenges in this context are likely to be faced by people who have either so far resisted deliberately an introduction to or use of the technologies or whose age and circumstances have caused them to avoid their use.

The complexity of ethical choices does not necessarily have to be simplified. However, it needs to be more easily understood using tools, techniques, and approaches that can aid decision-making. Understanding ethics in a specialist field is in itself challenging, however, understanding it in its more everyday context may be even more provocative. Analytical frameworks are needed to facilitate this, as well as means to apply more theoretical ethical thinking to actual practice.

We anticipate that the framework which we outline in this paper may facilitate a growing clarity of thinking with regard to the possible ethical options at stake in any given practical situation and the various rationales that underpin them.

CONCLUSION

In a larger context, there is a growing convergence among the various domains, services, technologies and applications that are under development and use in modern society. This trend is as relevant to eHealth as it is to other social and organisational domains. Indeed, it may be even more so, given the considerable challenges – social, organisational, demographic, and economic – to Europe's healthcare.

The range of technologies that can be used contemporarily is already impressive. This list is likely to be increased still more comprehensively in the future: this ever-widening range of possibilities is explored, for example, in work by the Institute for Prospective Technology Studies (IPTS) assisted by empirica[13] and projects such as The Senior Project[14]. The IPTS study explains that eHealth is helping to move healthcare from a more institutionally-based model to a patient-centred one (increasingly, there is also a portrayal citizen-driven healthcare). The technologies to be used are being operated close to the patient, whether e.g., on the skin of or even within a patient, or are located in a patient's more intimate, domestic sphere e.g. in her or his home. As these trends develop, an understanding of technologies and their ethical concerns will become increasingly relevant to patients themselves, their carers, and families.

There may indeed be trade-offs or compromises that need to be made among these various challenges. One potential polarity may be the ethics of computing use and the economics of technology use. On the other hand, these dilemmas may also share common ground. Today's focus on the sustainability of society provides a larger context in which such issues can be resolved and it may even encourage their resolution.

We can look forward to a greater in-depth investigation of ethical issues and ICT. Important examinations of applied ethics are already being undertaken in relation to a wide range of technological applications, whether contemporary or future-oriented. These occur in current European co-financed projects such as ETICA and EGAIS.[15] More specifically, in relation to eHealth, various ethical dilemmas are being explored in European projects such as ETHICAL.[16]

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ENDNOTES

[1]   See the conference declarations of at least three high-level (Ministerial) conferences in 2007 and, 2008, and 2009: http://ec.europa. eu/health-eu/news/ehealth/ehealth2007_ en.htm ; and http://www.ehealth2008. si/ ; and http://www.epractice.eu/en/library/281916 Accessed 5 January 2010

2   See the Council Conclusions of 1 December 2009: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2009:302:0012:0014:EN:PDF Accessed 6 January 2010

3   "eHealth strategies" http://www.empirica.com/themen/telemedizin/projekte_en.php Accessed 10 January 2010

4   http://www.epsos.eu/ Accessed 6 January 2010.

5   http://www.calliope-network.eu/ Accessed 6 January 2010.

6   https://www.eid-stork.eu/index.php?option=com_frontpage&Itemid=1/ Accessed 6 January 2010.

7   http://www.continuaalliance.org/ Accessed 5 January 2010.

8   Examples of relevant studies include ICT and ageing http://www.ict-ageing.eu/ Accessed 10 January 2010.

9   http://www.buslab.org/SummerSchool2008/schedule.html/ Accessed 7 January 2010.

10   One example is the possible future focii of a European Commission Directorate-General on justice, fundamental rights, and citizenship. A second is the increasing perception that the European Union's post-i2010 and EU2020 initiatives may concentrate, at least in part, on user rights in relation to the Internet.

11   A two-year project called Value+ (which ended in February 2010) developed a policy statement on patients' meaningful involvement in health-related projects, and produced a toolkit and handbook for patients' associations as well as project leaders. See http://www.eu-patient.eu/Initatives-Policy/Projects/ValuePlus/ Accessed 20 July 2010.

12   On the other hand, there may be individuals who for various reasons prefer not to have such an electronic health record held on their health data.

13   http://www.empirica.com/themen/telemedizin/projekte_en.php/ Accessed 10 January 2010.

14   http://www.seniorproject.eu/ Accessed 11 January 2010

15   ETICA http://moriarty.tech.dmu.ac.uk:8080/pebble/default/2009/05/28/1243516800000.html/ and EGAIS http://www.egais-project.eu/?q=node/3/ Accessed 10 January 2010.

16   http://www.ethical-fp7.eu/ Accessed 10 January 2010.